

The needs of older people with advanced chronic kidney disease choosing supportive care: a review

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Abstract

Aim: To explore primary research related to the needs of older people with advanced chronic kidney disease (ACKD) who have chosen supportive care as their treatment of choice.

Method: Databases including Medline, PubMed, CINAHL and Cochrane Interwiley Science Database were searched using the keywords: “supportive care”, “conservative management”, “palliative”, “terminal care”, “end-stage kidney disease”, “elderly”, “older person”, “symptoms”, “renal”, “decision-making” and “education”. Articles were limited to English full text articles dating from 1995 to 2011. Articles chosen investigated supportive care, the older person, education and decision-making.

Results: Twelve articles met the inclusion criteria and were reviewed by one nephrology nurse clinician and one nurse researcher. Eight studies were quantitative (survey, case note audit, comparative studies, tool development) and four were qualitative (interviews, focus groups). Three themes were revealed and developed: shared decision-making, perception of quality of life (QOL), and educational resource requirements.

Conclusion: This review revealed a growing body of research regarding the challenges of the older person with ACKD. More research is required exploring the educational needs of the older person with ACKD to contribute to their improved clinical care.

Keywords

Advanced chronic kidney disease, supportive care, conservative care, palliative care, patient education, dialysis, renal replacement therapy.

Introduction

Advanced chronic kidney disease (ACKD), defined as estimated glomerular filtration rate (eGFR) less than 30 mL/min/1.73 m² (Marrón *et al.*, 2010), is steadily increasing (Grace, Excell, & McDonald, 2011). Once a person is diagnosed with ACKD they are asked to make choices regarding their future health care. The choices are renal replacement therapy (RRT) (that is, transplantation, haemodialysis or peritoneal dialysis) or no RRT.

In Australia the largest increase in people receiving RRT has been in the age groups 65 to 74 years and >85 years, while the 75–84 years remain stable (ANZDATA Registry, 2009). This increase reflects similar global trends in other developed countries (Abdelhafiz, Ahmed, Flint, & El Nahas, 2011; Brown & Johansson, 2011). These older people receiving either dialysis or transplantation have multiple comorbidities; most frequently coronary and peripheral vascular disease, cerebrovascular disease and decreased cognitive function (Chambers, Germain, & Brown, 2006; Murray *et al.*, 2006; Stevens, Viswanathan, & Weiner, 2010).

Due to the numbers of older people being diagnosed with ACKD, supportive care is increasingly being discussed as a treatment option (Noble, 2008). Supportive care is the pathway where RRT is not chosen, but people are “not forgotten” and continue to receive health care from the renal team (Berzoff, Swankowski, & Cohen, 2008). Supportive care is also termed conservative management (Abdel-Rahman & Holley, 2010), maximum conservative management (Carson, Juszcak, Davenport, & Burns, 2009), palliative care (Harrison & Watson, 2011) or non-dialytic care (Noble & Rees, 2006; Wong, McCarthy, Howse, & Williams, 2007). Increasingly the term supportive care has been embraced by renal clinicians (Berzoff *et al.*, 2008) and developed because it infers active treatment with positive implications (Davison & Jhangri, 2010). Supportive care can also be differentiated from the terms palliative, which may have an association with imminent or immediate death, or conservative management which may imply limited, non-active treatment (Noble, Kelly, Rawlings-Anderson, & Meyer, 2007). The purpose of this literature review is to identify the challenges

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and needs of older people with ACKD choosing supportive care and identify future areas for research that will benefit the older person with ACKD and carers in their supportive care pathway decision-making.

Aim

To explore the peer-reviewed primary research exploring the needs of older people with ACKD who have chosen supportive care as their treatment of choice.

Method

Databases searched and keywords

Four different database search engines (Medline, PubMed, CINAHL and Cochrane Interwiley Science Database) were accessed, using the keywords: “supportive care”, “conservative management”, “palliative”, “terminal care”, “end-stage kidney disease”, “older person”, “symptoms”, “renal”, “decision-making” and “education”. The abstracts were all read for relevance and their reference lists were also searched for any further relevant articles.

Inclusion and exclusion criteria

Articles were limited to English, full-text, primary research dating from 1995 to 2011. Articles chosen reported primary research exploring supportive care, older people and decision-making in their choices. Articles were excluded if the articles only focused on symptom management of older people who had chosen supportive care, if they only discussed withdrawal of dialysis or if they only discussed the overall nephrology palliative care services available or lack of, or if they included other diagnoses (respiratory, chronic heart, cancer). Articles discussing the actual quality of patient’s death were excluded as this was not the aim of this literature review.

Results

Full-text articles were retrieved and reviewed for emerging themes and these were given a particular code and documented in a spreadsheet. This facilitated the manipulation of codes which were organised into overarching themes. Table 1 outlines the process for selection and review of articles. Using the above criteria, 121 articles were identified at Step 1 and 20 were retained at Step 2. These articles were read to ascertain their applicability to the aim of this review: to provide information on the needs of older people with ACKD who have chosen supportive care. A final 12 articles met the criteria of informing the aim and were selected for the literature review (Table 1).

All 12 articles were reviewed by one nephrology nurse clinician and one nurse researcher. Eight studies were quantitative (survey, case note audit, comparative studies, tool development) and four were qualitative (interviews, focus groups). In this review clinical research methods were not critically appraised because investigating the needs of older people with ACKD choosing supportive care is an emerging field of research. The three themes that were developed from the 12 articles were: shared decision-making, perception of quality of life (QOL) and educational resource requirement.

Shared decision-making

The first theme that emerged in this review was shared decision-making. Shared decision-making can be defined as a process of making decisions in accordance with people’s values, preferences and health professional’s advice (Marrón *et al.*, 2010). Although there was general consensus for shared decision-making between the patient, carer, family and health professionals, there were varying levels of input into these decisions with the nephrologist having the greatest input. Even though there was agreement that shared decision-making was important, the literature identified little discussion around supportive care and end of life.

These studies highlighted the view that the choice to dialyse should remain with the patient and carers. In a study exploring older Italian patients’ views, De Biase (2008) reported the need for the final decision of whether to dialyse or not to be made by the person and their caregivers. When choosing to dialyse or not, however, older people with ACKD and their caregivers were willing to defer the decision over to their physicians (Clement, Chevalet, Rodat, Ould-Aoudia, & Berger, 2005; Davison, 2010). The decision still belonged to the person with ACKD but they were happy to be strongly advised by the physician. But no matter who made the decisions regarding treatment choice, there was consensus that the historically limited discussion around supportive care was changing. Although Davison (2010) reported concerns over a lack of collaborative patient, family

Table 1. Search strategy.

Step 1

Search terms: supportive care, conservative management, palliative, terminal care, end-stage kidney disease, elderly, older person, symptoms, renal, decision-making and education

Databases: Medline, PubMed, CINAHL and Cochrane Interwiley Science Database

Inclusion dates: 1995–2011

Inclusion criteria: Peer-reviewed publications that addressed information, education and decision-making in their choice of RRT or supportive care.

Result: 121 full-text articles in English

Step 2

Exclusion criteria: focused solely on symptom management, withdrawal from dialysis, discussion of nephrology palliative care services or patients’ quality of death, included other diagnoses

Result: 20 full-text articles

Step 3

Articles were kept if deemed relevant to informing the aims of this review.

A final 12 articles met the aims of this review (Table 2)

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Table 2. Primary research contributing to the needs of older people with ACKD.

Author (year) country	Aim	Methods	Findings	Importance to educational needs ACKD: supportive care
Murtagh (2011) United Kingdom	Determine trajectories of symptoms and wider health-related concerns in the last year of life in stage 5 chronic kidney disease, managed without dialysis	Quantitative prospective	In the two months before death, patients reported a sharp increase in symptom distress and health-related concerns	Considerable individual variation and flexibility/responsiveness of care is important
Morton (2011) Australia	Determine the effect of patient and unit characteristics on the type and timing of information provided	Prospective national multicentre survey	Most patients were informed of their treatment options prior to starting treatment, albeit in late-stage CKD	Earlier education and support for informed decision-making may increase uptake of alternate therapy pathways
Harrison (2011) United Kingdom	Evaluate a nurse-led clinic to palliative care needs of chronic kidney disease	Survey	Clinic was well received by patients, carers, and other health professionals	Nurse led clinic may assist end of life strategies
Davison (2010) Canada	To evaluate end-of-life care preferences of CKD patients	Quantitative prospective	60.7% regretted their decision to start dialysis 51.9% reported it was the physicians wish to start dialysis	Communication and discussion about prognosis and advanced care planning are lacking in the routine care of renal patients
Visser (2009) Netherlands	To explore the considerations taken into account by elderly patients in deciding RRT	Qualitative prospective	Patients who declined dialysis were older, more often male and widowed	Decision based on personal values, beliefs and feelings towards life, not on effectiveness of treatment
Ellam (2009) United Kingdom	To measure survival in stage 5 conservatively managed patients	Quantitative retrospective	No individual comorbidities or comorbidity burden had any statistical effect on survival. Late presenters had less survival	Evidence ambiguous re survival off dialysis
Couchoud (2009) France	Develop and validate prognostic score for six-month mortality in elderly patients starting dialysis	Quantitative retrospective – prospective	Age not associated with early mortality Prognostic tool effectively predicts short-term prognosis	Prognostic score can assist in decision-making Used to facilitate discussion with patients and families
De Biase (2008) Italy	Report on clinical results of study	Quantitative prospective	Similar outcomes between the conservatively managed group and the dialysis group	No clear data outcomes, to educate and tell patients about 1 form of treatment being better than the other
Berzoff (2008) USA	Explore discussion on palliative and hospice referral	Focus group qualitative	Greater education of both patients and families required Ongoing support between patients, families needed Staff required for continuity of care, pain control and assistance with advance care planning	Greater education of both patients and families required
Murtagh (2007) United Kingdom	Compare survival of elderly patients managed with either dialysis or conservatively	Quantitative retrospective	Patients who commenced dialysis were younger. Survival rate > if dialysis chosen but survival advantage no longer apparent if patients on dialysis had ischaemic heart disease.	Need to explore the determinants of the dialysis decision
Clement (2005) France	Ethical perspective of the practices of French nephrologists	Qualitative	No systematic decision-making process of whether a patient should dialyse or not	Patients and nephrologists opinions may differ
Grbich (2006) Australia	Analyse the end-of-life care received; identify any deficits in care provision	Retrospective case note audit nurse interviews	Poor communication between medical and nursing staff and between nursing staff, patients and family around end-of-life issues Discussions regarding NFR decisions occurred too close to death	Poor communication that may be assisted by improved educational materials

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and physician decision-making, other studies noted increasing discussion (Ellam, El-Kossi, Prasanth, El-Nahas, & Khwaja, 2009; Harrison & Watson, 2011).

The complexities and individual nuances for each older person with ACKD facing the decision to dialyse or not requires a strong relationship between physician, carers and patient. Given the complexities of this decision (Harrison & Watson, 2011; Murtagh *et al.* 2007) older people with ACKD and their carers rely on the health care team to provide enough information and the right information at the right time. The development of trust contributes to the best decision, requiring a balance of compassion and honesty to ensure the patient has the information to make the most informed decision (Berzoff *et al.*, 2008).

Knowledge of the characteristics of people choosing supportive care can assist clinicians to provide information on prognostic quality and quantity of life. These characteristics include low body mass index, diabetes, congestive heart failure stages III–IV, peripheral vascular disease stages III–IV, dysrhythmia, active malignancy, severe behavioural disorder, impaired mobility and unplanned dialysis (Couchoud *et al.*, 2009). From these characteristics a prognostic scoring tool to assist clinicians in the shared decision-making process has been developed (Couchoud *et al.*, 2009). However, there is no single scoring system and no systematic way to go about these difficult decision-making processes so the trusting relationship between the health care team, family and patient is vital for shared decision-making.

Perception of QOL

The second theme emerging in this review was the perception of QOL being important to both the patient and health professional. Although the authors researched and commented on QOL, none of the papers included a definition of QOL. It was referred to when discussing the negative effect that dialysis treatment can have on QOL (Couchoud *et al.*, 2009; Ellam *et al.*, 2009), but was not explicitly defined.

Although not explicitly defined, the importance of QOL was reported as the major factor associated with the choice of supportive care and the discontinuation of dialysis treatment (Clement *et al.*, 2005) which guided the health care team in supporting the decision of the patient and carers (Ellam *et al.*, 2009). Even when older people with ACKD were told that dialysis may lengthen their life, their concerns about QOL held greater importance than length of life (De Biase *et al.*, 2008). Given the subjective nature of QOL and the complex unique characteristics of each older person with ACKD, the communication and trusting relationship between the health care professional and the patient requires great attention.

Unfortunately discussion around QOL, particularly with the older person with ACKD, was not always overt. Some clinicians may find aspects of the patient journey difficult to discuss, leading to treatment choices that are not well understood by the patient (De Biase *et al.*, 2008). Values and beliefs, spiritual and psychosocial concerns are all relevant to treatment choice and require skilled, experienced clinicians to incorporate these into QOL discussions (Clement *et al.*, 2005; Visser *et al.*, 2009; Murtagh *et al.* 2011). This reinforces the importance of a trusting relationship between the health care team, family and patient that is pivotal in discussing some of these sensitive issues.

The role of educational resources

The third theme to emerge in this review involves around the role of educational resources. These resources may be pamphlets, booklets, DVDs or websites that are used in the education between clinicians and the older person with ACKD (Morton, Howard, Webster, & Snelling, 2011). Regardless of the type of educational materials, they are insufficient without a trusting relationship between the health professional and patient (Berzoff *et al.*, 2008). Thus not only is a decision influenced by the type and amount of information that is provided but also by the quality of the context that the information is provided in (Visser *et al.*, 2009) and how it is supported by the clinical team.

There was varying agreement from the research studies over the importance of education materials. Two studies reported that not enough information was provided to older people with ACKD and their families (Berzoff *et al.*, 2008; Davison, 2010) while another study indicated that supportive care was not a priority in discussions with health care professionals (Grbich *et al.*, 2006). This supported the findings of Visser (2009) who found that most of those who had decided on supportive care had done so prior to receiving information.

Varying approaches to supportive care education practices were also highlighted in the literature. Although clinicians may have good intentions, some written educational materials such as brochures and booklets were difficult for people to understand (Morton, Howard, Webster, & Snelling, 2010). Morton *et al.* (2010) suggested that an increase in the use of peer education from people who have had to make these decisions was beneficial. Reviewing current accepted educational materials and practices may be required to ensure the most appropriate materials for supportive care decision-making.

Discussion

This review has highlighted three major themes: shared decision-making, perceptions of QOL and the role of educational resources. A shared decision-making approach is endorsed by the American Renal Physicians Association National Clinical Practice Guidelines (2010) and is consistent with other clinical literature (McCaffery *et al.*, 2011; Salzburg Global Seminar, 2011). In decisions regarding RRT, every person's situation is unique. Experienced health care professionals are encouraged to become adept at striking a balance between the traditional health professional dominant model of decision-making and a model of independent decision-making by the patient with the clinician as a neutral observer (Berzoff *et al.*, 2008). Caring, compassionate clinicians should be aware of the power of their medical knowledge to ensure every encounter is balanced between best health care outcomes from the clinical and personal perspective.

Shared decision-making depends on the premise that the health care clinician has fully disclosed information regarding the benefits and burdens of the decision, the possible course of the disease until death and the supports that will be provided (Germain, Davison, & Moss, 2011; Lowance, 2002). This is not always apparent given resource, time, education and communication constraints (Moss, 2010). Disclosure of the best

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information possible by the health provider is inherent in the responsibility of all health professionals to ensure an informed decision by the older person with ACKD.

Enhancing QOL is a major responsibility of the renal clinician. In defining QOL, renal guidelines are specific in recommending that it is only the patient who can define their own QOL (Renal Physicians Association, 2010). The health care professional cannot make a subjective opinion regarding another person's QOL and what is important to them, which highlights the need for shared decision-making.

Informed decision-making is an important goal for people facing choices regarding RRT options. There is little written about the older ACKD patient education to assist them in making their choice. Furthermore, there was no mention of the possible risk of harm that communication or miscommunication through educational and decision-making aids may pose to patients (Bugge, Entwistle, & Watt, 2006). Harm may occur through the misinterpretation of information, reinforcing the notion that the provision of information alone is not enough to ensure people make an informed choice. Clinicians need to assist the older person with ACKD to evaluate the benefits and risks of each treatment in terms of their own values (Woolf, Chan, & Harris, 2005).

Minimal research has been undertaken to determine whether verbal consultations, printed materials, DVDs, unit tours or websites are suitable to meet the needs of the older person with ACKD (Morton *et al.*, 2011). In a recent British survey of printed educational materials given to people with chronic kidney disease (CKD), most were considered "very hard to understand" (Calderon & Zadshir, 2004). This was based on the Flesch readability scale, a validated scale that rates educational material (for example, pamphlets, websites) on a 100-point scale. Poor readability scores suggest that educational material may be inappropriate for people with CKD and inadequate to facilitate informed decision-making (Morton *et al.*, 2011). Thus, even though clinicians may have good intentions, they may be providing material at an inappropriate literacy level.

Educational interventions should be delivered in ways that are accessible to all patient literacy levels. Literacy levels of some people with ACKD have been reported as low as Years 8 and 9 school level (Owen, Kohne, Douglas, Hewitson, & Baldwin, 2009). This may be associated with the reported uraemic-related cognitive impairment of some people suffering from CKD (Murray *et al.*, 2006; Stevens *et al.*, 2010). Awareness of the health literacy level, cognitive status and perceived informational needs could facilitate the development of quality educational programmes for this complex patient population (Lewis, Stabler, & Welch, 2010). Once health professionals are aware of health literacy needs, strategies and resources can be developed to actually facilitate quality educational experiences.

Limitations

We limited our search to full-text papers that provided full information on context, methods, results (where applicable) and conclusions. Although there is much written about supportive care in the grey literature (that is, non-peer reviewed conference proceedings, news reports and educational pamphlets) we chose not to include this in our search as we could not be confident

of the full context of the information. A second limitation was the variation in the definitions used such as supportive care, palliative care, elderly, older person and aged. These definitions vary from discipline to discipline and from culture to culture and definitions were not always clear in the literature. Finally, although a summary of articles and thematic analysis was undertaken in this review, research methods were not critically appraised. This is a relatively new area of investigation and we felt it more important to summarise than critically appraise the research methods.

Conclusion

The major aim of review was to identify the needs of older people with ACKD choosing supportive care. In addition, we endeavoured to identify future areas for research that would benefit the patient and carers in their decision to choose supportive care. This review revealed a paucity of research regarding the education requirements of the older person with ACKD who has been asked to make a decision regarding RRT or supportive care. Furthermore, there appeared to be a difference in what information a patient feels they need to help them make a decision to have dialysis or not, compared to what the health professional thought they required. In particular, research exploring these needs of the older person with ACKD will greatly inform nephrology clinicians.

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