Patient and healthcare professional decision-making to commence and withdraw from renal dialysis: a systematic review of qualitative research

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Abstract

Background and objectives. To ensure decisions to start and stop dialysis in end stage kidney disease are shared, the factors that affect patients and healthcare professionals in making such decisions need to be understood. This systematic review aims to explore how and why different factors mediate the choices about dialysis treatment.

Design, setting, participants, and measurements. Medline, Embase, CINAHL and PsychINFO were searched for qualitative studies of factors that affect patients' and/or healthcare professionals' decisions to commence or withdraw from dialysis. A thematic synthesis was conducted.

Results. Of 494 articles screened, 12 studies (conducted: 1985-2014) were included. These involved 206 predominantly haemodialysis patients and 64 healthcare professionals (age range: patients 26-93; professionals 26-61 years). (i) *Commencing dialysis:* patients based their choice on 'gut-instinct' as well as deliberating the impact of treatment on quality-of-life and survival. How individuals coped with decision-making was influential, some tried to take control of the problem of progressive renal failure, whilst others focussed on controlling their emotions. Healthcare professionals weighed-up biomedical factors and were led by an instinct to prolong life. Both patients and healthcare professionals described feeling powerless. (ii) *Dialysis withdrawal*: Only after prolonged periods of time on dialysis, were the realities of life on dialysis fully appreciated and past choice questioned. By this stage however patients were physically treatment dependent. Similar to commencing dialysis, individuals coped with treatment withdrawal in a problem or emotion-controlling way. Families struggled to differentiate choosing versus allowing death. Healthcare teams avoided and queried discussions regarding dialysis withdrawal. Patients however missed the dialogue they experienced during pre-dialysis education.

Conclusions. Decision-making in end stage kidney disease is complex, dynamic, and evolves over time and towards death. The factors at work are multi-faceted and operate differently for patients and health professionals. More training and research on open-communication and shared decision-making is needed.

Introduction

Dialysis brings high treatment burden to patients and families, considerable costs to health services, and high mortality, with 65% dying within 5 years(1). Over three quarters of those with end-stage kidney disease (ESKD) are treated with dialysis(2), however decisions whether to start, continue, or stop dialysis remain poorly informed by evidence, and rely predominantly on observational studies with all their inherent limitations(3-5).

In order to help patients, families and healthcare professionals make joint decisions about dialysis treatment, clinical practice guidelines were developed by the Renal Physicians Association (RPA) for shared decision-making in the appropriate initiation of and withdrawal from dialysis(6). These support patient preferences, while acknowledging the limitations in the evidence. A large number of quantitative studies have looked at physiological(7-10), social(8, 10-14), educational(15-17), and geographical factors(18) that influence the decision to commence and withdraw from dialysis(15-22). These studies have provided insights into influential factors, however their largely survey-based methodology does not further our understanding of why and how different factors operate.

Qualitative research provides an in-depth and interpreted understanding of the factors that affect decision-making, with a focus on how and why patients and healthcare professional make sense of their experiences and perspectives(23). An inductive approach can help determine new hypotheses and theories for subsequent empirical testing(23). Two systematic reviews(24, 25) including qualitative studies in this area, have examined factors that influence patient decisions, however factors that affect healthcare professionals and their interactions with patients in the decision-making process are still largely unexplored. As healthcare professionals and patients are partners in the shared decision-model advocated by the RPA(6) and National Service Framework (2005)(26), this is an important gap in the current evidence-base.

In order to address this gap, this systematic review aimed to identify and synthesise existing qualitative research, to explore: how and why different factors influence patients and healthcare professionals in the decision to commence and withdraw dialysis as ESKD progresses. The synthesis of primary qualitative studies creates a cumulative body of evidence that builds and develops theory for practice in ways that individual studies can not(27). This will therefore further our understanding of how decisions are made in this context and how effective shared-decision making can be facilitated.

Materials and methods

Selection criteria

Participants included in the studies were adult patients with CKD, who had made a decision for or against dialysis. Studies that explored healthcare professionals' views of caring for such patients during the decision-making process were also included. This group included physicians, dialysis nurses, student nurses, and social workers.

Literature search

MeSH terms and text words for ESKD, dialysis, conservative kidney management (CKM) and decision-making were combined with validated terms for qualitative studies(28) (Appendix A).The search was performed in Medline, EMBASE, CINAHL, and PsychINFO and last updated in May 2014. Reference lists of relevant papers and contents pages of relevant journals were searched. Two researchers independently assessed titles, abstracts and full-texts against the inclusion criteria.

Quality appraisal

All papers were assessed against the Hawker et al (29) appraisal checklist. Inter-rater agreement was assessed on a purposive selection of five studies with a range of scores (kappa = 0.9).

Synthesis of findings

The papers were synthesised systematically using thematic synthesis(30), an established and widely used method of analysing qualitative research. This synthesis was approached from a realist perspective and aimed to provide recommendations for clinical practice. This school of thought considers reality to exist independent of those observing it, however recognises the importance of understanding the participants' own interpretation of events(31). As thematic analysis is not restricted theoretically, and enables both inductive and deductive analysis, it provides an appropriate method for such a synthesis. The analysis was managed using ATLAS.ti (v.7) and reported in accordance with the Enhancing Transparency in REporting the synthesis of Qualitative research (ENTREQ) guidance(32).

Results

Literature search and study descriptions

Of the 494 articles screened, 12 studies involving 206 patients and 64 healthcare professionals, were included in the synthesis (**figure1)**. **Table 1** summarises the studies included in the review and **table 2** illustrates how many codes, items of evidence and papers contributed to each theme. Most studies were conducted between 1997-2014, in Europe (n=5)(33-37) and the USA (n=5)(38-42), with the remainder in Australia(43) and Taiwan(44). Five studies were conducted in single-payer healthcare systems (33-34, 36-37, 44), two in two-tier systems (35, 43), and five in a country with an insurance mandate (38-42). Researchers, independent of the healthcare team and patient, conducted all interviews, focus groups, and observations.

Quality appraisal

The Hawker et al (2002)(29) quality assessment scores ranged from 21-33 (**table 3**), which indicated fair to good quality of all studies.

Synthesis

The decision-making process evolved as patients progressed along their disease trajectory. The factors and how they influence choice will be presented according to the decision whether to (i) start dialysis and (ii) withdraw from treatment. These will be presented as patient factors, healthcare professional factors and their interaction (see **table 4** for exemplars).

Commencing or with-holding dialysis: patient-level factors

Deliberation of factors

Patients considered a variety of factors when deciding whether to start dialysis, and these were different for each individual. **Figure 2** illustrates the categories that contributed to this theme. Patients deliberated about the influence of the treatment choice on their quality of life (QoL)(33, 34, 36, 37, 40, 41, 43, 44), which was then weighed against the survival benefits(33, 34, 36, 37, 41, 43, 44). Whether the impact on QoL outweighed survival advantage, or vice versa, was a personal judgement, and not something healthcare professionals and family members could predict(41). For many patients, the effect of treatment on QoL was more important than medical effectiveness(40), and maintaining a good QoL outweighed having a 'long life'(33).

Gut instinct

Patients also based the decision to start dialysis on their intuition on whether to:

- Opt for the life prolonging treatment, regardless of the personal cost

or

- Accept dying as a natural course, given the 'loss of self-identity… source of great hardship and suffering, and a fragmentation of lifestyle'(44) associated with dialysis.

Some individuals did not have a strong instinct for either of these, and they described the choice as one between 'two evils'(37, 42, 44). Dialysis was considered by these patients to be the 'lesser of two evils(37),' given their significant pre-dialysis symptom burden and the inevitability of death without treatment. Nonetheless, it was not a decision these individuals wanted to make, but one they were forced to, as their renal function deteriorated(37).

How individuals coped with the decision-making process was important. Two types of coping responses were evident(33, 36, 37, 39-41, 44): (i) control the problem, (ii) control emotions. Problem-controlling patients aimed to gain command of the situation and sought information, advice and opinions(37, 39-41). Emotion-controllers instead focussed on how to handle the negative emotions associated with the situation(38). These emotions ranged from 'shock'(42, 44), to 'anger'(36), 'fear'(42, 44), and 'torture'(44). They employed a variety of methods to minimise emotions, including false hope(42), avoidance(38, 42), dependence on others to make decisions, and passive acceptance of treatment(33).

Commencing or with-holding dialysis: healthcare professional factors

Bio-medical criteria

The healthcare professionals' decision whether to start dialysis was predominantly influenced by medical criteria and clinical experience(34), rather than patient preference. Patients perceived that maintenance of 'physiological balance' was the healthcare professional's aim(33). The medical criteria weighed-up by physicians were primarily age, comorbidities, physical function, prognosis, and cognitive impairment(34, 35). Due to the unpredictable and asymptomatic nature of disease progression, blood tests were often relied upon to predict and educate patients about when dialysis may be required(42), however patients often 'lacked understanding of the blood test value's meaning relative to their own experience'(42).

Physicians were also cognizant of when it was unethical to prolong life, particularly with frail patients and those with a terminal illness(34). They acknowledged that dialysis could prolong 'the suffering and the process of dying, rather than adding quality days to the patient's life(34).' Nonetheless, even when healthcare professionals did not think someone would benefit from dialysis, they continued to offer the treatment, because to withhold treatment was difficult(34) and they were led by their instinct to 'err on the side of life'(34).

Commencing or with-holding dialysis: Patient and healthcare team interaction

Power and communication

An important barrier to shared decision-making was the perceived power and dominance of the healthcare team. Healthcare professionals were considered to own the knowledge 'and decided what the patient needed to know(33, 42)'; and the patient relied on the team to share any knowledge(33). Healthcare professionals however also described their own 'sense of powerlessness'(42) when faced with ESKD patients, given the inevitability of disease progression.

Lelie (2000) found that physicians had typical 'ideal' ways to provide information to patients of different age groups(35), with younger patients less likely to be informed of the option of CKM. Some patients were satisfied with the information they received(33) and thought they had made an informed independent decision(36, 37). Others felt uninformed, did not feel they could ask questions, or did not know what to ask(33, 42). Moreover some misunderstood the information(36) and in particular its potential impact on their lives(42).

Acutely unwell patients often had little time to make a decision, could not always remember what had happened(33), or were unable to 'deliberate' about treatment(39). The information provided was not consistent and was considered as 'accidental' in its delivery(33). These patients often did not consider the decision to be their own(39).

The way information, and in particular risk, was presented influenced patient's decisions(36, 40, 43). Some patients, after discussion with healthcare professionals, did not think a decision needed to be made(36). When healthcare professionals did communicate the uncertainty around the choice of treatment, this resulted in fear(40), however more information about the future was still considered better than none by patients(42).

In addition, the person who provided the information and whether they were trusted by the patient was important(33, 36, 40, 43). The majority felt that 'if you wanna live'(40) they had to trust the physician to offer treatments that gave them future hope(40). The decision was unique and complex and so 'who else you gonna trust(40)' was expressed to justify a dependence on professional judgement, which commonly nudged patients towards the choice considered to be medically optimal(39).

Dialysis withdrawal: patient-level factors

Life on dialysis

Participants remained convinced of their choice to have dialysis whilst they continued to experience the symptomatic benefits of treatment(40). At this stage dialysis had made them feel better, and this furthered their trust in the healthcare team(33). However, once their condition was no longer improving, past choice was questioned(40, 42). This was typically after a prolonged period of time, i.e. years on dialysis, when the 'arduous' realities of life on dialysis were more fully appreciated(36, 40-44). For many, particularly emotion-controlled patients, 'their passive acceptance later generates profound questions about the meaning and worth(39)' of life on dialysis. This resulted once again in a feeling of powerlessness about one's own life; and a weariness(41) described as 'sick of coming here', 'had enough', and 'just don't want to do this anymore.'(41)

Facing withdrawal

Over time, participants reported that dialysis came to be seen as a 'death sentence' in itself(44). Unfortunately by this stage patients were dependent on treatment and withdrawal would result in imminent death, often within days(45). Therefore the anxiety around such a decision was heightened, especially for those who had avoided the decision to commence dialysis in order to control their emotions(34, 44), and were now faced with the same difficult choice between life on dialysis or death, but with more acute consequences if they chose the latter(34).

As with the decision to with-hold treatment, individuals coped with dialysis withdrawal in a problem-controlling or emotion-controlling way. For some problem focussed patients, it was important to know they could stop treatment, as this gave them back control(41). In contrast, the emotion-controllers did not want to face such a decision, and so focussed on the present to avoid thoughts about future uncertainties(42).

Family influence

From the family's perspective the decision to withdraw treatment was equally difficult. Families found it difficult to differentiate between 'allowing death and choosing it(41),' and so 'guilt(41)' was closely associated with such decisions.

Avoidance

Despite the worries expressed by patients on dialysis, healthcare professionals acknowledged their own concerns about initiating discussions about treatment withdrawal(34, 39, 42). This was because: they did not want to upset patients by being 'too explicit'(41); the uncertainty of disease progression(42); and the moral and ethical burdens associated with such decisions(43). There was also evidence that over an extended period of time a close relationship develops between patients and the renal team(41). This made it difficult for healthcare professionals to separate their own instinct from the patient's choice(41).

Genuine request

Healthcare professional's also found it difficult to distinguish between a genuine request for withdrawal, from an attempt to simply discuss the goals of therapy and complain given the demanding nature of dialysis(39, 41). This resulted in cautious interpretation of patient cues to discuss withdrawal, with depression and other treatable causes considered at first(41). Whether patients fully understood the implications of treatment withdrawal was also a concern(41).

Dialysis withdrawal: Patient and healthcare team interaction

Doing trumps talking

Patients 'missed engaging in the dialogue(33)' which was once easily accessible, 'rote(41)' and 'procedural(41)' during pre-dialysis education. The task-orientated conduct of the dialysis team made patients feel 'controlled and incapacitated(33).' Healthcare professionals however considered patients as 'voting with their feet', with 'doing' considered to 'trump talking.'(41) These individuals attended dialysis week after week, and the team interpreted this as evidence of on-going consent to treatment. Lack of acknowledgement that under the 'veneer of straightforward participation in the treatment, are doubt and ambivalence(41),' was thought to result from the team's presumption that patients must want to choose life and therefore continued to attend for dialysis (34, 41).

If not now, when?

Even when healthcare professionals judged that treatment was futile and patients continued to deteriorate despite dialysis, with-holding treatment was frequently delayed until it became physiologically necessary(34, 40). From both the patient's and healthcare professional's perspective, the point of withdrawal remained in the future, once all alternatives had been exhausted(41).

Discussion

Decision-making in ESKD is complex, dynamic, and evolves over time and towards death. The factors at work operate differently for patients and healthcare professionals. Our findings resonate with results from previous quantitative and qualitative studies, however this synthesis expands on these and provides a deeper understanding of how and why different factors influence decisions about dialysis.

To facilitate informed shared decision-making it is important to incorporate decision-making theory into tools designed to make such processes explicit to stakeholders, such as the RPA clinical practice guidance on shared decision-making(6). We found that patients made their choice through careful deliberation of multiple factors, as well as their gut instinct. This is consistent with Dual Processing Theory which proposes there are two modes of thinking: System 1 which is intuitive i.e. based on gut instinct and System 2 which is analytical i.e. deliberation of factors(46-48). System 2 requires high cognitive effort and is often employed when decision accuracy is pertinent(49), such as in ESKD. System 1 however requires less cognitive effort(49), therefore patients with cognitive impairment secondary to uraemia or comorbidities, may rely on this. Healthcare professionals also used System 1 and 2 processing. They relied predominantly on the deliberation of biomedical and ethical factors, but were also driven by an instinct to 'err on the side of life(34).' To make such cognitive processes transparent to patients, family members, and healthcare professionals, through the shared decision-making process advocated by the RPA guidance(6), is a necessary step to ensure decisions are informed and consistent with the patient's preference.

How patients coped with emotions was also important. The impact of emotions on choice is well described and it is suggested that an emotional reaction to a stimulus is the most important factor to guide decisions(50). Two coping mechanisms, problem-controlling and emotion-controlling were evident. These are consistent with Folkman and Lazarus' (1988)(51) theory of problem and emotion-focussed coping. Problem-focussed individuals deal with unpleasant emotions and situations by attempting to solve the underlying problem, whereas emotion-focussed individuals cope through the minimisation of thoughts and feelings about the problem(51). Healthcare professionals also found decision-making a challenge, as patients gradually progressed along an unpredictable trajectory towards death. Support for healthcare professionals is not addressed in current guidance on shared-decision making(6). Acknowledgement and regular assessment and support for the emotional impact of decision-making in this context is therefore required, how to provide and implement this requires further research.

The synthesis also highlighted how factors that affect choice for patients and healthcare professionals evolve over time, and in particular how pre-dialysis education did not prepare patients sufficiently for their personal experience of life on dialysis. In view of this and the difficulties in initiating discussions about treatment withdrawal, one recommendation is for the role of pre-dialysis nurses to be extended to continue throughout the disease trajectory. This will provide continuity in discussions about treatment with a designated individual, who has already invested time to understand the patient's priorities; and will therefore enable the RPA guidance to be applied in a sensitive and timely manner.

The majority of studies in this review were from Western developed countries (n=11) and did not commonly report ethnicity, level of education, and the socioeconomic class of patients. Few studies provided information on those who chose conservative management. Patients with cognitive impairment were not included in the original studies. Also the experiences of those waiting for renal transplants were not within the scope of this review. These are areas that require further research.

The nephrology community has made significant advances to address the issue of advance care planning in ESKD. To ensure such decisions are shared and informed, System 1 and 2 information processing, and how individuals cope with the decision-making process, must be further understood and incorporated into decision-making tools. Furthermore, continuity of patient-centred communication throughout the disease trajectory may facilitate timelier joint decision-making with regards to dialysis withdrawal.

Disclosures

Conflicts of interest: None to declare.

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References

1. Song MK, Lin FC, Gilet CA, Arnold RM, Bridgman JC, Ward SE: Patient perspectives on informed decision-making surrounding dialysis initiation. *Nephrol Dial Transplant* 28(11): 2815-23, 2013
2. Fensenius Medical Care: ESRD Patients in 2011: A global perspective. In: Frenius Medical Care, Germany, 2012.
3. Hussain JA, Mooney A, Russon L: Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease. *Palliat Med* 27(9): 829-

39, 2013
4. Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood RN, Farrington K: Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrol Dial Transplant* 26 (5):1 608-14, 2011.
5. Murtagh FE, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE.: Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transplant* 22(7): 1955-62, 2007.
6. Renal Physicians Association Working Group: Shared decision-making in the appropriate initiation of and withdrawal from dialysis: clinical practice guideline. *Renal Physicians Association* [Online] Available from: http://www.renalmd.org/WorkArea/DownloadAsset.aspx?id=2710, [Accessed Jan 2015], 2010
7. Ahmed S, Addicott C, Qureshi M, Pendleton N, Clague JE, Horan MA: Opinions of elderly people on treatment for end-stage renal disease. *Gerontology* 45(3): 156-9, 1999.
8. Bajwa K, Szabo E, Kjellstrand CM: A prospective study of risk factors and decision making in discontinuation of dialysis. *Arch Intern Med* 156(22): 2571-7, 1996.
9. Davison SN, Jhangri GS: The impact of chronic pain on depression, sleep, and the desire to withdraw from dialysis in hemodialysis patients. *J Pain Symptom Manage* 30(5): 465-73, 2005.
10. Tse DMW: Experience of a renal palliative care program in a Hong Kong center: Characteristics of patients who prefer palliative care to dialysis. *HKJN* 11(2): 50-8, 2009.
11. Bapat U, Nayak SG, Kedleya PG, Gokulnath: Demographics and social factors associated with acceptance of treatment in patients with chronic kidney disease. *Saudi J Kidney Dis Transpl* 19(1): 132-6, 2008.
12. Joly D, Anglicheau D, Alberti C, Nguyen AT, Touram M, Grunfeld JP, Jungers P: Octogenarians reaching end-stage renal disease: cohort study of decision-making and clinical outcomes. *J Am Soc Nephrol.* 14(4): 1012-21, 2003.
13. Navaneethan SD, Kandula P, Jeevanantham V, Nally JV, Jr., Liebman SE: Referral patterns of primary care physicians for chronic kidney disease in general population and geriatric patients. *Clin Nephrol* 73(4): 260-7, 2010.
14. Sekkarie MA, Moss AH: Withholding and withdrawing dialysis: the role of physician specialty and education and patient functional status. *Am J Kidney Dis.* 31(3): 464-72**,** 1998.
15. Cohen LM, Germain M, Woods A, Gilman ED, McCue JD: Patient attitudes and psychological considerations in dialysis discontinuation. *Psychosomatics* 34(5): 395-401, 1993.
16. Hines SC, Badzek L, Moss AH: Informed consent among chronically ill elderly: Assessing its (in)adequacy and predictors. *J Appl Commun Res.* 25(3): 151-69, 1997.
17. Morton RL, Howard K, Webster AC, Snelling P: Patient INformation about Options for Treatment (PINOT): A prospective national study of information given to incident CKD Stage 5 patients. *Nephrol Dial Transplant* 26(4): 1266-74, 2011.
18. McKenzie JK, Moss AH, Feest TG, Stocking CB, Siegler M: Dialysis decision making in Canada, the United Kingdom, and the United States. *Am J Kidney Dis* 31(1): 12-8, 1998.
19. Hirsch DJ: Death from dialysis termination. *Nephrol Dial Transplant* 4(1): 41-4, 1989.
20. Leggat Jr JE, Bloembergen WE, Levine G, Hulbert-Shearon TE, Port FK: An analysis of risk factors for withdrawal from dialysis before death. *J Am Soc Nephrol* 8(11): 1755-63, 1997.
21. Orsino A, Cameron JI, Seidl M, Mendelssohn D, Stewart DE: Medical decision-making and information needs in end-stage renal disease patients. *Gen Hosp Psychiat.* 25(5): 324-31, 2003.
22. Parry RG, Crowe A, Stevens JM, Mason JC, Roderick P: Referral of elderly patients with severe renal failure: questionnaire survey of physicians. *BMJ* 313(7055): 466, 1996.
23. Powers B.A: Generating evidence through qualitative research. In: Melnyk BM, Fineout-Overholt E, editors. Evidence-Based Practice in Nursing and Health

Care, Philadelphia, Lippincott Williams & Wilkins; 2005.
24. Morton RL, Tong A, Howard K, Snelling P, Webster AC: The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BMJ* 340:c112, 2010.
25. Murray MA, Brunier G, Chung JO, Craig LA, Mills C, Thomas A, Stacey D. A systematic review of factors influencing decision-making in adults living with chronic kidney disease. *Patient Educ Couns.* 76(2): 149-58, 2009.
26. Department of Health: National Service Framework for Renal Services-Part Two: Chronic kidney disease, acute renal failure and end of life care. In: Department of Health, ed. London, UK: 2005.
27. Flemming K: The synthesis of qualitative research and evidence based nursing. *Evid Based Nurs* 10: 68-71, 2007.
28. Flemming K, Briggs M: Electronic searching to locate qualitative research: evaluation of three strategies. *J Adv Nurs* 57(1): 95-100, 2007.
29. Hawker S, Payne S, Kerr C, Hardey M, Powell J: Appraising the evidence: reviewing disparate data systematically. *Qual Health Res* 12(9): 1284-99, 2002.
30. Braun V, Clarke V: Using thematic analysis in psychology. *Qual Res Psychol* 3(2): 77-101, 2006.
31. Robson C: Real world research, 2nd edition, Oxford: Blackwell.
32. Tong A, Flemming K, McInnes E, Oliver S, Craig J: Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 12(1): 1-8, 2012.
33. Aasen EM, Kvangarsnes M, Heggen K: Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. *Scand J Caring Sci.* 26(1): 61-9, 2012.
34. Halvorsen K, Slettebo A, Nortvedt P, Pedersen R, Kirkevold M, Nordhaug M, Brinchmann BS: Priority dilemmas in dialysis: the impact of old age. *J Med Ethics.* 34(8): 585-9, 2008.
35. Lelie A: Decision-making in nephrology: Shared decision making? *Patient Educ Couns.* 39(1): 81-9, 2000.
36. Noble H, Meyer J, Bridges J, Kelly D, Johnson B: Reasons renal patients give for deciding not to dialyze: a prospective qualitative interview study. *Dial Transplant.* 37(3): 82-9, 2009.
37. Tweed AE, Ceaser K: Renal replacement therapy choices for pre-dialysis renal patients. *Br J Nurs.* 14(12): 659-64, 2005.
38. Breckenridge DM. Patients' perceptions of why, how, and by whom dialysis treatment modality was chosen. *ANNA J* 24(3): 313-21, 1997.
39. Kaufman SR, Shim JK, Russ AJ: Old age, life extension, and the character of medical choice. *J Gerontol B Psychol Sci Soc Sci* 61(4):S175-84, 2006.
40. Kelly-Powell ML: Personalizing choices: patients' experiences with making treatment decisions. *Res Nurs Health.* 20(3): 219-27, 1997.
41. Russ AJ, Shim JK, Kaufman SR: The value of "life at any cost": talk about stopping kidney dialysis. *Soc Sci Med.* 64(11): 2236-47, 2007.
42. Schell JO, Patel UD, Steinhauser KE, Ammarell N, Tulsky JA: Discussions of the Kidney Disease Trajectory by Elderly Patients and Nephrologists: A Qualitative Study. *Am J Kidney Dis.* 59(4): 495-503, 2012;.
43. Ashby M, op't Hoog C, Kellehear A, Kerr PG, Brooks D, Nicholls K, Forrest M: Renal dialysis abatement: lessons from a social study. *Palliat Med.* 19(5): 389-96, 2005.
44. Lin C, Lee B, Hicks FD: The phenomenology of deciding about hemodialysis among Taiwanese. *West J Nurs Res* 27(7): 915-34, 2005;.
45. Murtagh F, Cohen LM, Germain MJ: Dialysis discontinuation: quo vadis? *Adv Chronic Kidney Dis* 14(4):379-401, 2007.
46. Kahneman D, Frederick S: Representativeness revisited: attribute substitution in intuitive judgment. In: T. Gilovich D. Griffin, D. Kahneman editors. Heurisitics and biases: The psychology of intuitive judgement, New York, NY, Cambridge University Press, 2002, p. 49-81.
47. Sloman SA: The empirical case for two systems of reasoning. *Psychol Bull* 119:3-22, 1996.
48. Stanovich KE, West RF: Individual differences in reasoning: Implications for the

rationality debate? In: T. Gilovich, DW Griffin, D. Kahneman eds, Heurisitics and biases: The psychology of intuitive judgement, New York, NY, Cambridge University Press, 2002, p. 421-40.
49. Kahneman D. A perspective on judgment and choice: mapping bounded rationality. *Am Psychol* 58(9): 697-720, 2003.
50. Zajonc RB: Feeling and thinking: preferences need no inferences. *Am Psychol*; 35(2): 151-75, 1980.
51. Folkman S, Lazarus RS. Coping as a mediator of emotion. *J Pers Soc Psychol* 54(3): 466-75, 198

Figure legends
Figure 1. PRISMA 2009 Flow Diagram

Table 1. Summary of studies included in the review

Study ID	Aim	Population	Method	Results
Aasen et al, 2011 Location: Norway	Explore how elderly patients with end stage kidney disease undergoing haemodialysis perceive patient participation in decision-making. **Patients/Health professional view** Patients	**N=**188 patients who had had dialysis for 2 months, of these 11 were recruited **Age:** 1:72 years, 2:75-78 years, 6:80-85 years, 2:90 years **Gender:** 4 females/ 7 males **Ethnicity:** Not reported **Education level:** 2: higher level, 3:lower level, 6:none	**Methodology:** Critical discourse analysis **Date collection:** Open-ended qualitative interview **Recruited from** 5 hospitals by nurses	2 discourses identified: 1. The healthcare teams power and dominance 2. The patient's struggle for shared decision-making. The elderly patient's right to participate in dialysis treatment did not seem to be well incorporated into the social practices of the unit.
Ashby et al, 2005 Location: Australia	To explore the reasons why some patients choose to stop or not start dialysis and the personal and social impact of this decision. **Patients/Health professional view** Patients and carers	**N=** 52, of these 41 were ineligible Response rate= 11, resulting in 16 interviews **Age:** Mean 77 years (range 57-89) **Gender:** 9 females/7 males **Ethnicity:** 3 from non-English speaking backgrounds **Education level:** Not recorded	**Methodology:** Grounded theory **Data collection:** Semi-structured interviews **Recruited from** 2 tertiary centre hospitals	Reasons given included -Not to burden others -Experience of deteriorating quality of life -Prognostic uncertainty -Sense of abandonment
Breckenridge et al 1997 Location: United States	To elicit patient's perceptions of why, how and by whom their dialysis treatment was chosen. **Patients/ Health professional view** Patients	**N=**22 **Age:** Mean 53.8 years (29-69) **Gender:** 9 females/13 males **Ethnicity:** 17 black/5 white **Education level:** Not recorded	**Methodology:** Grounded theory **Data collection:** Semi structure interviews **Recruited from** 4 dialysis units	11 themes identified: Self decision; access-rationing decision; significant other decision; to live decision; physiologically dictated decision; expert decision; to be care for decision; independence versus dependence decision; no patient choice in making decision; patient preference/choice; and

				switching modalities due to patient preference/choice.

Study ID	**Aim**	**Population**	**Method**	**Results**
Halvorsen et al, 2008 Location: Norway	Explore the priority dilemmas in dialysis treatment and care offered to elderly patients. **Patients/ Health professional view** Physicians and nurses	**N**=9 (5 physicians and 4 nurses) **Diagnosis:** renal failure **Age:** Physicians range 48-61 years, nurses range 26-55 years **Gender:** 7 females/2 males **Ethnicity:** Not recorded **Education level:** Physicians 17-30 years experience, nurses 4-30 years experience	**Methodology:** Hermeneutical analysis **Data collection:** Semi structured interviews **Recruited from** part of a larger multi-site study on healthcare for elderly patients	-Dilemmas concerning with-holding and withdrawing treatment -Advance age is rarely an absolute or sole priority criterion -Advance age appears to be a subtler criterion in relation with comorbidities, performance status, and cognitive impairment. -Nurses prioritise specialised dialysis care and not comprehensive nursing care, the complex needs for elderly patients are therefore not always met.
Kaufman et al, 2006 Location: United States	To describe the socio-medical features of treatment that shape provider understanding of the nature of choice and no choice. To illustrate the effects of treatment patterns and provider practices on patients' perceptions of their options for treatment and for life extension. Patients with cardiac disease and renal transplantation were also studied. **Patients/ Health professional view** Patients and health professionals	**N**=18 health professionals, 43 patients **Diagnosis:** Renal failure and cardiac disease **Age:** 70-93 years range **Gender:** Not reported **Ethnicity:** Diverse **Education level:** Not reported	**Methodology:** Ethnography **Data collection** Interviews and observation in dialysis clinics. **Recruited from** clinics, using snowball sampling, part of a larger study.	Neither patients nor the health professionals made choices about the start or continuation of life-extending treatment that were uninformed by -The routine pathways of treatment -The pressures of technological imperative -Growing normalisation, ease and safety of treating older patients -There was a difference between cardiac, dialysis and renal transplant procedures with regards the locus of responsibility for maintaining and extending life.
Kelly-Powell 1997 Location: United States	To explore the experiences of adults with potentially life-threatening conditions in their decisions regarding treatment options. Included cardiac, cancer and renal conditions. **Patients/ Health professional view** Patients	**N**=18 patients recruited, 9 of which had renal failure **Diagnosis:** Renal failure, cardiac disease and cancer **Age:** Range 26-81 **Gender:** 9 females/9 males **Ethnicity:** 15 Caucasian, 2 African-American, 1 Native American **Education level:** Not recorded	**Methodology:** Grounded theory **Data collection:** Interviews **Recruited from** large urban teaching hospital, outpatient dialysis centre, family practice.	Patients make decisions about treatments based on a broad set of values and beliefs and that may have little to do with effectiveness of a treatment and more to do with perceived impact of treatment on personal lives and their families.

Study ID	**Aim**	**Population**	**Method**	**Results**
Lelie et al, 2000 Location: Netherlands	Identification of the general practical rules, norms, and values underlying therapeutic decisions. Focused on what the physician considered to be good usual care. **Patients/ Health professional view** Patients with progressive kidney disease and physician interaction	**N=**59 interactions observed, between 30 patients and 4 nephrology residents and one attending **Diagnosis:** renal failure **Age:** Not reported **Gender:** Not reported **Ethnicity:** Not reported **Education level:** Not reported	**Methodology:** Not described **Data collection:** Observation of the interaction between physicians and patients whilst discussing dialysis therapy. **Recruited from** outpatient clinic, part of a larger study.	-Choice of therapy: was discussed as a choice, discussed months in advance, patients perceptions were considered important. -Moral persuasion was allowed. -No patients were informed that dialysis is more expensive and gives allocation problems. -When to start treatment is not discussed in a shared manner. -There was evidence of differing approaches to the young, elderly and severely ill, and patients with multiple comorbidities.
Lin et al, 2005 Location: Taiwan	The purpose of this study was to describe the experiences of making a decision about haemodialysis among a group of Taiwanese with end stage renal failure. **Patients/ Health professional view** Patient	**N=**12 **Diagnosis:** renal failure **Age:** Mean 38.9 years, range 28-53 **Gender:** 6 females/6 males **Ethnicity:** Taiwanese **Education level:** Educated to high school level	**Methodology:** Colaizzis phenomenological method **Data collection** Semi structured interviews **Recruited from** dialysis centres	3 broad categories were identified: 1. Confronting the dialysis treatment: fear was thought to be caused by false belief, threat to life, impairment of self concept, fear of physical limitations 2. Seeking further information: patients sought opinions of family, professional confirmation, and explored alternatives 3. Living with dialysis: Patients discussed worsening symptoms, family support, and cultural beliefs about the cause of their illness.
Noble et al, 2009 Location: United Kingdom	To gain an understanding of the decision that some patients make not to embark on dialysis **Patients/ Health professional view** Patients and caregivers	**N=**30 patients and 17 caregivers **Diagnosis:** renal failure **Age:** Not reported **Gender:** Not reported **Ethnicity:** Not reported **Education level:** Not reported	**Methodology:** Constant comparative **Data collection:** Observation of naturally occurring consultations **Recruited from** Clinic, part of a larger study	-17 felt they made an autonomous decision. -7 no option but to refuse as it would have been of no benefit and would have ultimately caused their death. -2 opted for medical management without dialysis and felt both would have given the same outcome. -4 thought there was no decision to be made.

Study ID	**Aim**	**Population**	**Method**	**Results**
Russ et al 2007, Location: United States	Explores the value of an extended old age made possible by dialysis. **Patients/ Health professional view**	**N=** 21 health professionals members (4 physicians, 5 nurses, 5 social workers, 2 dieticians, 2	**Methodology:** Grounded theory **Data collection:** Interviews and observations of	Most elderly patients did not want or choose dialysis. Neither, however, did they want to die. Most grudgingly accept treatment until the burdens were considered to

	Patients and health professionals	technicians, 3 administrators), 43 patients, 7 family members **Diagnosis:** renal failure **Age:** Patients over 70 years old **Gender:** Patients: 27 females/16 males **Ethnicity:** Patients- 24 white, 13 African-American, 5 Asian, 1 Latino **Education level:** Not reported	consultations **Recruited from** 2 dialysis units	outweigh the benefits, when family and healthcare professionals initiated discontinuation. There was evidence of some patients discussing withdrawal proactively however these were the exception. Most patients question life on dialysis however choose to withdraw from treatment later.
Schell et al, 2012 Location: United States	To describe how nephrologists and older patients discuss and understand the prognosis and course of kidney disease leading to renal replacement therapy. **Patients/ Health professional view** Patients and health professionals	**N= 11** nephrologists and **N=29** patients Diagnosis: chronic kidney disease predialysis and on dialysis **Age:** CKD 68 years, HD 72, nephrologist 50 **Gender:** CKD 64%male HD 50%, nephrologist 90% **Ethnicity:** CKD 55% white, HD 28%, nephrologist 73% **Education level:** not reported	**Methodology:** Not described ('qualitative approach') **Data collection:** Focus groups and interviews **Recruited from** academic and community nephrology units.	6 themes 1.Patients are shocked by diagnosis 2. Patients are uncertain about how their disease will progress 3. Patients lack preparation for living with dialysis 4. Nephrologists struggle to explain illness complexity 5. Nephrologists manage a disease over which they have little control 6. Nephrologists tend to avoid discussions of the future. Discussions about prognosis are rare. Patients focussed on the future to help them cope with the present. Nephrologists were concerned about upsetting patients.
Tweed and Ceaser 2005 Location: United Kingdom	To assess the decision making process by pre-dialysis patients **Patients/ Health professional view** Patients	**N=9** **Diagnosis:** renal failure **Age:** Mean 54 years, range 29-69 years **Gender:** 4 females/ 5 males **Ethnicity:** Not reported **Education level:** Not reported	**Methodology:** Interpretative phenomenological analysis **Data collection:** Semi-structured interviews **Recruited from** pre-dialysis clinic	4 main themes: -Maintaining ones integrity and preserving normality was important. -Patients felt they were forced to adapt to treatment -Individuals received support and information through peers -Staff provided support and the experience of illness shaped beliefs about renal disease and treatment options. These themes emerged regardless of the treatment chosen.

Table 2. Formation of themes

Over-arching theme	Theme	Number of codes associated with theme	Number of items of evidence associated with theme	Number of papers associated with theme
Commencing or with-holding: patient factors	Deliberation of factors	45	228	11
	Gut instinct	28	45	10
	Coping mechanisms	34	61	9
Commencing or with-holding: healthcare team factors	Bio-medical criteria	17	62	11

	Ethical dilemma	6	17	2
Commencing or with-holding: patient and healthcare team interaction	Power and communication	71	124	10
Dialysis withdrawal: Life on dialysis	Experiential knowledge	42	30	9
Dialysis withdrawal: patient factors	Facing withdrawal	39	62	8
	Family influence	7	29	5
Dialysis withdrawal: healthcare team factors	Avoidance	49	67	4
	Genuine request	10	15	3
Dialysis withdrawal: Patient and healthcare team interaction	Doing trumps talking	29	34	7
	If not now, when?	19	7	5

Scores for each category are out of 4, with 1= very poor; 2= poor; 3= fair and 4= good.

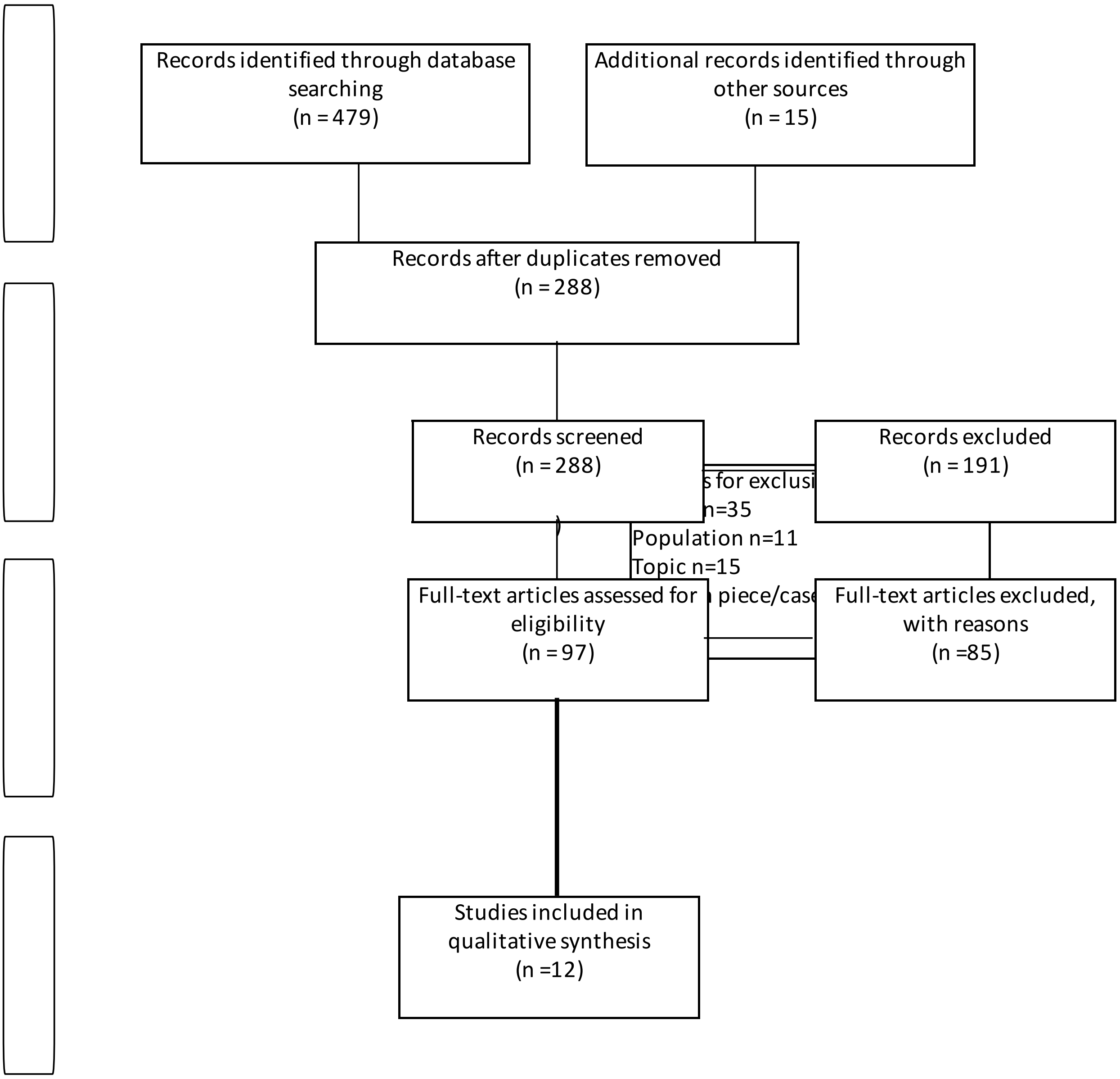
Commencing and with-holding dialysis: Patient factors	
Deliberation of factors	**Past personal experience**: *"I've gone through heart surgery without any problem...I figured that I could stand it (dialysis) no matter what without any trouble."* [Kelly-Powell, 1997[38]] **Illness experience:** *"I vomited all night; tea, medicine, everything I ate. It was painful. I stayed up all night… I told my husband I couldn't take it anymore." (Female)* [Lin et al, 2005[39]] **Peer experience:** *"You think you're the only one in the world and I found there were lots of other people and people that were younger than me. I know it sounds awful but it helps me...." (Female)* [Tweed and Caesar, 2005[35]] *"My brother… he was doing that for five years and I realise how hard it was for him to do it." (Male)* [Tweed and Caesar, 2005[35]] **Being a burden:** *"Well I couldn't see that it was really going to achieve anything apart from disrupting everybody's life… I wouldn't consider it under any circumstances." (Female, 82 years old)* [Ashby et al, 2005[37]] **Burden of treatment:** *"I made my decision … I couldn't see meself going back and forth three times a week, waiting for a taxi to get home and there and waiting for a taxi to get back. No it's not for me." (Male, 78 years old)* [Ashby et al, 2005[37]] **Financial burden:** *"I think I'll become a burden to my family and cause financial problems… You'll ruin the family." (Male, Taiwan)* [Lin et al, 2005[39]] "Dialysis treatment will be helpful, besides the health insurance pays for it" (Taiwan) [Lin et al, 2005] "I would pay anything for any helpful remedies." (Taiwan) [Lin et al, 2005] **Ethics- justice:** *"We are living longer and we are becoming quite a problem. In general we older people are presenting quite a problem. And it is a problem for us to know what to do." (Female, 85 years old)* [Ashby et al, 2005[37]] **Maintaining normal social roles:** *"If you can't have some semblance of a normal life, then why would you want to live?"* [Tweed and Caesar, 2005[35]] **Family:** *"I became very ill. My mother was worried … She consulted those who had taken dialysis treatment. She was told it was all right and the patients were all in good condition. Finally, she urged me to receive it."* [Lin et al, 2005[39]] *"My husband disagrees with the treatment. He was too busy to take me to the hospital. Besides, the kids need me."* [Lin et al, 2005[39]] **Culture and religion:** *"In the environment that we grew up in and how the families thought and … you pick a lot of that up and carry it through life… And I guess that's one reason I could make that kind of decision."* [Kelly-Powell, 1997[38]] *"Physicians of western medicine tell you that dialysis treatment is the only solution. Chinese herb doctors are different. They'll do their best to cure the illness." [Lin et al, 2005[39]*] **Spirituality:** " …a decision of the heart…" [Kelly-Powell, 1997[38]] **Quality of life before longevity:** *"If you are supposed to really follow that regime, I would rather cut a couple of years off my lifespan…There is almost nothing you can eat… I am not able to do this."* [Aasen et al, 2011[36]]

	*"At any rate… it defies explanation who finds the treatment bearable and who does not, this is the mystery of quality of life on dialysis." (*Health professionals*)* [Russ et al, 2007[83]]
Gut instinct	**Opt for life prolonging treatment:** *"And they give you a choice…you can die now or you can die later. I chose later." (Male, 82 years)* [Russ et al, 2007[40]] *"I had no choice…I wanted to live."* [Kaufman et al, 2006[42]] **Accept dying as a natural course:** *"The idea of it that eventually it's going to kill me it never phased me at all because I am at the downhill side of my life anyhow... When my time comes I'll just choof off and that's it." (Female, 82 year old)* [Ashby et al, 2005[37]] *"So if I'm going to be fixed and all right, fine. If not, then I lived what I lived and I enjoyed what I had."(Male, 26 years old)* [Kelly-Powell, 1997[38]] **Lesser of two evils:** *"I told my husband I couldn't take it (symptoms) anymore. I would rather die. My husband took me to the hospital. I cried bitterly when I signed the agreement."* [Lin et al, 2005[39]] *"I suppose in the back of your mind you think, 'I don't want this', cos you don't want any of it really." (Female)* [Tweed and Caesar, 2005[35]]
Coping mechanism:	**Problem-controlling:** *"More you get use to it, the more you think about it and you think, 'well, it's not going to be a problem is it?' You know, soon get round that"* [Tweed and Caesar, 2005[35]] *"It's the difference between us and animals… we have the knowledge and free will; we can choose and act on that choice."* [Russ et al, 2007[40]] **Emotion-controlling:** *"I don't know about anyone else, but the topic is really scary. I'd rather not hear the answer and whatever the answer is, I hope to outlive it."* [Breckenridge, 1997[43]] *"A big part of me says I'm going to stay stable and won't have to do it (commence dialysis)…I'll deal with it when it comes."* [Schell et al, 2012[41]]
Commencing and with-holding dialysis: Healthcare team factors	
Biomedical criteria	**Medical criteria:** *"the decisive factor should be biological age and not chronological age."* [Halvorsen et al, 2008[32]] *"If a patient had dementia or other severe malign diseases, the physicians were more restrictive about starting treatment."* [Halvorsen et al, 2008[32]]
Ethical dilemma	**Unethical to prolong life:** *"It is not like I stand in a situation where I have to choose this patient and not that patient… rather… the situation is more about whether or not it is ethically right to prolong life at any price."(Physician)* [Halvorsen et al, 2008[32]] **Patients continued to be offered treatment:** *"When I say no to treatment, it seems very decisive. It is difficult to make these decisions. It is a question of life and death." (Physician)* [Halvorsen et al, 2008[32]] *"My experience is that it is a lot easier to say yes than to say no, and that we start treatment on too many patients."* [Halvorsen et al, 2008[32]]
Commencing and with-holding dialysis: Patient and healthcare team interaction	
Power and communication	**Power and dominance of the healthcare team:** *"These doctors always think they ought to decide and that I should listen to them. And maybe they are right because if I don't then it may not end up so well…"* [Aasen et al, 2011[36]] **Healthcare professionals felt powerless:** *"You can do the best you can and*

	know you are going to minimize (disease progression)… beyond that whatever is going to happen happens” [Schell et al, 2012[41]] **Patients felt uninformed:** *“People just don’t know what you got on your brain. You smiling (and) they think you’re not worried”* [Schell et al, 2012[41]] *“I haven’t been told what the futures like except you go on dialysis every other day …You have to do it or you die.”* [Schell et al, 2012[41]] **Presentation of risk:** *“In the clinics we observed, physicians and other staff framed the need for dialysis in terms of ‘when you will need to start dialysis’ and not ‘if.’”* [Kaufman et al, 2006[42]] *“Well, we didn’t make it [decision], that’s what he said, she couldn’t have it. Basically, she could not be put on dialysis because of her heart. So I thought, you must know best.”* [Noble et al, 2009[34]] **Communicating uncertainty:** *“… it was a guessing game sort of thing.”* [Male, 77 years] [Ashby et al, 2005[37]] *“They can’t tell you, you know, how long you have to go…With all the modern stuff and all that, they still don’t know.” [Male, 78 years old]* [Ashby et al, 2005[37]]. **Who provided the information was important:** *“I just thought, ‘what the heck’ he should know what he’s doing.”* [Kelly-Powell, 1997[38]] **Healthcare professionals influenced patient choice:** *“Don’t you want to continue living for your grandson? Don’t you want to see his children-don’t you want that for him? If you want to see his kids, you have to get a fistula this summer…”(physician to patient)* [Kaufman et al, 2006[42]]
Dialysis withdrawal: Patient factors	
Life on dialysis	*“… it started with an emergency situation… It’s presented as short-term treatment. It doesn’t click, wait a minute, this is full-on life support. And it was probably three years before she even started saying or admitting it was life support.” (Son)* [Russ et al, 2007[40]] *“When they begin to see themselves as completely dependent on systems to keep them alive, that’s when you start hearing them talk about death and dying and they just don’t see themselves ‘going on this way’…”(Social worker)* [Russ et al, 2007[8]]
Facing withdrawal	**Problem-controlling:** *“I have this tremendous control…one that people with cancer don’t have…Doctor said I’d probably live three to thirteen days without dialysis, and that it could be made very comfortable for me.” (Male, 76 years old)* [Russ et al, 2007[40]] *“It’s the only thing that makes it bearable… I don’t know if I will quit voluntarily, but I like to know I can.”* [Russ et al, 2007[40]] **Emotion-controlling:** *“Most patients… are evasive in their answers, they say they ‘have to think about it’, they push it aside. They’re not willing to admit they want to give up.” (Nurse)* [Russ et al, 2007[40]] *“It’s rare someone actively discontinues…patients self-discontinue through passive-aggressive behaviour. Patients who pull out their catheter, or it just keeps coming out. ‘Cause they can’t directly say, ‘I don’t want to do this anymore. Take out my catheter. Make me comfortable’” (Social worker)* [Russ et al, 2007[40]]
Family influence	**Families found it difficult to make the decision to withdraw treatment:** *“The family won’t hear of it, so patients don’t feel they’re allowed to stop treatment.” (Social worker)* [Russ et al, 2007[40]] *“Up till the end, she’d (patient) say ‘This is no way to live. You need to stop this.’ And we’re (family) going ‘We need to stop what? We’re not doing anything’… I’m not asking her to give up what she wants; I’m asking her to postpone it…” (Son)* [Russ et al, 2007[40]]
Dialysis withdrawal: Healthcare team	
Avoidance	**Health professionals’ difficulties in discussing withdrawal:** *“It’s hard to quantify how much someone will tolerate, what they will tolerate … or how they want to die.” [Nephrologist]* [Schell et al, 2012[41]]

	"... unhelpful to beat them over the head with mortality statistics." [Nephrologist] [Schell et al, 2012[41]] **Caring relationship:** *"A patient who recalled being 'nagged' by nurses to come into dialysis agreed; she registered their entreaties as a 'sign of caring.'"* [Russ et al, 2007[40]] *"...she doesn't believe she has any quality of life. Yet...never once has she said, I think it's time to stop. So I don't say that either. Ever. You want your caregiver to get on the phone and say 'get in here'" (Dialysis Nurse)* [Russ et al, 2007[40]]
Genuine request	**Difficult to determine if it is a genuine request for treatment withdrawal:** *"She's miserable and feels dialysis is the culprit. But she doesn't want to withdraw from dialysis; she wants to withdraw from the symptoms. It's confusing because the signs of depression...get confused with the symptoms of dialysis."* [Russ et al, 2007[40]]
Dialysis withdrawal: Patient and healthcare team interaction	
Doing trumps talking	**Patients missed dialogue:** *"One would think that it had to be in their interest to know what we think and maybe we could get some indications about how they think...it is much one-way communication....I haven't experienced being asked about what we feel..." (Male)* [Aasen et al, 2011[36]] *"I want more information...Nurses do not tell me anything, other than blood percentages..."* [Aasen et al, 2011[36]] *"They probably have got tired of me after so many years. Probably, they aren't that interested anymore. It's like I've become a piece of furniture."* [Aasen et al, 2011[36]] **Voting with their feet:** *"What is important on dialysis...is what you do, you keep showing up... Look, he keeps coming. Not regularly, but he's here today. Sometimes a patient will say, maybe I won't come in tomorrow...But then they'll come in the next day or two, which always interests me-because that means they're not really ready to stop."* [Russ et al, 2007[40]]
If not now, when?	**Limit of frailty remains in the future:** *"The problem...(is that) no one wants to take responsibility for saying 'no.'" (Nurse)* [Russ et al, 2007[40]] *"Patients thus choose to be choosers...and they choose to choose later."* [Russ et al, 2007[40]] *"...most get so sick, they wind up in the hospital and it (withdrawal) just happens." (Nurse)* [Russ et al, 2007[40]] *"When you see that the patient coming in is not doing well, and is supposed to have dialysis no matter what...There is something about being allowed to die... Sometimes I think we should have withdrawn the treatment a little earlier." (Nurse)* [Halvorsen et al, 2008[32]]

Figure 1. PRISMA 2009 Flow Diagram[30].



1. Past personal experience
2. Illness experience
3. Promoting hope for the future
4. Peer experience
5. Being a burden
6. Burden of treatment
7. Financial burden
8. Ethics: justice
9. Maintaining normal social roles
10. Family
11. Culture and religion
12. Spirituality

Supplementary material

Search strategy developed in MEDLINE

Searched via Ovid interface.
Database: Ovid MEDLINE (1946 onwards)
Search strategy:

qualitative*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]; 143984
findings*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]; 1253309
interviews*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier];110513
renal fail*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]; 71444
renal failure.mp. or exp Renal Insufficiency/;150987
chronic kidney disease.mp. or exp Renal Insufficiency, Chronic/; 89455
end stage renal failure.mp. or exp Kidney Failure, Chronic/;80091
exp Renal Insufficiency, Chronic/ or exp Renal Insufficiency/;122641
exp Peritoneal Dialysis, Continuous Ambulatory/ or renal replacement therapy.mp. or exp Renal Dialysis/ or exp Renal Replacement Therapy/ or exp Peritoneal Dialysis/;171090
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haemodialysis*.mp.;11422
peritoneal dialysis*.mp.; 25875
dialysis*.mp.; 130563
Hemodialysis, Home/ or home dialysis*.mp.; 1841
active treatment.mp.; 6915
life prolonging treatment*.mp.; 225
conservative management*.mp.; 8572
conserve manage*.mp.; 1
dialysis withdrawal*.mp. or exp Treatment Refusal/; 10797
withdrawal*.mp.; 76979
exp Palliative Care/ or exp Hospices/ or palliative care*.mp. or exp Patient Care Team/ or exp Terminal Care/; 128459
exp Informed Consent/ or exp Patient Participation/ or exp Choice Behavior/ or exp Decision Making/ or patient choice*.mp. or exp Patient Satisfaction/; 219893
exp "Patient Acceptance of Health Care"/ or exp Patient Preference/ or patient preference*.mp.; 168350
decision mak*.mp.; 123085
shared decision making.mp.; 1942
patient choice*.mp.; 1106
patient acceptance of health care.mp.; 31467
patient participation.mp.; 18459
choice behaviour.mp.; 151
physician patient relationship.mp.; 1434
patient education.mp. or Patient Education as Topic/; 78811
exp Cooperative Behavior/ or cooperative behaviour.mp.; 28136
decision support techniques.mp. or exp Decision Support Techniques/; 61347
patient acceptance of health care.mp.; 31467
Communication Aids for Disabled/ or Communication/ or Health Communication/ or Interdisciplinary Communication/ or Communication Barriers/; 77785
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Physician's Role/ or physicians.mp. or Physician's Practice Patterns/; 276660
nephrologist.mp.; 1383
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Kidney/ or Nephrology/ or nephrology*.mp.; 237891
Interprofessional Relations/ or Health Personnel/ or Patient Care Team/ or healthcare team*.mp.; 111644
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1 or 2 or 3; 1441794
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limit 45 to (english language and humans and yr="1985" and "all adult (19 plus years)" and english and humans); 2093
limit 46 to (english language and humans and yr="1985" and "all adult (19 plus years)" and english and humans); 14232
limit 47 to (english language and humans and yr="1985" and "all adult (19 plus years)" and english and humans); 5191
48 and 49 and 50; 135