Patient-Reported Outcome Measures for Fatigue in Patients on Hemodialysis: A Systematic Review

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Background: Fatigue is a prevalent and debilitating symptom in patients receiving hemodialysis. We aimed to identify and evaluate the characteristics and psychometric properties of patient-reported outcome measures for fatigue in patients receiving hemodialysis, to inform the selection of a robust and feasible measure for use in randomized trials in hemodialysis.

Study Design: Systematic review of outcome measures for fatigue.

Setting & Population: Patients receiving hemodialysis.

Search Strategy & Sources: MEDLINE, Embase, PsycINFO, and CINAHL from inception to April 2017 were searched for all studies that reported fatigue in patients receiving hemodialysis.

Analytical Approach: With a focus on addressing methods, items (individual questions) from all measures were categorized into content and measurement dimensions of fatigue. We assessed the general characteristics (eg, number of items and cost) and psychometric properties of all measures.

Results: From 123 studies, we identified 43 different measures: 24 (55%) were developed specifically for the hemodialysis population (of which 18 were nonvalidated author-developed measures for use in their study only), 17 (40%) for other populations, and 2 (5%) for chronic kidney disease (all stages). The measures assessed 11 content dimensions of fatigue, the 3 most frequent being level of energy (19 [44%]), tiredness (15 [35%]), and life participation (14 [33%]); and 4 measurement dimensions: severity (34 [79%]), frequency (10 [23%]), duration (4 [9%]), and change (1 [2%]). The vitality subscale of the 36-Item Short Form Health Survey (SF-36) was the most frequently used (19 [15%] studies), but has only been tested for reliability in hemodialysis. Of the fatigue-specific measures, the Chalder Fatigue Scale was the only one evaluated in hemodialysis, but the full psychometric robustness remains uncertain.

Limitations: For feasibility, we searched for validation studies in the hemodialysis population using the names of measures identified in the primary search strategy.

Conclusions: A very wide range of measures have been used to assess fatigue in patients receiving hemodialysis, each varying in content and length. Many have limited validation data available in this population. A standardized and psychometrically robust measure that captures dimensions of fatigue that are important to patients is needed to estimate and improve this disabling complication of hemodialysis.

Complete author and article information provided before references.

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Fatigue is a common symptom that affects 60% to 97% of patients receiving hemodialysis and is associated with an increased risk for cardiovascular events, mortality, and decreased quality of life in patients on maintenance hemodialysis therapy.[1-3] Patients receiving hemodialysis have described fatigue as debilitating, preventing them from being able to work and participate in social and recreational activities, which can lead to decrements in mental health and poor satisfaction with life.[1,2] Patients have rated fatigue to be of higher importance than death and other dimensions of quality of life.[1-4] Although there have been efforts to develop pharmacological and lifestyle interventions, fatigue remains under-recognized in the hemodialysis population.[5]

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Fatigue has generally been defined as a subjective state of tiredness or exhaustion and the reduction of capacity for normal activity.[6] In the context of chronic illness, there is no commonly accepted definition due to the variability of factors affecting fatigue as experienced by different patients. Previous qualitative work with patients treated by hemodialysis has demonstrated complexity and multidimensionality of fatigue as experienced in this population.[4,5] Although there has not been systematic work done to compare fatigue in different patient populations, fatigue is likely to be unique to this patient group, in part due to the highly disruptive intervention itself. Complications related to end-stage kidney disease and treatment may exacerbate the severity, impact, and nature of fatigue.[2]

To target fatigue as a critical complication in patients receiving hemodialysis, clinicians and clinical trialists need to recognize and accurately measure fatigue in this setting. The varied estimates of fatigue may be due to the different measures used to assess fatigue.[5] Currently, measures of fatigue developed for other patient populations are being used in the hemodialysis population,[5] but this may not be

appropriate. In nephrology, the Standardized Outcomes in Nephrology–Hemodialysis (SONG-HD) initiative was formed to establish core outcomes to be reported in all trials conducted in patients receiving hemodialysis, with fatigue identified as a core outcome domain.[3] The aim of this study, which was conducted as part of the SONG-HD Initiative, was to identify the content, general characteristics, and psychometric properties of outcome measures used to assess fatigue in patients receiving hemodialysis, to inform the selection of a robust and feasible measure suitable for use in randomized trials conducted in this setting. An accurate assessment of fatigue through a suitable measure may provide better understanding of factors associated with fatigue and would allow for a robust and reliable evaluation of the efficacy of interventions targeting factors such as comorbid conditions or mood to manage fatigue.

Methods

Selection Criteria

Based on a preliminary search for clinical trials reporting fatigue in patients receiving hemodialysis that yielded very few studies and a small range of measures, we broadened the inclusion criteria to all study designs (randomized, nonrandomized,[7] and descriptive studies[8]) that involved adult patients (aged ≥18 years) on maintenance hemodialysis therapy (for ≥90 days) and reported at least one measure of fatigue. Studies published in peer-reviewed journals were included; unpublished studies and gray literature were excluded. No language restrictions were placed on the search. Studies using a global measure (ie, a composite measure for health status, quality of life, or health-related quality of life that did not only assess fatigue) were included if they reported a fatigue-specific score (based on results from the fatigue subscale within the measure). Those that reported only a composite score that included a fatigue domain such as an overall quality-of-life score were excluded. Based on the patient-defined scope of fatigue (general feeling of extreme exhaustion and tiredness for most of the time),[4] we excluded studies that assessed only sleep disturbances (such as insomnia) or physical frailty. These outcomes have previously been conceptualized as distinct from fatigue.[4,9,10] Also, studies that enrolled only patients with non–dialysis-dependent chronic kidney disease, those treated by peritoneal dialysis, and those having a kidney transplant were excluded.

Study Sources and Measures

The search strategies are provided in Table S1. We conducted searches in MEDLINE, Embase, PsycINFO, and

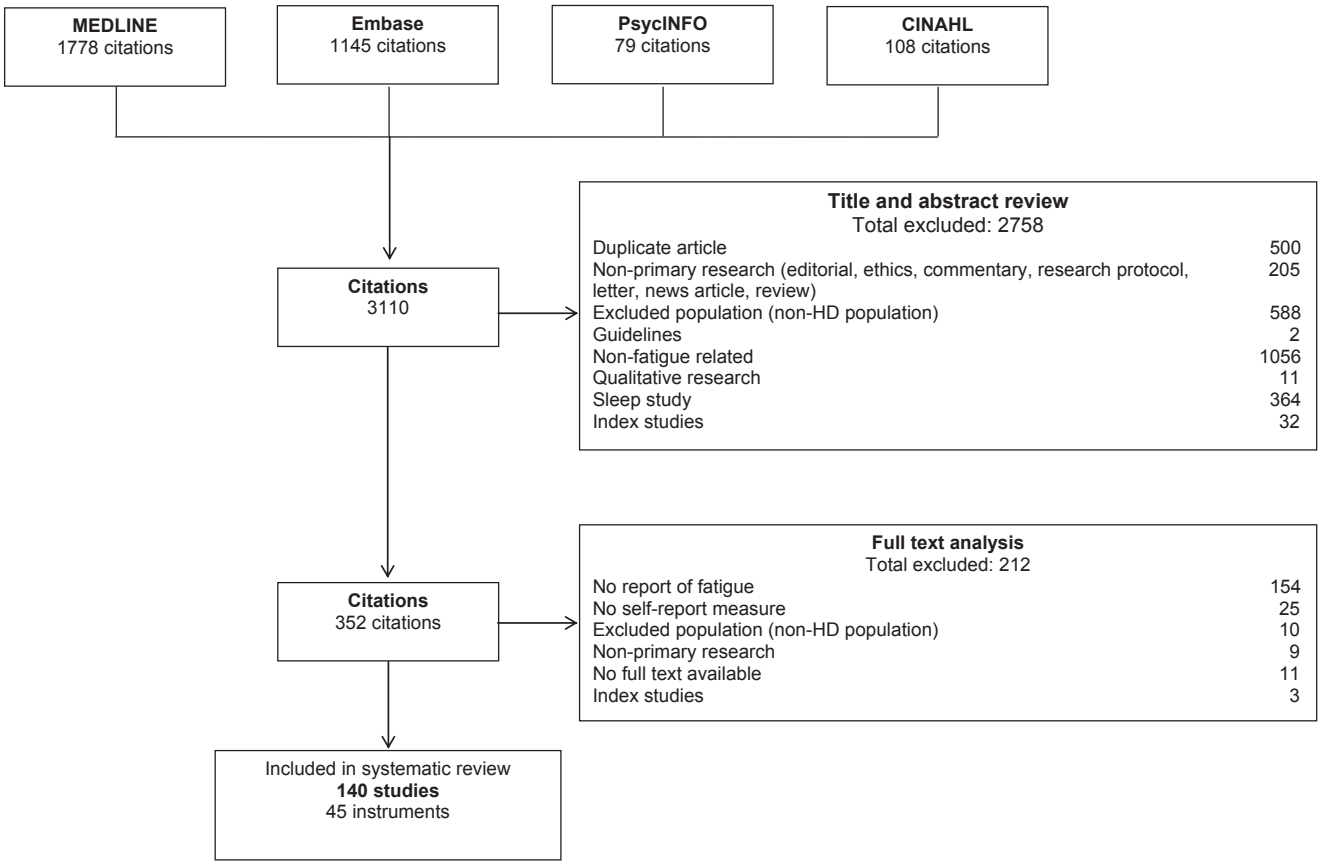

Figure 1. Literature search. Abbreviation: HD, hemodialysis.