



Review

A systematic review of factors influencing decision-making in adults living with chronic kidney disease

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ABSTRACT

Objective: To identify factors influencing patient involvement in decision-making in the context of chronic kidney disease (CKD) and effective interventions to support their decision-making needs.

Methods: A systematic review included studies and decision support tools that involved: (1) adults with CKD, (2) studies published from 1998–2008; and (3) a focus on patient decision-making needs, and/or barriers and facilitators to shared decision-making. Studies were quality appraised.

Results: Forty studies were appraised. These studies mainly focused on the decisions patients with CKD faced around the choice of renal replacement therapy and withholding/withdrawing dialysis. Moreover, studies typically focused on health care professional's provision of information about the decision rather than identifying decisional conflict and supporting patients in decision-making. No studies were found that identified the patient's point of view about factors that might influence or inhibit quality decision-making. Factors influencing CKD patient's participation in decision included: (1) interpersonal relationships; (2) preservation of current well being, normality and quality of life; (3) need for control; and (4) personal importance on benefits and risks. Of the four patient decision aids identified, none had been evaluated for effectiveness.

Conclusion: Patients with CKD face decisions that are likely to cause decisional conflict. Most studies focused on information needs related to renal replacement therapy and withdrawing or withholding dialysis. There was less focus on other decision-making needs in the context of those choices and across the trajectory of CKD. Although patient decision aids and implementation of shared decision-making have been evaluated in patients with other medical conditions, little is known about interventions to support patients with CKD making quality decisions.

Practice implications: Patients with CKD have decision-making needs across the trajectory of their illness. Although little is known about supporting patients with CKD decision-making, support could be provided with protocols and tools that have been developed for other chronic illness situations. Development of CKD-specific clinical practice guidelines that include decision support best practices could benefit CKD patients. Research priorities include development and evaluation of CKD focused decision support tools and processes.

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1. Background

Chronic kidney disease (CKD) is a global health issue associated with significant mortality and morbidity [1]. Outcomes of CKD include kidney failure and complications from decreased kidney function. End stage CKD is managed by dialysis, renal transplant or supportive end-of-life care. Patients with end stage renal disease (ESRD), not receiving active renal replacement therapy, will die from their kidney failure. In addition to managing multiple physiologic changes patients living with CKD frequently experience psychosocial stress.

Patients living with CKD face numerous decisions throughout their illness. While many patients want to participate in health related decisions [2–5] they may experience decisional conflict when considering options and the importance they attach to the pros and cons associated with those options [6]. Modifiable factors

such as knowledge gaps, uncertainty regarding outcomes, lack of clarity about what matters most, and feeling pressured to choose a particular option exacerbates the decisional conflict [7]. For instance, patients' attitudes towards decisions such as whether or not to accept the offer of a living donor kidney transplant can vary. Patients with unresolved decisional conflict are more likely to change their mind, delay decision-making, have regret and/or blame providers [8,9].

Effective interventions to guide patients in decision-making are decision aids and shared decision-making [10]. Patients exposed to decision aids are more likely to be informed, have realistic expectations of outcomes of options, participate actively in decision-making, and feel lower decisional conflict [11]. However, research shows that practitioners have inadequate skills in supporting patient decision-making. Practitioners have identified time constraints, patient characteristics or clinical situation,

Database: Ovid MEDLINE(R) <1996 to October Week 5 2007>
Search Strategy:

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1  Kidney Failure, Chronic/nu, px, dt, rh, th [Nursing, Psychology, Drug Therapy, Rehabilitation,
Therapy] (14553)
2  Kidney Failure/nu, dt, px, rh, th [Nursing, Drug Therapy, Psychology, Rehabilitation, Therapy] (1163)
3  Kidney Diseases/nu, dt, px, rh, th [Nursing, Drug Therapy, Psychology, Rehabilitation, Therapy]
(3121)
4  renal dysfunction.tw. (4299)
5  chronic kidney disease$1.mp. (3063)
6  ckd.ti.ab. (1531)
7  renal insufficiency/ or renal insufficiency, chronic/ (660)
8  progressive renal insufficiency.mp. (161)
9  cri.ti.ab. (634)
10 (cri du chat or credibl$3 interval or constant rate infusion or central research institute or
cardiovascular research institute or cholic acid retardation index or complement receptor or catheter
related infection$1 or central venous catheter related infection$1 or coronary resistance index or
characteristic root index or cumulative risk index or coping responses inventory or complete residual
inhibition).ti.ab. (2126)
11 9 not 10 (456)
12 end stage renal disease$1.mp. (8358)
13 esrd.ti.ab. (4390)
14 chronic renal failure.mp. (7601)
15 crf.ti.ab. (4166)
16 (corticotrop?in releasing: or classical receptive field$1 or circulating recombinant:).tw. (4976)
17 15 not 16 (2399)
18 renal failure.tw. (26055)
19 Chronic Disease/ (68230)
20 or/1-8,11-14,17-19 (117496)
21 decision:.mp. (95731)
22 decision making/ or choice behavior/ or negotiating/ or uncertainty/ (35323)
23 decision support techniques/ (4763)
24 (choice: or preference:).mp. (113866)
25 or/21-24 (202665)
26 harm reduction/ or health behavior/ or patient compliance/ or treatment refusal/ (35618)
27 consumer participation/ or patient participation/ (12689)
28 consumer satisfaction/ or patient satisfaction/ (33470)
29 Health Education/ (15049)
30 cooperative behavior/ or (collaborative care or collaboration).mp. or communication/ or
communication barriers/ or language/ or nonverbal communication/ or exp manual communication/
(52588)
31 or/26-29,30 (139786)
32 and/25,31 (18102)
33 ((patient$1 or consumer$1) adj1 (decision: or choice: or preference: or participat:)).tw. (7479)
34 ((personal or individual or famil$3) adj1 (decision: or choice: or preference: or participat:)).tw. (1866)
35 (shar$3 decision: or informed decision: or informed choice:).mp. (2654)
36 or/32-35 (26655)
37 and/20,36 (791)
38 Nurse's Role/ or exp nurses/ or exp nursing staff/ (57519)
39 Case Management/ or care coordinator:.tw. (5599)
40 or/38-39 (62572)
41 and/20,36,40 (46)
42 (decision coaching or motivational interviewing or decisional conflict$1or shared decision making or
risk communication or health coaching).mp. (899)

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Fig. 1. Search Strategy used in MEDLINE database.

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