Shared decision making in chronic kidney disease

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Learning outcomes
On completion of this continuing professional development activity, participants should be able to:

- Articulate important evidence-based recommendations regarding shared decision making, for persons with chronic kidney disease.
- Suggest practical strategies to improve decision making, taking the individual’s context into account.
- Recognise that shared decision making encompasses the entire realm of kidney disease.
- Suggest how decision aids may assist patients in recognising what’s important to them.
- Reflect upon how clinicians may empower patients to recognise changing options as they develop, through their evolving disease trajectory.
- Acknowledge that not all patients with kidney disease wish to be actively involved in the shared decision-making process — although this should never be assumed.

Keywords
Evidence-based summaries, best practice, shared decision making, end-stage kidney disease, renal replacement therapy.

"You tell me and I forget, you teach me and I may remember, you involve me and I learn" — Benjamin Franklin

Introduction
Chronic kidney disease (CKD) has five stages of disease progression, based on the glomerular filtration rate, with Stage 5 being end-stage kidney disease (ESKD). Stage 5 is also sometimes referred to as end-stage renal disease (ESRD). For patients with ESKD, treatment options include pre-emptive transplantation, peritoneal dialysis (PD), in-centre haemodialysis (HD), home HD or supportive non-dialytic management, also known as conservative care (Morton et al., 2011). Shared decision making (often referred to as SDM) allows a clinician and patient to participate jointly in making a health decision, taking into account the benefits and harms of all the options and considering the patient’s values, preferences and circumstances (Hoffman et al., 2014; Murray et al., 2013). SDM has also been described “as a decision situation, in which 1) at least two participants are involved, who 2) both share information and 3) take steps to build a consensus about the preferred treatment, and where 4) an agreement is reached on
the treatment with joint responsibility” (Robinski et al., 2016, p. 563). Renal function in patients with CKD usually declines gradually, which provides multiple opportunities for clinicians to discuss renal replacement therapy (RRT) and supportive care with patients and their families (Tuso, 2013). The importance of initiating discussions about RRT or conservative care earlier in the disease progression has been highlighted, with SDM considered critical when the patient enters Stage 4 CKD. SDM is important when the patient is about to start RRT or when there is no evidence that further therapy will prolong life (Tuso, 2013). It is essential for renal clinicians to maintain communication with patients regarding prognosis and treatment options and participate in a process of SDM so patients and family members remain fully informed (Tuso, 2013).

**Methods**

This is the fourth continuing professional development (CPD) paper which comprises an evidence summary from the Joanna Briggs Institute (JBI) renal care node. This evidence summary was conducted using a streamlined rapid review approach and is based on a structured search of selected evidence-based health care databases (Munn et al., 2015). The databases searched included the JBI Database of Systematic Reviews, the Cochrane Library, the Database of Abstracts of Reviews of Effects (DARE), Medline (PubMed), CINAHL, and Google Scholar. A range of keywords and subject headings appropriate for each database were used. Titles and abstracts of search results were screened to identify the “best available” evidence, according to the JBI levels of evidence (Figure 1). Full-text articles of identified studies were retrieved and further assessed for relevance to the evidence summary topic. Articles identified as relevant were assessed for methodological quality using an abridged set of critical appraisal tools (Munn et al., 2015). The characteristics and key points arising from the evidence are listed for each study, along with the JBI evidence level. Based on the evidence presented, best practice recommendations are reported separately, with Grade A suggesting a “strong” recommendation and Grade B a “weak” recommendation (Table 1).

**Question**

What is the best available evidence regarding shared decision making, for patients at all stages of kidney disease?

**Table 1: The Joanna Briggs Institute Grades of Recommendation**

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<thead>
<tr>
<th>Grade</th>
<th>Description</th>
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<tr>
<td>Grade A</td>
<td>A ‘strong’ recommendation for a certain health management strategy where: 1. it is clear that desirable effects outweigh undesirable effects of the strategy; 2. where there is evidence of adequate quality supporting its use; 3. there is a benefit or no impact on resource use; and 4. values, preferences and the patient experience have been taken into account.</td>
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<tr>
<td>Grade B</td>
<td>A ‘weak’ recommendation for a certain health management strategy where: 1. desirable effects appear to outweigh undesirable effects of the strategy, although this is not as clear; 2. where there is evidence supporting its use, although this may not be of high quality; 3. there is a benefit, no impact or minimal impact on resource use; and 4. values, preferences and the patient experience may or may not have been taken into account.</td>
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**Figure 1:** The Joanna Briggs Institute levels of evidence for effectiveness (used with permission)
Shared decision making in chronic kidney disease

Key points from the evidence

Factors involved in shared decision making

- A systematic review including 18 qualitative studies synthesised the views of patients and carers on decision making regarding treatment for CKD (Morton et al., 2010). The review identified four major themes as being central to treatment choices: “confronting mortality (choosing life or death, being a burden, living in limbo)”; “lack of choice (medical decision, lack of information, constraints on resources)”; “gaining knowledge of options (peer influence, timing of information)”; and “weighing alternatives (maintaining lifestyle, family influences, maintaining the status quo)” (Morton et al., 2010, p. 1). The reviewers concluded that factors influencing treatment decisions included experiences of other patients, the problematic timing of information about treatment options and simultaneous creation of vascular access, and a preference to maintain the status quo. Recommendations for practice based on the findings of the review were presented, including:

  o Formal incorporation of peers (other patients) with CKD as mentors or educators into the orientation of new patients to the renal unit.

  o Updating of clinical practice guidelines for optimal timing of education about treatment options to recommend giving information at stage 4 disease, well before the creation of access for dialysis.

  o Formal care pathways for pre-emptive transplantation, home dialysis, and palliative management for patients not wishing to dialyse should be developed, to facilitate provision of treatments more aligned with patient preferences. (Level 1)

- A systematic review including 16 qualitative studies examined how people with CKD make decisions about the type of dialysis modality to use (Harwood & Clark, 2013). The review found common elements across patients’ decisions, including “the illusion of choice — a matter of life or death”; “minimization of the intrusiveness of dialysis on quality of life, autonomy, values, sense of self”; and “decision-making in the context of wider knowledge and support” (Harwood & Clark, 2013, p. 109). The reviewers concluded that there is a need for planned and timely discussions about all modalities and that health professionals should focus on patient and family preparation, knowledge of different modalities and the lifestyle implications of different modality choices. (Level 2)

- A prospective, multicentre, observational study of patients with unplanned dialysis start (UPS) was undertaken between 26 centres in six European countries, over 12 months, with the aim of determining predictive factors for patients receiving education, making a decision, and receiving their preferred modality choice (Machowska et al., 2016). The authors acknowledge that 24–49% of patients begin dialysis in an unplanned (sudden) manner, and despite the need for rapid clinical decision making a modality choice is not routinely provided, meaning that many typically remain on in-centre HD. Therefore, they examined the use and effectiveness of an UPS education program (UPS-EP), within their overarching OPTIONS study (Offering Patients Therapy Options in Unplanned Start). Their program utilised three decision support tools: the Ottawa online decision aid; a self-completion balance scale; and a set of decision cards. Results from their sample (n=270), indicated that the majority of participants (n=214) were able to use the UPS-EP, many being capable of making a decision (n=177); although not all patients received their preferred choice (n=159) (Machowska et al., 2016). The authors conclude by stating that success of their program requires equity of access to it, especially for the elderly; and that future work is still required to “improve patient pathways to ensure that modality preference is enacted” (Machowska et al., 2016, p.2229). (Level 3)

- A retrospective survey (n=482) aimed to compare differences in SDM and treatment satisfaction (TS) between German patients undertaking HD or PD, within 6–24 months of initiation of dialysis (Robinski et al., 2016). The authors found strong patient reasoning behind their decisions to choose either modality, with positive correlations between SDM and TS (0.16 ≤ r ≤ 0.48; p ≤ 0.0001). They suggest SDM be initiated at an early stage to screen patient preferences, adding an awareness of consultation bias, careful use of terminology and participation encouragement of passive patients is important; although no comment was made in regard to conservative/supportive care options. (Level 4)

- A qualitative study whose objective was to “describe the decision-making needs from the perspective of patients with advanced CKD, professionals and others involved in decision care” (Loiselle et al., 2016, p. 463), used a standardised needs assessment questionnaire based on the Ottawa Decision Support Framework (ODSF) to elicit information, via interviews and a focus group. Their findings centred on five specific stages requiring decisional support: “1) Progress toward acceptance of dialysis, 2) Receive information, 3) Take some time for personal reflection, 4) Seek opinion and support of other, and 5) Re-evaluate one’s choice” (Loiselle et al., 2016, p. 463). (Level 3)
An opinion piece describing the potential for SDM in kidney transplantation discusses challenges which include “fragmented patient–provider relationships, the time-sensitive and unpredictable nature of deceased organ offers, decision-making process by transplant providers serving as both organ guardians … versus advocates for specific patients…” (Gordon et al., 2013), yet they contend SDM may progress with this population through improved clinical care organisation, communication and education. The authors provide information indicating multiple opportunities exist for SDM engagement, suggesting particular discussion points to elicit patient expectation and values. They also make important comment on the overlap between the common goals of SDM and informed consent in transplantation, notwithstanding the complexities of such critical decisions from a time, resource and risk perspective. They briefly compare notions of the organ acceptance “choice” potential kidney recipients have, compared to the limited choice of lung-heart recipients; finally suggesting that “SDM may increase adherence to transplant treatment plans as patients recognise their active role in the decision-making process” (Gordon et al., 2013, p. 1156). (Level 5)

A opinion piece aimed to “explain how shared decision making can allow the nephrology nurse’s perspective of renal replacement therapy be heard so as to advocate for the elderly patient” (Hallock, 2014) — in considering the moral concerns and distress often encountered by nurses at the decision to withdraw RRT. A clinical practice guideline published by the Renal Physicians Association/ American Society of Nephrology in 1999 is summarised along with a case presentation. (Level 5)

An opinion piece reviewed the need to include prognostic factors in considering SDM principles through discussion of risk/benefit and exploration of values and preferences, in persons of advanced age, at pre-dialysis evaluation (Koncicki & Swidler, 2013). The authors suggest using an approach incorporating four topics of SDM: medical indications, patient preferences, quality of life and contextual features. Within this framework their approach considers patient prognosis, and they offer a diagrammatic review of the four most likely disease profile projections of chronic illness, displaying functional status changes through time. They suggest discussion of recommendations with patients and families, along with integration of geriatric renal palliative care concepts, in considering options for dialysis, or non-dialysis medical therapy. They remind us that all SDM topics be re-evaluated regularly and during sentinel events, in line with recommendations by the Renal Physicians Association’s Guidelines. (Level 5)

A literature review aiming to explore the needs of older persons with advanced CKD (Moustakas et al., 2012) searched four databases and found 12 relevant articles meeting their inclusion criteria. Eight quantitative and four qualitative papers were reviewed, to reveal three themes of importance: SDM; perception of quality of life; and educational resource requirements. The authors concluded “… there appeared to be a difference between 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” (Moustakas et al., 2012, p. 74). (Level 5)

An opinion piece addressed the importance of an integrated approach in determining supportive care principles for persons with advanced CKD (Moss, 2017). In suggesting the imperative for SDM from the outset, the author makes recommendations as appropriate for initiation and withdrawal from dialysis (per Clinical Practice Guideline), and offers tabulated information under the heading of informed consent for older patients considering dialysis. Recognising specialty differences between nephrologists and supportive care specialists, summary comment is made that improved collaboration between the two disciplines may improve care quality and enhance SDM for these patients. (Level 5)

A qualitative descriptive study aimed to explore the experiences of persons >70 years in the SDM process (Thomas et al., 2016). The authors acknowledged that various factors including education, cultural/ethnic values and age-related mental decline may frequently cause patients to defer to physician-directed care in decision making. Their research design is unique as they trained a patient and carer group (PCG) in the research process, allowing them to develop interview questions for a group of older people (n=29) who had recently made dialysis care decisions. The use of peer supporters in this manner was considered advantageous as the PCG was able to empathise with their participants, putting them at ease and improving communication of their experiences. Their findings suggest that most of the patients were involved in dialysis care discussions, although some information quality could have been improved. (Level 3)

**Decision aids**

- The development by a multidisciplinary Australian and New Zealand team of a decision aid, “My Kidneys, My Choice”, is based on best practice principles and current decision-making theory. The authors note the aid was initiated to “support the philosophy of structured shared decision making for those engaging in, and those health
professionals supporting, RRT treatment decisions ..., to promote comprehensive treatment option education fulfilling the principles of informed choice” (Fortnum et al., 2014, p. 82). Specifically, because “the primary drivers of choice for those with ESKD are lifestyle concerns” (p. 85). Written in a patient-centred manner and sectioned into five titles, brief strategies are offered for the completion of each; although there is limited discussion on supportive care options. In print format, each section of the aid allows easy and concise completion by the patient, and a health professional guide is also available. (Level 5)

- The development of an online decision aid by Medical Education Institute (MEI) to move the emphasis from how treatment options work to what the patient’s life preferences are, is suggested by the author to be a paradigm shift in education options (Schatell, 2015). The author acknowledges that dialysis burdens and risks are rarely considered prior to deciding upon treatment options, and suggests that this tool may assist consumers to make decisions based on their personal values at one of four critical points: whilst pre-dialysis; if they “crash” into dialysis suddenly; if they have a failing transplant; or are currently unhappy with dialysis life. Whilst the terms “shared decision making” are absent from their article, the author states the tool may better assist clinicians in supporting patients “to help them live on their own terms” (Schatell, 2015, p. 153). (Level 5)

- A review of several patient decision aids centred around either dialysis initiation or conservative kidney management, compared 10 international decision aids which had main emphasis on RRT at time of dialysis initiation, and three relatively new aids regarding conservative care (Davis & Davison, 2017). The authors discuss SDM, consider care gaps and challenges, difficulties in prognostication, and acknowledge difficulties in conservative kidney management conversations. In their comparison of decision aid tools, displayed in tables, they describe the format, organisation/country of origin, and give additional contemporary information regarding updates. Their review of the aids in line with specific case examples offers insightful comment on the need to enhance communication between patients and care providers. (Level 5)

### Prognosis and risk prediction to assist shared decision making

- In acknowledging that “as comorbidities go up, the survival advantage of starting renal replacement goes down, and survival between patients started on RRT and those with conservative care become similar” (Peeters et al., 2016, p. 2), an observational study aimed to externally validate a risk stratification model utilising the Renal Epidemiology Information Network (REIN) registry. In the prognostic model, baseline co-morbidity data was calculated for each patient (n=2679), and a final abbreviated REIN (aREIN) score was ascribed. Mortality rates at 3, 6 and 12 months were calculated; in the final RoC analysis, the aREIN score had an AUC (area under the curve) of 0.74 for prediction of survival at 3, 6 and 12 months. For those with aREIN score ≤4 or ≥9, mortality at 6 months rose incrementally from 5.6 to 45.8%, respectively. The authors state that the “aREIN score delivers meaningful discrimination between low and high-risk populations” (p. 1). Importantly, individualised data may be presented to the patient pictographically, to convey helpful and realistic prognostic information during the SDM process. As a clinically valid risk stratification tool, the authors conclude “Such a tool is crucial to assist evidence-based shared decision making on whether to start dialysis or opt for conservative care” (Peeters et al., 2016, p. 9). (Level 3)

- Recognising the need to adequately inform patients approaching ESKD of appropriate treatment options, an opinion piece examined several risk prediction models to facilitate information transference, in an individualised manner (Stryckers et al., 2016). The authors suggest the estimation of likelihood to achieving end stage is significant in relation to a patient’s age and general prognosis, and consider several risk prediction models that may assist nephrologists in providing SDM at this point. Using realistic mortality prediction scoring, they contemplate the steps of each model, examining potential pitfalls and problems and offering potential strengths, so personal care expectations may be tailored to realistic and achievable outcomes. (Level 5)

### Guidelines

- A revised clinical practice guideline on SDM in the initiation and withdrawal from dialysis included ten recommendations for adult patients with acute kidney injury (AKI), CKD or ESKD (Moss, 2010, p. 2382). The recommendations from the Renal Physicians Association in the United States are:

2. “Fully inform AKI, stage 4 and 5 CKD, and ESRD patients about their diagnosis, prognosis, and all treatment options.”
3. “Give all patients with AKI, stage 5 CKD, or ESRD an estimate of prognosis specific to their overall condition.”
4. “Institute advance care planning.”
5. “If appropriate, forgo (withhold initiating or withdraw
ongoing) dialysis for patients with AKI, CKD, or ESRD in certain, well-defined situations."

6. “Consider forgoing dialysis for AKI, CKD, or ESRD patients who have a very poor prognosis or for whom dialysis cannot be provided safely.”

7. “Consider a time-limited trial of dialysis for patients requiring dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis.”

8. “Establish a systematic due process approach for conflict resolution if there is disagreement about what decision should be made with regard to dialysis.”

9. “To improve patient-centred outcomes, offer palliative care services and interventions to all AKI, CKD, and ESRD patients who suffer from burdens of their disease.”

10. “Use a systematic approach to communicate about diagnosis, prognosis, treatment options, and goals of care.” (Level 5)

Other comment

- All papers reviewed in this summary acknowledge the significance of SDM, most offering decisive and succinct suggestions on improving communication in the decision-making process — as elucidated. However, one paper reminds that the ethical principle of autonomy is contingent upon patients having the choice to be involved. “Respect for patient autonomy means that patients are free to relinquish their decision-making autonomy to providers” (Gordon et al., 2013, p. 1150), and the choice to make decisions, or be actively involved in their own care, is something not all persons are comfortable accepting. Yet, conversely, such should never be assumed. In fact, “the assumptions that some patients are not able or do not want to participate in decision making is inconsistent with both the evidence and contemporary models of care” (Politi et al., 2013, p. 1). Therefore, it is pivotal to recognise that it is through successful and contextual discussion and ultimately commencement of the SDM process that determination of the patient’s preferred level of involvement will be made apparent.

Best practice recommendations

- Clinicians should receive education about SDM and strategies to facilitate its successful implementation. (Grade A)

- Clinicians should ensure that CKD patients are adequately informed of different treatment options and the associated impacts on lifestyle, giving them the ability to participate in SDM about treatment decisions. (Grade A)

- SDM as an approach is continually appropriate, at initiation, through continuance of treatment especially at sentinel instances, and at stopping treatment/dialysis. (Grade A)

- Clinicians should consider the use of decision-making aids as suitable to the individual’s situation. (Grade A)

- Incorporation of other patients with CKD as mentors or educators of new patients may be beneficial. (Grade B)

- Optimal timing of education about treatment options may be at the beginning of Stage 4 CKD, to allow SDM before the creation of access for dialysis. (Grade B)

Conclusions

If quality of life has any merit for any person it is determined by the choices the individual makes, within the context of the beliefs and values they hold. As international health care agencies transition from traditional disease models to contexts of patient-centred health care, the imperative to involve the patient in all stages of their care becomes more obvious (WHO, 2016). Acknowledging that simple information sharing does not constitute SDM (Thomas et al., 2016), the decisive elements of evidence-based best practice and consideration of the patient’s preferences will offer guidance for their active collaboration in health care decisions. In the SDM way, the most appropriate treatment strategies can be utilised and with ongoing review, the best outcomes may be realised in a meaningful manner.

Additional patient resources:


To obtain general consumer-oriented information on kidney disease and treatment options:

For further nephrology information, see the KHA-CARI guidelines:
www.cari.org.au/

References


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Pollitt, C., Dixon, D., Frosch, D., Kuzemchak, M., & Stiggelbout, A. (2013). Importance of clarifying patients’ desired role in shared decision making to match their level of engagement with their preferences. *BMJ, 347*, 1–3. doi:10.1136/bmj.f7086


