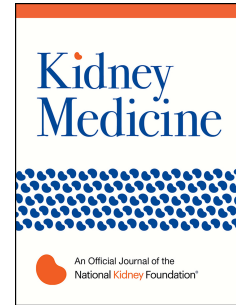


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Perceived Life Expectancy Among Dialysis Recipients: A Scoping Review

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Perceived Life Expectancy Among Dialysis Recipients: A Scoping Review

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Abstract

Rationale & Objective: Greater prognostic understanding is associated with higher quality care at the end of life. We undertook a scoping review to explore how long dialysis recipients expect to live.

Study Design: Scoping Review

Setting and Study Population: People with kidney failure over 18 years old.

Search Strategy & Sources: Studies were identified by searching Medline, Embase, APA PsycINFO, HMIC and ProQuest Database for terms related to “life expectancy”, “self -estimated” and “end stage kidney disease”.

Data Extraction: Search strategies yielded 349 unique, potentially eligible studies, with 8 meeting the inclusion criteria after screening.

Results: Significant mismatches between dialysis recipients and their healthcare provider estimations of prognosis were reported, with patients predicting significantly higher life expectancies than healthcare professionals and almost no agreement between patient and nephrologist estimates of one-year survival. Documented cognitive impairment did not affect 1- or 5-year prognosis estimates, neither did gender, age, time on dialysis or discussing perceived life expectancy. Dialysis recipients who thought they were on the transplant-list or self-identified as black had higher perceived life expectancy: people who were 75 years or older, or with fair/ poor self-reported health status had lower. Those with lower perceived life expectancy preferred care focusing on relieving pain and discomfort: people who thought they had a higher chance of survival were significantly more likely to prefer life-extending care.

Limitations: There is a marked paucity of research in this area with most studies conducted in North American cohorts.

Conclusions: Optimistic patient prognostic expectations persist in dialysis recipients. Given the effects of perceived life expectancy on treatment choices and subsequent quality of life, it is important that transparent discussions regarding prognosis are conducted with people receiving dialysis and their families.

Key words: Prognosis Expectations, Perceived Life Expectancy, Treatment choices, Prognostic uncertainty, Shared Decision-Making, Haemodialysis, Dialysis, Renal Replacement Therapy

Plain language summary

Understanding illness severity and prognosis allows people to make decisions and prioritise areas of their life important to them. We undertook a scoping review to explore how long dialysis recipients expect to live. We found significant mismatches between perceived life expectancy of people on dialysis and their healthcare providers. Perceived life expectancy influenced treatment choices: those who thought they would die sooner prioritised care focusing on relieving pain and discomfort. Those who thought they had a higher chance of survival were more likely to prefer life-extending care (with potential effects on quality of life). It is important to have frank discussions about prognosis with people receiving dialysis, to empower individuals and help them to make informed decisions about their care.

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Introduction

Patient-clinician communication underpins all areas of medicine. When done well, it can improve illness experience[1], mental health[2], patient satisfaction[3], recall and understanding of information[4]. Similarly, when done poorly, it can negatively affect inter-personal relationships[4] and patient health outcomes[1]. Sharing prognosis information has traditionally been viewed as one of the more challenging areas of communicating with patients, and clinicians have highlighted numerous potential barriers. Sufficient time is needed within the clinical encounter, cultural and linguistic difficulties can hinder open conversations, some healthcare professionals find these conversations uncomfortable, and there is a lack of formal communication skills training [5-8].

But, most patients want to know their prognoses and their options for end of life care[9, 10]. Moreover greater prognostic understanding is associated with decreased preferences for more intensive treatment [11] and higher quality care at the end of life [12, 13]. It has been recognised that people with advanced Chronic Kidney Disease (CKD) tend to experience less high quality end-of life care, and receive more aggressive care compared to people with other non-cancer diagnoses (such as those with heart failure or dementia) suggesting that prognostic understanding amongst people with advanced CKD is perhaps lower[14-17]. Furthermore, health literacy is often limited among older people with kidney failure, creating further barriers to achieving greater prognostic understanding[18]. Individuals who do not have accurate prognostic awareness do not feel empowered to make informed decisions [19], yet people with CKD have to make many decisions over their illness trajectory and across different care

settings and sectors[20]. Consequently, improving shared decision making has been highlighted as key patient research outcome priority within the Nephrology community [21].

Understanding prognostic expectation of people with kidney failure has been an area of increased research interest over the last few years. There is an extensive literature base exploring prognostic expectations in oncology, but only more recently has this been investigated in non-cancer patients. Developing a better understanding of prognostic expectations of people receiving dialysis is a key initial step in improving supportive and end of life care for nephrology patients. As such, we sought to undertake a scoping review to explore how long dialysis recipients expect to live.

Methods

Study design

We chose to undertake a scoping review as this was an exploratory study. We wanted to identify the available literature[22, 23] and scoping reviews are particularly useful for examining emerging evidence[24, 25]. We utilised established guidance to inform search strategies, extraction, and synthesis of evidence [24, 26]. The PRISMA-ScR reporting tool was used to provide guidance on reporting of findings [26] (Table S1).

Search strategy

Studies were identified by searching Medline (OVID), Embase, APA PsycINFO, HMIC (Health Management Information Consortium) and ProQuest Database, from study inception to 30/09/21. A manual search of relevant grey literature (ProQuest dissertations, Europe PMC) was also conducted. The protocol for search terms was piloted and reviewed by an external clinical librarian. Search terms related to “life

expectancy”, “self -estimated” and “end stage kidney disease” were used. Full details of the search strategy can be found in Item S1.

Inclusion/Exclusion criteria

Studies were included where adults (18 years old or older) were asked to estimate how long they would live for. Studies that included duration or defined time periods, as well as chance/risk (for example, what is the chance you will be alive in one year) were included. When studies reported diseases other than end-stage kidney disease (for example heart failure, chronic obstructive pulmonary disease), data presented was assessed to see if individual diseases were reported separately and included only if kidney failure, or kidney failure with replacement therapy was distinctly reported. Studies were limited to those published in English only.

Data extraction (selection and coding)

Studies were selected independently by two reviewers with disagreements resolved by discussion. This involved initial title and abstract screening followed by full-text screening against the inclusion criteria. For relevant reviews, individual studies within the review were screened against the inclusion criteria. The software programme Covidence was used to manage the process[27].

Assessment of Risk of bias

Assessment of risk of bias was undertaken using the RoBANS tool (Risk of Bias Assessment tool for Non-randomised Studies) [28]. This tool assesses six domains and ranks each with a high, low, or unclear risk of bias. The six domains are selection of participants (selection bias caused by the inadequate selection of participants), confounding variables (selection bias caused by the inadequate confirmation and

consideration of confounding variable), measurement of exposure (performance bias caused by the inadequate measurement of exposure), blinding of outcome assessments (detection bias caused by the inadequate blinding of outcome assessments), incomplete outcome data (attrition bias caused by the inadequate handling of incomplete outcome data) and selective outcome reporting (reporting biased caused by the selective reporting of outcomes) [28].

Results

Search strategies yielded 349 unique, potentially eligible studies, with 8 meeting the inclusion criteria after screening (Figure 1). Table 1 summarizes the characteristics of included studies. Studies were published between 2010 and 2021 and were undertaken in Canada[29], the United States of America (USA) [30-35] and the United Kingdom (UK) [36]. Six studies were quantitative[29-32, 35, 36] and two studies were qualitative in nature [33, 34]. Figure 2 shows the risk of bias assessment per study.

Perceived life expectancy

Optimistic patient prognostic expectations were reported by most studies. Quantitatively, when participants were asked about their chance of survival over the next twelve months, 81% felt they had 100% chance of survival [32] and 81% thought they had 90% chance of survival[30] (both studies undertaken in the USA). In contrast, only 37% of participants thought they had 95% chance of 1-year survival in the UK [36]. Similarly, when asked about their chance of survival over the next 5 years, in the USA studies, 67% [32] and 42% [30] thought they thought they had a 90% chance of living for 5 years or more, compared with 25% predicting a 95% chance of survival at 5 years in the UK [36].

Significant mismatches between patient and provider estimations of prognosis were reported, with people receiving dialysis predicting significantly higher life expectancies than healthcare professionals and almost no agreement between patient and nephrologist estimates[30, 32, 36]. One study compared nephrologist and named hemodialysis nurse predictions of prognosis and found no difference between the two estimates [36]. Two studies included only seriously unwell participants ($\geq 20\%$ one-year mortality risk) [30, 36]. Notwithstanding, findings from all studies were very similar, suggesting that there is a marked lack of prognostic understanding amongst dialysis recipients.

It is not possible to know exactly how much prognostic expectations differed between nephrologists and people receiving dialysis, due to differences in study reporting. Three of the included studies directly examined prognostic discordance[30, 32, 36]. Two took similar approaches to analysis, comparing patient and nephrologist/healthcare professional, and dividing into 5 groups depending on estimate of survival (%) [30, 36]. Reporting methods from one study enabled discordant pairs to be easily identified (80% of pairs when estimating 1-year survival, 70% of pairs when estimating 5-year survival)[36]. The second study used a different scale for patient and nephrologist responses, meaning direct comparison was not possible[30]. Both of these studies reported grouped outcomes as opposed to individual differences[30, 36]. The third study reported only when $>20\%$ prognostic discordance was present[32]. Overall, nephrologists and healthcare professionals appeared to overestimate and patients underestimate mortality risk when compared to actual outcomes[30, 36], with patient estimates closer to survival rates seen.

Alongside optimistic prognostic expectations, significant optimistic transplant discordance was also noted, including in the seriously unwell [30, 36]. Despite very few participants being listed for transplantation, many felt that they were both suitable candidates and/or were listed on the transplant waiting list.

Prognostic uncertainty

Both people receiving dialysis and nephrologists reported uncertainty about how their/their patients' disease would progress, which hindered open conversations about prognosis. As a result, nephrologists “*generally do not discuss prognosis and the future, unless prompted, either by the patient or in the setting of acute illness*” [33]. This finding was supported by quantitative studies; in one study 0%, and in another 53% of participants reported that their nephrologists had discussed prognosis with them [30, 32]. Challenges to engaging in prognosis conversations were described, specifically, an “*inability to predict the patient's (disease) course*”, and “*concerns that discussions would be perceived as negative and remove patient's hope*” [33].

Desire to know prognosis

Reported desire to know prognosis was variable. In one study 90% of people with kidney failure wanted to know detailed information about their medical condition, including prognosis [29]. This contrasts with only 54% wishing to know prognosis in another study [35] and 47% specifying they actively did not want to discuss prognosis with their nephrologist in a third [32]. Similarly, 76% of people receiving dialysis who had not already discussed end of life plans with a healthcare professional, did not wish to explore this further [36]. Two of the included studies were qualitative in nature and so examined this in more detail. One, when exploring perceptions on “how (the) disease will

progress” reported that “*patients’ coped through avoidance and false hope*”[33], which might explain the high numbers of participants not wanting to discuss prognosis in detail. The other found that perceptions of prognosis were “*gained from experiential learning at the dialysis centre and own experience, not from conversations with healthcare professionals*”[34], which may also affect desire to engage in discussions of prognosis with nephrologists. One study reported that whilst 54% of participants wanted to learn about their prognosis, only 62% knew what the term prognosis meant[35] highlighting limited health literacy may be a significant contributory factor to people’s willingness to engage in these discussions[18].

Factors influencing perceived life expectancy

Documented cognitive impairment did not affect 1 or 5-year prognosis estimates (although in many studies, people with cognitive impairment were excluded, table 1), neither did gender, age or time on dialysis. However, people receiving dialysis who thought they were on the transplant list were significantly more confident they would be alive at both 1- and 5-years. Discussing end of life care plans had no effect on perceived life expectancy [36]. Dialysis recipients who were ≥ 75 years, or with fair or poor self-reported health status were less likely to have a prognostic expectation of >10 years, whereas those who self-identified as black were more likely [31].

Interplay between perceived life expectancy and treatment choices

Multiple studies explored the interplay between prognostic expectations and treatment choices. Most participants did not want life-extending treatment at the expense of prolonging pain and discomfort [29-32]. However, those with lower perceived life expectancy preferred care focussing on relieving pain and discomfort[36] and those who

thought they had a higher chance of survival were significantly more likely to prefer life-extending care [30, 37]. People receiving dialysis who were more optimistic than their nephrologist about transplant likelihood were also more likely to report a preference for life-extending care [30].

Discussion

In a scoping review, we identified seven full studies and one additional abstract exploring perceived life expectancy among dialysis recipients, with the majority being published in recent years. This illustrates the increased recognition of importance of conducting research in this field and the developments in routine advance care planning in practice. Thus far, studies undertaken have been mostly conducted in North America. One study has been conducted in the United Kingdom, but further research in Europe, Africa, Asia, and Australia/Oceania are urgently needed.

People receiving dialysis have optimistic expectations of life expectancy and transplant suitability. This is not unique to people with kidney disease, indeed similar studies have shown optimistic prognostic expectations in people with advanced cancer, heart failure and chronic obstructive pulmonary disease[38-41]. Similarly, included studies demonstrated a significant mismatch between patient perception of prognosis and that of their care providers. This is also regularly reported in oncology literature, even if prognostic discussions have occurred in the three months preceding the study[42]. It is therefore critically important to have frank and open discussions surrounding estimated prognosis, and to check patient and family understanding of the conversations.

Within nephrology, optimistic transplant discordance is associated with increased perceived 1-year and 5-year survival estimates [36]. This may offer a unique opportunity

for nephrologists to screen dialysis recipients for optimistic prognostic expectations.

Thus, providing an opening point for discussion and facilitating deeper conversations about perceived life expectancy, treatment expectations or advance care planning.

Both people receiving dialysis and nephrologists reported uncertainty about how their/their patients' disease would progress, which hindered open conversations about life expectancy. Challenges to estimating accurate prognoses are well recognised[43]. A seminal early paper reporting the SUPPORT study (The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) described a randomised control trial providing physicians with computer generated prognostic estimates, to see whether this improved end of life care[38]. Despite the generated prognostic estimates, <20% of physicians discussed prognostic information with their patients suggesting a reticence amongst physicians to facilitate discussions around prognosis even when estimates were available. Similarly another study found that when hospice patients requested survival estimates from physicians, they received them only 37% of the time[44]. This is concerning: lack of prognostic understanding may impede treatment decisions, and result in later referrals to, or underutilisation of hospice care[6, 12, 45].

This scoping review might suggest that people receiving dialysis in the UK have better prognostic understanding than those from North America, although only one study met inclusion criteria from the United Kingdom. The underlying reasons for this are not clear. At a systems level, differences in palliative care infrastructure and funding between the two countries may underpin some of the differences seen [46, 47]. However inter-centre variation was also noted[36], so differences in prognostic understanding may also reflect more the communication and influence of individual practicing physicians.

Reported desire to know prognosis in included studies was very variable. Again, reasons for these variations are unclear. Within the oncology evidence-base, people with terminal cancer have identified a sense of ambiguity regarding prognostic information: that is, they want to be told, but simultaneously do not want to know [48].

Interestingly one of the included studies (abstract only) reported that whilst 54% of participants wanted to learn about their prognosis, only 62% knew what the term prognosis meant[35], highlighting the importance of checking patient understanding. Other studies have suggested that understanding of terminology used in end of life conversations in people receiving dialysis is even lower[18]. Limited health literacy is common in all stages of CKD, with a meta-analysis reporting a median prevalence of 23%[49], reiterating the importance of not only having open prognostic discussions but checking and confirming understanding.

Very few factors appear to influence perceived life expectancy among dialysis recipients. Predictors of reporting a low perceived life expectancy amongst adults without kidney failure included older age, male sex and having a diagnosis of cancer or diabetes[50]. This contrasts to findings of this study, where gender and age had no significant influence on perceived life expectancy. A low sense of control over life, low satisfaction with life and worse self-reported health was associated with low perceived life expectancy amongst older adults without kidney failure[50], whereas poor self-reported health status was found to have an impact on people with kidney failure[51, 52]. This highlights the complex interplay between perceived health and life expectancy.

This study found those with lower perceived life expectancy preferred care focussing on relieving pain and discomfort [36] and those who thought they had a higher

chance of survival were significantly more likely to prefer life-extending care [30, 37]. People receiving dialysis who were more optimistic than their nephrologist about transplant likelihood were also more likely to report a preference for life-extending care [30]. The influence of perceived life expectancy on treatment choices has also been explored in people with lung, colon, bladder and breast cancer [11, 53, 54]. Similar to the results from this study, people with advanced cancer who thought they were going to live longer, were more likely to favour life-extending and aggressive therapy over comfort care[11].

Discordance between prognostic estimations of dialysis recipients and physicians is important, as disparities between patients and clinicians can be associated with negative outcomes including reduced treatment adherence, higher rates of hospitalisation and lower hospice use[55-57]. Furthermore, recognising that pessimistic estimations of life expectancy can negatively affect quality of life of both people with cancer and their carers[58], Oncology services have reported successful interventions such as the provision of psychosocial support to improve wellbeing of people with limited life expectancy [59, 60]. Studies are also currently in progress to evaluate the efficacy of communication support programmes given challenges to communicating uncertainty about prognoses [61]. Similar findings have been reported in Nephrology, with nephrologists choosing to avoid end of life discussions and an absence of formal training in how to communicate prognostic uncertainty[8, 62]: formal communication skills training for nephrologists in advance care planning could be beneficial.

A major strength of this study is the use of a scoping method; it has allowed us to present a broad overview of available literature and to present, compare, and contrast

both qualitative and quantitative research. The main limitation of this study is the paucity of research in this area with a lack of available literature and bias towards North American studies. Despite this, key findings have been identified and highlighted (Box 1), and will act as a starting point for future research.

In conclusion, optimistic patient prognostic expectations persist amongst dialysis recipients. Even when patients were selected for higher mortality risk, very few felt they had a reduced chance of survival, highlighting limited prognostic understanding. Given the effects of perceived life expectancy on treatment choices and subsequent quality of life, it is important that transparent discussions regarding prognosis are conducted with people receiving dialysis and their families.

Supplementary Material

Item S1. Detailed search strategy

Table S1. PRISMA-ScR checklist

Descriptive Text for Online Delivery

Supplementary File (PDF)

Item S1, Table S1

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Table 1: Patient characteristics and study details

Authors (Year)	Patient group studied and setting	Cognitive Impairment	Race/Ethnicity	Study Design	Study Size
Davison et al. (2010)[29]	Patients with Stage 4 or 5 Chronic Kidney Disease in a university-affiliated renal program in Canada (North Alberta).	Excluded	80.5% White 7.2% Aboriginal 8.1% Asian 1.4% African 2.4% Other	Questionnaire based study	584 Patients: 238 Pre-dialysis (41%) 222 Haemodialysis (38%) 73 Peritoneal dialysis (12.5%) 51 Transplant (9%)
Wachterman et al. 2013 [30]	Haemodialysis patients with estimated 1-year mortality risk of 20% or greater. 2 community based Haemodialysis centres affiliated with tertiary medical care centres in USA (Boston).	Excluded	19 (31%) White 32 (52%) Black 5 (8%) Asian 1 (2%) Other 5 (8%) Not documented	In-person interviews	62 Haemodialysis patients 14 Nephrologists
O'Hare et al. 2019 [31]	Patients at 31 dialysis facilities in USA (Washington and Tennessee).	Included if cognitively able to provide informed consent	563 (56.7%) White 268 (27.0%) Black 83 (8.4%) Asian 16 (1.6%) American Indian or Alaskan Native 30 (3.0%) Native Hawaiian or other Pacific Islander 33 (3.3%) Other or missing	Questionnaire based study	993 Patients: 988 Haemodialysis patients (99.5%) 5 Peritoneal dialysis patients (0.5%)
Ghanem et al. 2020 [32]	Haemodialysis patients at a single dialysis centre in North America (New York)	Excluded	49 (74%) White 13 (20%) Black 4 (6%) Other	Questionnaire based study	66 Haemodialysis patients 4 Nephrologists
Beckwith et al. 2021[36]	Haemodialysis patients with estimated 1-year mortality risk of 20% or greater. 3 Haemodialysis centres affiliated with tertiary medical centre in England (London).	Included	29 (57%) white 16 (31%) non-white 6 (12%) not documented	Structured interview (44/51, 86%) or mixed-methods questionnaire (7/51, 14%).	51 Haemodialysis patients, their named nurse and nephrologist.
Schell et al. 2012 [33]	Patients over 65yo with stage 3-5 Chronic Kidney Disease or on Haemodialysis and nephrologists (note not necessarily the included patients' nephrologists). Two centres in USA (North Carolina)	Excluded	11 (38%) Caucasian 18 (62%) Black	Qualitative Semi-structured interviews	29 patients: 11 with Chronic Kidney Disease (38%) 18 Haemodialysis patients (62%) 11 Nephrologists.
Elliott et al. 2016 [34]	Older dialysis patients (>70y) and their family members at a single centre in	Excluded	27 (87%) White 4 (13%) not documented	Qualitative interview study	20 dialysis patients (does not state if Haemodialysis or

	North America (Minnesota)				Peritoneal Dialysis patients) 11 family members
Manda et al. 2013 (abstract only) [35]	Dialysis patients at two community dialysis centres in North America (Massachusetts)	Does not specify	Does not specify	Prospective, non- randomised, mixed methods study	37 patients (does not state if Haemodialysis or Peritoneal Dialysis patients)

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Figure Legends

Figure 1: Flow chart for study inclusion criteria

Figure 2: Risk of bias assessment per included study, the Risk of Bias Assessment tool for Non-randomised Studies (RoBANS) [28]

*Given outcome assessments for this study were patient-reported (perceived life expectancy), a low risk of bias was assigned to all studies.

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Box 1.

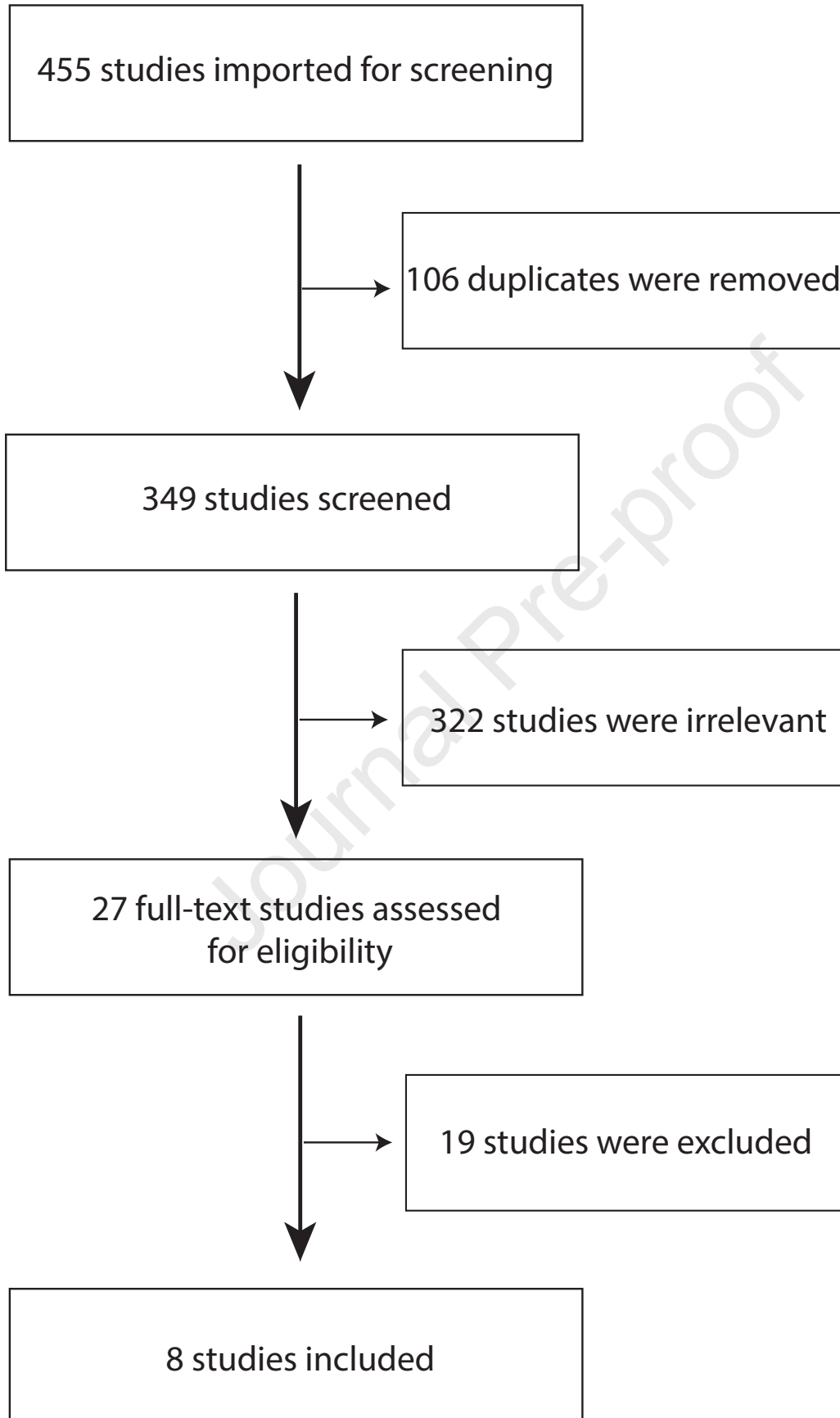
Key Messages











































This scoping review explores how long dialysis recipients expect to live.

We found:




- Optimistic prognostic expectations among people receiving dialysis
- Almost no agreement between patient and nephrologist estimates of one-year survival
- Perceived life expectancy influenced treatment choices

We suggest that transparent discussions regarding prognosis should be conducted with people receiving dialysis and their families.



Study	Domain					
	Selection of participants	Confounding variables	Measurement of exposure	Blinding of outcome assessments*	Incomplete outcome data	Selective outcome reporting
Davison 2010 ²⁹						
Wachterman 2013 ³⁰						
O'Hare 2019 ³¹						
Ghanem 2020 ³²						
Beckwith 2021 ³⁶						
Schell 2012 ³³						
Elliott 2016 ³⁴						
Manda 2013 ³⁵	Abstract only. Insufficient details to assess					

Key:

-  High risk of bias
-  Low risk of bias
-  Unclear risk of bias