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8Patient perspectives on the meaning and impact of fatigue in hemodialysis: systematic

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10review and thematic analysis of qualitative studies

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Short title: Fatigue in hemodialysis

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Abstract

Background Rationale and objective: Fatigue is a highly prevalent and debilitating symptom in patients on hemodialysis ~~that may be the~~ due to the uremic milieu, hemodialysis and other comorbidities and the ~~treatment itself~~. Yet, fatigue remains under recognized and the consequences underappreciated because it may not be visible in clinical settings. This study aims to describe the lived experience of fatigue in patients undergoing hemodialysis.

Study design: Systematic review and thematic synthesis of qualitative studies

Setting and population: Patients on hemodialysis

Search strategy and sources: MEDLINE, Embase, PsycINFO, CINAHL, reference lists and PhD dissertations were searched from inception to October 2018.

Data extraction: All text from the results/conclusion of the primary studies.

Analytical approach: Thematic synthesis ~~was used to analyze the findings.~~

Results: In total, 65 studies involving 1713 participants on hemodialysis were included. We identified four themes related to fatigue: debilitating and exhausting burden of dialysis (bodily depletion, trapped in a vicious cycle of post dialysis exhaustion, vigilance and worry inhibiting rest, tiresome and agonizing regimen, without remedy and relief); restricted life participation (deprived of time, managing energy reserves, frustrating need to rest, joys foregone); diminishing capacities to fulfil relationship roles (losing ability to work and provide for family, failing as a parent, lacking stamina for sexual intimacy, relying on others); and vulnerable to misunderstanding (being criticized for the need to rest, failing to meet expectations).

Limitations: Non-English articles were excluded and most studies were conducted in high-income countries.

Conclusion: For patients on hemodialysis who experience fatigue, fatigue is a profound and relentless exhaustion that pervades the whole body and encompasses ~~pain and~~ weakness. The fatigue drains vitality in patients and constrains their ability to do usual activities and fulfill their roles and meet personal aspirations.

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Explicit recognition of the impact of fatigue and establishing additional effective interventions to improve fatigue are needed.

Index words: fatigue, qualitative research, patient-centered care, dialysis, [outcomes](#)

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Plain language summary

Fatigue is a critically important outcome for patients on hemodialysis. Yet, the nature and pervasive impact of fatigue on the lives of patients may be underrecognized. We aimed to describe patients' perspectives on the nature, meaning, and impact of fatigue in hemodialysis. We conducted a comprehensive review of existing studies and identified 65 studies involving 1713 patients. Patients felt debilitated and exhausted by the burden of dialysis, restricted in being able to participate in life, diminished in their capacity to fulfill relationship roles, and misunderstood by others. Effective strategies to manage and improve fatigue in patients on hemodialysis are needed.

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Introduction

Fatigue is a debilitating and highly prevalent symptom affecting 60% to 97% of patients on hemodialysis, and is associated with impaired quality of life, cardiovascular disease and mortality¹⁻⁶. Patients on hemodialysis have consistently rated fatigue to be a critically important outcome, even above survival, cardiovascular disease, mobility and pain^{1,7-10}. The causes of fatigue in patients on hemodialysis are complex and multifactorial, and may include uremia, anemia, depression, and physical deconditioning¹¹. Also, the chronic, invasive and burdensome nature of dialysis may mean the fatigue as experienced by patients on hemodialysis is distinct compared with other illnesses¹².

Fatigue has been defined as “an uncommon abnormal or extreme whole bodily tiredness which is not related to activity or exertion”¹³. Patients on hemodialysis report feeling limited by their weakened bodily condition^{14,15}, and attribute poor quality of life to fatigue^{14,15}. Fatigue impairs concentration and motivation, and restricts daily activities and social participation^{14,15}. Despite this, fatigue remains under recognized and the consequences may not be fully appreciated as the evidence on the patient experiences of fatigue in hemodialysis is fragmented and limited, and is not routinely measured in clinical practice¹⁴⁻¹⁶.

A synthesis of data on patient perspectives on fatigue across multiple studies can yield comprehensive and in-depth insights across healthcare contexts and populations. The aim of this study was to describe patients’ perspectives on the nature, meaning, and impact of fatigue in hemodialysis. Such experiential evidence of fatigue in the context of hemodialysis may increase awareness and inform strategies to address this patient-important outcome.

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Methods

We followed the Enhancing Transparency of Reporting the Synthesis of Qualitative research (ENTREQ) framework¹⁷.

Selection Criteria

Qualitative studies that described the experiences and perspectives of fatigue in adults aged 18 years and over on chronic hemodialysis (at least three months) were eligible. All modalities (i.e. thrice-weekly in-center, home, frequent dialysis) were eligible. The perspectives on all dimensions of fatigue (lack of energy, post-dialysis fatigue, weakness, tiredness) were included¹⁸. Non-English studies were excluded due to limited resources for adequate and meaningful translation.

Data Sources and Searches

The search strategy is provided in Table S1. Searches were conducted in MEDLINE, Embase, PsycINFO and CINAHL (Cumulative Index to Nursing and Allied Health Literature) from database inception to October 23, 2018. Reference lists of relevant articles, Google Scholar were also searched. We also searched Pro-Quest Dissertations and Theses Database, British Library Electronic Theses Online Service (EThOS), and the DART-Europe E-theses Portal for published doctoral dissertations. Two authors (J. J. and A.J.) independently screened the titles and abstracts of the search results and excluded those that did not meet the inclusion criteria. The full texts of potentially relevant articles were assessed for eligibility.

Data Extraction and Quality Assessment

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The comprehensiveness of reporting of each qualitative study were independently assessed by three authors (J.J., A.J., A.B.) using the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) framework, which includes criteria specific to research team, study methods, study context, and method of analysis and interpretations¹⁹. Any discrepancies were resolved by discussion.

Data Analysis

We used thematic synthesis as described by Thomas and Harden to analyze the data²⁰. The scope included perspectives on the causes, experience and consequences of fatigue in patients on hemodialysis. All participant quotations and text under the “results/findings” or “discussion/conclusion” section from the included studies were entered into the software HyperRESEARCH version 3.7.3 (ResearchWare Inc) for data management. Author J.J. conducted line-by-line coding of each study using the software and inductively identified concepts about fatigue. Similar concepts were grouped into themes and subthemes. Authors (A.J. and A.T.) read the papers, and reviewed and discussed, and revised the preliminary analysis until all the investigators agreed to ensure that the full range and depth of data were included in the analysis. Author J.J. developed an initial thematic schema to indicate conceptual patterns and links among themes by examining the data from the primary studies (i.e. quotations that contributed to multiple themes), and this was reviewed and, which was refined based on discussion with authors A.J/A.T.

Results

Literature Search and Study Description

Of the 3172 articles retrieved (Figure 1), 65 studies fulfilled the inclusion criteria and were included. These studies involved 1713 participants from 15 countries including Australia, Bahrain, Brazil, Canada, Denmark, Greece, Indonesia, Iran, New Zealand, Saudi Arabia, Sweden, Taiwan, Thailand, the UK and US (Table 1,

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8 Table S2). Only 9 (14%) studies explicitly included fatigue in the aim of the study, and the remaining
9 studies included perspectives of fatigue embedded within the broader scope of the study. Unstructured and
10 semi-structured interviews (in person and by telephone), focus groups, observations, and surveys with open
11 text responses were used to collect the data.
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16 Comprehensiveness of reporting

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20 Across studies, reporting was variable with studies reporting from 1 to 21 of the 24 items in the COREQ
21 framework (Table 2). The participant selection was described in 56 (86%) studies. The method of
22 recruitment was stated in 44 (68%) of studies. Data saturation was reported in 20 (31%) studies; and
23 software and member checking (providing preliminary findings to the participants for review) were reported
24 in 14 (22%) and 24 (37%) studies, respectively.
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30 Synthesis

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34 Four major themes were identified: debilitating and exhausting burden of treatment, restricted life
35 participation, debilitating and exhausting burden of treatment, diminishing capacities to fulfil relationship
36 roles, and vulnerable to misunderstanding. The respective subthemes are described below and selected
37 participant quotations to illustrate each theme are provided in Table 3. A thematic analytical schema of the
38 relationship between themes is shown in Figure 2.
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45 **Debilitating and exhausting burden of treatment**

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48 **Bodily depletion:** Some pPatients perceived fatigue in hemodialysis to be more distressing than being tired
49 or sleepy, and inseparable from pain, weakness, heaviness, or dizziness²¹. Fatigue overwhelmed their whole
50 being and they felt “limp”²², as if “poisoned”²³, “hollow”²³, “drained,”²⁴ or simply “gone”²². The fatigue
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because of hemodialysis was described as that which “nobody knows but a dialysis patient.”¹⁰ Some were constantly troubled by fatigue²⁵ while others generally felt well but experienced frequent drops in their level of energy as if “someone is pushing a button”²³ that exhausted them of their strength.

Trapped in a vicious cycle of post dialysis exhaustion: Some Ppatients felt that each hemodialysis session depleted them of all their energy and strength. They felt “worn out”²⁶ and “exhausted”^{22,27} by the treatment. Some felt drained “as soon as they unhook [you]”¹⁴ and needed to return home quickly where they could collapse”²⁸. They recuperated and restored their energy by taking time to rest. However, the need to recover after treatment prevented them from doing any other activities, which “ruined the entire day”²³. This shortened periods of feeling well between treatments – “I just start to get over that real tiredness, but then you turn around and start all over.”²⁹ Often patients did not feel better until the following day but then they had to “go right back [to dialysis] the next day”³⁰.

Rest inhibited by vigilance and worry: For some participantpatients who had recently commenced hemodialysis, the fear of treatment combined with the unexpected diagnosis of kidney disease caused them to lose sleep³¹. The invasive nature of the hemodialysis and possibility of a technical malfunction provoked anxiety such that some felt unable to rest or sleep during treatment for fear they may “bleed to death if the lines leak [as] the machine doesn’t know to stop.”³² Some forced themselves to stay awake to be constantly vigilant in monitoring the hemodialysis procedure – “~~I could not close my eye I could not close my eyes, I was watching everybody and I was the monitor in that room. I was so tired when I came out of there... I was afraid to close my eyes...~~”³²es...I was the monitor in that room”³², which worsened their fatigue.

Tiresome and agonizing regimen: The grueling, ongoing, and constant cycle of fatigue and recovery due to the hemodialysis regimen was described as a “treadmill”³¹ requiring ongoing effort. The ever-present fatigue meant that some participants had to exert extra effort to get to dialysis, to wait in the waiting room, to complete the 3 or 4-hour exchange, to return home, only to repeat the experience every second or third day.

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The effort of living became constant; “you have to fight against it all the time.”¹⁵ For some who had been on dialysis for a longer period of time, the unrelenting fatigue and having to endure treatment became intolerable such that they questioned whether death would be preferable – “They do all these to keep us going and you wonder if you shouldn’t just take some pills—and END it...I’m just so tired. How many years can this go on?”³³. Another patient said, “I am so tired mentally that I hate myself. I feel the burden of all worlds is on my shoulders...”³⁴

Without remedy and relief: Fatigue was “bothersome and challenging to manage”²⁷ and some suggested that adjusting fluid removal could be effective. There was no medication or treatment available to improve fatigue, unlike for other symptoms such as itching²⁷. Some were skeptical about psychological therapies to address fatigue – “I can’t see how talking can help with it”⁶. They believed that their energy levels could only be improved with kidney transplantation⁶.

Restricted life participation

Deprived of time: ~~For some patients, t~~The dialysis regimen along with the need to rest meant that they felt denied time; “I only have a 4-day week because the dialysis days don’t count because I am too tired to do anything”³⁵. The time during which participants felt well was substantially diminished because of hemodialysis. Dialysis days were described as “write-off days”¹⁴ but the need to rest the following day prevented participants from making plans for their days off dialysis³⁶.

Managing energy reserves: ~~Some patients~~ ~~Participants~~ had less stamina after commencing hemodialysis and adapted their lifestyle accordingly by limiting their activities and making time to rest. They paced themselves to avoid depleting their energy reserves; “I’ll tire out quicker now...if I pace myself, I can go all day”³⁷. They recognized that “it’s acknowledging maybe doing too much, maybe needing to take things down a bit.”⁶ Others said they “budgeted”¹⁶, “scheduled”¹⁶, “organized”³⁸ or “managed”¹⁵ their limited

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8 energy in order to achieve as much as they could. Sometimes this meant participants could not go on
9 vacation³¹, attend social events³⁶ or stay up late²². They had to prioritize activities for their health and family
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11 “I save my energy for going to the mall to buy my little girl a dress”³⁶.
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15 *Frustrating need to rest*: Efforts to be physically active and to do daily activities were frustrated by the need
16 to rest, which meant tasks were not finished or took longer than intended²³. As one participant said, “I get up
17 in the morning and I want to do a lot around the house; but I always find myself feeling tired...I must sit
18 down, but I haven't really accomplished anything”²¹. Some felt they could do nothing but rest – “I am
19 sleeping my life away”²⁶.
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25 *Joys foregone*: Dialysis deprived some participants of the energy and strength to do activities they enjoyed,
26 such as shopping, cooking, taking vacations, which collectively symbolized their previous, healthy state;
27 you can't lead a normalish [sic] life...you can't do sports and that because the tiredness...”³⁸ They had to
28 give up social activities – “We always used to go out dancing and visit friends, but I don't have the strength
29 any longer. I tell my husband that he may go out alone but... I miss it very much”²⁸. Some
30 patients felt “hopeless”³⁹ and “shackled”⁴⁰ in their restricted lifestyle. Others said dialysis had
31 changed their goals in life and so were more accepting of their limitations; “I take one day at a time...it
32 seems like if I just wake up, that's enough.”³¹
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36 **Diminishing capacities to fulfil relationship roles**

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41 *Losing ability to work and provide for family*: Some became unable to work, which denied them of their role
42 as a provider for the family, or as a contributing member of society. Work was important to their identity –
43 It's [work] part of me...it's something that's under my skin.”⁴¹ Some felt to be without purpose and were
44 just sitting around the house not doing nothing.”³¹ They found it demoralizing to lose their financial
45 independence and ability to provide the same standard of living for their family – “I feel bad...when my
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8 daughters ask me for something and I tell them I have to wait ‘til I done paid the bills or bought the
9 groceries...that makes me feel horrible.”³¹ Without work, they questioned, “what do I contribute to society?
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11 just stopped working, but I don’t volunteer...I’m just so tired.”⁴²
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15 *Failing as a parent:* Some patients felt sad and guilty because fatigue limited their role as parents. Fatigue
16 deprived some of quality time with their children. They could not go to the shops, and some had to be in
17 bed all day.”³⁶ Some did not have energy for strenuous activities such as camping. One participant felt that
18 his inability to play ball with his son made him less of a father.³¹ They were too tired to discipline their
19 children with one mother saying “my youngest have gotten away with a whole lot the older ones didn’t.”³¹
20 In a study conducted in Saudi Arabia, some mothers blamed themselves as their children had to take on
21 extra responsibilities, such as ironing and caring for younger siblings, because of fatigue²¹.
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29 *Lacking stamina for sexual intimacy:* Fatigue inhibited sexual relations, particularly on dialysis days when
30 fatigue ~~and~~ weakness ~~and pain~~ were the most severe. Some said hemodialysis drained their energy and
31 sexual desire. For others, the desire persisted but they lacked the physical strength for sex; ~~“I’m so drained, I~~
32 ~~can’t perform.”~~⁴³ Some felt more energetic in the morning but this conflicted with morning dialysis
33 schedule. They felt guilty about disappointing their partners. One participant attributed her husband’s
34 extramarital affair to her inability to have sex because of her fatigue from hemodialysis.
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41 *Relying on others:* Fatigue made ~~some~~ participants dependent on family members for help with housework,
42 shopping and transportation to and from dialysis. Some relied heavily on their spouses for care but worried
43 about being “a nuisance”³⁹ and appreciated their patience and understanding – “There are a lot of times I just
44 don’t feel good, and he has to be very understanding...He has to be a lot more understanding of me than I of
45 him”⁴⁴. They also felt vulnerable and worried about being unable to cope without their spouse ~~“If my wife~~
46 ~~would get sick, then I wouldn’t manage. That’s what’s worrying me most actually.”~~³⁹ For some, their
47 children became the decision-makers and caregivers, which in some led to restricted independence – “My
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children were afraid that I might faint when driving~~afraid that I might faint when driving~~. They took away my car keys. I felt like I was trapped in my own house.”⁴⁵

vulnerable to misunderstanding

Being criticized for the need to rest: Some pParticipants felt unfairly judged by family members as being lazy”²¹ or “depressed”⁴⁶. Participants became frustrated with needing to defend the legitimacy of their physical exhaustion, with some choosing to withdraw from relationships – “I’m tired of explaining my illness to...my relatives. I rather stay away from them.”²¹ They believed that others failed to recognize both the extent of their fatigue but also the extra effort required to achieve daily tasks—~~“we struggle to be like everybody else and we need to be understood.”~~⁴¹ Some parents said their children did not understand the extent of fatigue, particularly on non-dialysis days.

Failing to meet expectations: Some pParticipants found it difficult to meet the expectations of their friends and to contribute and function as normal despite their fatigue – “My family thinks I am the same person as before; taking care of...everything...Now I need someone to care for me.”²¹ Others reported being misunderstood as they did not appear to be suffering from fatigue – “Technically you have a walking handicap, and yet when they see you...playing tennis, they...say, this must be a piece of cake.”⁴⁴

Discussion

For some patients on hemodialysis, fatigue meant bodily exhaustion. They felt devoid of energy, strength and motivation. This limited their ability to participate in all aspects of life including work, hobbies, family responsibilities and social commitments. Consequently, this eroded their identity and self-esteem. The constant and frustrating need to rest caused them to feel deprived of time. Some pPatients harbored guilt in being unable to fulfil their responsibilities, particularly within their family, and felt increasingly vulnerable

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8 in having to rely on their family. The invisibility of fatigue meant that patients did not appear unwell, and
9 thus felt judged and unable to meet the expectation of others.
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13 In our synthesis, sSome differences in the experiences and impact of fatigue were apparent based on dialysis
14 vintage^{31,33}, their social roles^{21,31,36}, country and gender²¹. Patients experienced more severe fatigue as their
15 condition deteriorated and noted that they took longer to recover after dialysis, feeling drained for an
16 extended period of time before they returned for another treatment. They continued with dialysis to survive
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18 yet were trapped in an intensifying trajectory of fatigue without reprieve. Among patients with spousal or
19 parental roles, some felt guilt for having to depend on and burden their spouse or children. Parents felt they
20 were disappointing their children when they lacked energy to spend time with them or were unable
21 to discipline them. Those who were once the family breadwinner struggled with being unable to provide for
22 their family and believed that they were no longer contributing to the family. In the study conducted in
23 Saudi Arabia, women were particularly distressed in being unable to complete the duties expected of them
24 as housekeepers and mothers because of fatigue²¹.
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34 Much of the focus in research has been on post-dialysis fatigue, as this can be observed or more frequently
35 reported in clinical settings¹⁰. We found that patients experienced an intense fatigue after dialysis. Dialysis
36 drained them of energy, leaving them “hollow” and needing to rest for hours to recover²³. This fatigue was
37 described as inseparable from weakness, body aches and dizziness that patients attributed to dialysis²³.
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41 However, patients requiring hemodialysis also experience fatigue as constant and debilitating, with profound
42 consequences on their self-esteem, relationships, and overall life satisfaction. This overall fatigue has been
43 rated to be of higher importance than post-dialysis fatigue⁷. The extent of this fatigue may be under
44 recognized in clinical settings⁴⁷, and our findings may help in increase awareness and support
45 communication and education about the persistent and pervasive nature of fatigue in patients on
46 hemodialysis.
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8 There are some similarities in the nature and impact of fatigue in patients with other chronic conditions
9 including cancer, cardiovascular disease, multiple sclerosis and fibromyalgia, who have also described
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11 fatigue as beyond a usual tiredness. Fatigue has been referred to as a severe exhaustion that restricts social
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13 participation. Patients have also felt misunderstood and perceive a lack of empathy by others⁴⁸⁻⁵¹. They
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15 contend with guilt about disappointing their loved ones, and are vulnerable in having to rely on others⁴⁸⁻⁵⁰.
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17 However, our review has identified some experiences and attitudes that are unique in the context of
18 hemodialysis, which largely relate to the perception that the hemodialysis regimen intensified or worsened
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20 fatigue. Patients believed that the treatment, to some extent, caused symptoms that contribute to fatigue.
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22 The time and effort to travel for dialysis consumed their already limited energy, and the dialysis schedule
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24 deprived them of time they needed to rest, for example, having to wake early for a morning session. This
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26 unrelenting regimen exhausted their depleted energy reserves such that they could not participate in
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28 activities of living and interfered with social functioning. All this in addition to the consequence of the
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30 disease. Some patients accepted fatigue as their ‘new normal’ and attempted to organize their activities
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32 around their dialysis schedule.
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34 We developed a comprehensive framework of themes by systematically synthesizing qualitative evidence.
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36 However, there are some potential limitations. Firstly, few of the studies included were focused specifically
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38 on fatigue in hemodialysis, which may limit the breadth of data available. Thus, we conducted a sensitive
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40 search to ensure data related to fatigue, embedded within studies with a broader scope, were included in the
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42 synthesis. We were unable to compare the perspectives of fatigue based on other factors including dialysis
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44 prescription, home or facility dialysis, wait listing status for transplantation, as these were not reported in the
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46 included studies. We also note that direct comparisons between hemodialysis and peritoneal dialysis were
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48 absent. Most studies were conducted in high-income countries and non-English studies were excluded. Thus,
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50 the transferability of our findings beyond these settings is uncertain.
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Given the impact of fatigue on the burden of treatment and life participation, effective interventions are urgently needed to manage this symptom¹⁰. However, addressing fatigue remains highly challenging as the causes are multifactorial, overlapping and interacting, and a plethora of social, demographic, biochemical and clinical variables have been associated with fatigue^{1,52}. Currently, high quality evidence for interventions to improve fatigue for patients on hemodialysis is lacking^{47,53}. Strategies such as cognitive behavioral therapy (CBT) have been found to be effective in treating fatigue in multiple sclerosis by giving patients more control over fatigue-related thought and in doing so reducing symptom severity⁵⁴. There is also some evidence for CBT and exercise therapy in managing fatigue in hemodialysis⁵⁵⁻⁶⁰. Deconditioning in patients on hemodialysis can also impact of fatigue⁶¹⁻⁶³. Exercise interventions may improve muscle and functional outcomes, and could thus be considered in managing fatigue^{61,64,65}. Pharmacological (including erythropoiesis-stimulating agents to manage hemoglobin levels and anemia)^{66,67}), psychological interventions (including stress-management and relaxation techniques) and complementary and alternative therapies (including reflexology, aromatherapy and acupuncture) have also been evaluated^{52,53,68-70}. Although findings suggest there is some evidence to suggest that these interventions are potentially effective in improving fatigue, however larger, high quality randomized trials are needed to confirm these data. Studies have consistently demonstrated an association between fatigue and depression, and it has been suggested that routine screening and interventions for depression may improve fatigue⁷¹. More studies are needed to ascertain the effect of interventions for depression on fatigue⁷¹. Frequent and longer nocturnal dialysis have been associated with marked improvement in post-dialysis and global fatigue⁷²⁻⁷⁴, and may also be effective approaches to improve fatigue, though the evidence remains limited and uncertain^{53,57,72,75-77}. Treatment of depression, or frequent hemodialysis, and improving access to kidney transplantation are other approaches to improve fatigue.

We also recognize the challenges of conducting trials to address fatigue. One is the absence of a suitable measure. A recent systematic review of trials and observational studies involving patients on hemodialysis found that 43 different measures were used to assess fatigue in hemodialysis, yet these measures do not

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8 include patient-important dimensions such as loss of independence and erosion of self-esteem as we found
9 in this review¹⁸. Only 30% of these measures included a dimension for 'life participation' in hobbies, work,
10 social commitments and chores. To this end, the Standardized Outcomes in Nephrology in Hemodialysis
11 (SONG-HD) initiative is currently working to establish a validated measure of fatigue which reflects the
12 dimensions that are most important to patients⁷⁸.
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18 For patients on hemodialysis who experience fatigue, fatigue is a profound and relentless exhaustion that
19 encompasses weakness. Patients perceive that dialysis drains their whole body of energy and having to
20 adhere to the demanding treatment schedule also consumes much of the patients' time and drive.
21
22 Consequently, this constrains their ability to do their usual activities and fulfil their roles, diminishing
23 independence and identity. Distinguishing the disease from treatment and the psychosocial sequelae in
24 trying to assess and manage fatigue is clinically challenging. Better strategies to assessing, recognize and
25 address the severity and impact of fatigue in clinical settings appear warranted, and the development of
26 effective interventions for managing and improving this symptom for patients on hemodialysis, are needed.
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Figure Legends

Figure 1. Search sults

Figure 2. Thematic Schema

The ‘debilitating and exhausting burden of fatigue’ led to ‘restricted life participation’ and ‘diminishing capacities to fulfil relationship’ roles. These two themes led to patients feeling ‘vulnerable to criticism and misunderstanding’. Some patients struggled to participate in activities of life, restricted by their limited energy and need to rest, which were perceived to be ‘decreasing life satisfaction’. Being criticized and misunderstood by others meant that some patients felt ‘lacking in acceptance by others’. Some patients believed that the inability to fulfil their relationship roles and to contribute to their family and community caused ‘lowering of self-esteem.’ Collectively, these three aspects intensified the ‘tiresome and agonizing commitment’ of dialysis.”

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Supplementary Files

Supplementary Table 1: Search strategies

Supplementary Table 2: Characteristics of the included studies

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9 AT; data acquisition: JJ, AJ, AB, KM, AT; data analysis/interpretation: JJ, AJ, AB, MU, DO, GO, JCC, JD,
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Table 1. Characteristics of the studies*

Characteristics	N (%) of studies
Number of participants	
1-10	15 (23%)
11-20	21 (32%)
21-30	8 (12%)
31-40	8 (12%)
More than 40	13 (20%)
Country	
United States	29 (45%)
Australia	8 (12%)
Sweden	7 (11%)
Canada	5 (8%)
Other**	16 (25%)
Method of data collection	
Unstructured interview	1 (2%)
Semi-structured interview	43 (66%)
Interview (type not specified)	12 (18%)
Survey with open text response	6 (9%)
Focus group	4 (6%)
Observation	4 (6%)
Consensus workshop	1 (2%)
Method of analysis	
Thematic analysis	18 (28%)
Grounded theory	9 (14%)
Content analysis	12 (18%)
Constant comparison	4 (8%)
Other	23 (35%)

*Detailed characteristics are provided in Supplementary Table 2. Numbers (%) may not equal 65 (100%) as categories may not be mutually exclusive/due to rounding errors; **Bahrain, Brazil, Denmark, Greece, Indonesia, Iran, Saudi Arabia, Taiwan, Thailand

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Table 2. Comprehensiveness of reporting in included studies

Item	Studies reporting each item (references)	Number of studies
Personal Characteristics		
Interviewer / facilitator identified	14-16,21-24,26,27,29-46,79-98	47
Occupation of the interview of facilitator	14-16,23,24,26,31-33,35,37-39,41,42,79,83,84,86-89,93,94,96,97,99	26
Experience or training in qualitative research	15,24,31,34,86,100	6
Relationship with participants		
Relationship established prior to study commencement	14,15,41-43,86,89,94,97,100	10
Participant Selection		
Selection strategy (<i>e.g. snowball, purposive, convenience, comprehensive</i>)	6,15,16,21,23-26,29,31,32,34,36,40-43,45,46,79-82,85,86,89,91-94,96-98,100-104	38
Method of approach or recruitment	14-16,21,23,26,27,30-32,34,36-43,45,46,79-82,84-86,88,90-93,95,98-101	39
Sample size	6,14-16,21-46,79-103,105-111	63
Number and/or reasons for non-participation	16,22-26,36,38-40,42,43,83,85,88,91,94-96,98,100	21
Setting		
Venue of data collection	6,14-16,21-43,45,46,79-100,103,105,108-111	57
Presence of non-participants (<i>e.g. clinical staff</i>)	14,16,21,25,33,34,39,43,45,46,79,81,85,93,97,99,100,103	18
Description of the sample	14-16,21,22,24-27,29-46,53,79-82,84-86,88-103,105-108,110	56
Data Collection		
Questions, prompts or topic guide	6,15,16,21-29,31,32,34-36,38-43,45,46,80-82,84-86,88,92-96,98,100-103,106,108-111	47
Repeat interviews / observations	14-16,21,26,29,34,39,42-46,81,95,100,111	17
Audio / visual recording	14-16,21-23,25,26,28-32,35-41,43-46,79,81-89,92,93,99,101,103,105,6,24,27,34,94-98,100,108-111	54
Field notes	14,16,21,26,27,31,32,34,36,41-43,45,80,81,87,89,92,93,97,99,100,103,111	24
Duration of data collection (interview or focus group)	6,15,16,21-25,27,29-46,79-84,86-90,92-101,103,105,110	51
Protocol for data preparation and transcription	6,14-16,21-32,34-46,79,80,82-89,92,94-103,105,108-110	55
Data (or theoretical) saturation	6,15,16,23-25,27,29,31,34,37,79,81,85,88,89,94,96,97,102,110	21
Data Analysis		
Researcher/expert triangulation (multiple researchers involved in coding and analysis)	6,14-16,22,24,25,27-32,34,37-42,46,80,81,84,89,91-96,98,100,101,103	35
Derivation of themes or findings (<i>e.g. inductive, constant comparison</i>)	6,14-16,21-32,34-46,79-103,105,108-111	59
Use of software (<i>e.g. NVivo, HyperRESEARCH, Atlas.ti</i>)	6,26,27,29,31,40,41,45,46,79,92,95,96,100	14
Member checking (participant feedback on findings)	14-16,22,25,27,30,32,34,36,37,40,42,43,46,79,81,84,87-89,93,97,100	24
Reporting		
Participant quotations or raw data provided (<i>picture, diary entries</i>)	6,14-16,21-46,79,81-111	62
Range and depth of insight into participant perspectives on fatigue in haemodialysis (>25% of themes)	6,14-16,23-25,27	8

Table 3. Illustrative quotations

Theme	Selected Illustrative Quotes	Contributing Studies
Depleting and exhausting burden of treatment		
Bodily depletion	"... it's a kind of tiredness that you wouldn't wish on your worst enemy ... when you can't read, you're too tired to watch the telly [television], you're too tired to do anything, because your brain is so tired like all of you ... it feels like you're kind of hollow inside ... like it's only a kind of shell that's functioning."²³ "You feel like you're poisoned ... the feeling of fatigue is something like that."²³ "My body aches, I feel tired and when I'm tired, my body aches. It's all the same to me."²¹ "I've got no energy whatsoever and it's a bit like having a big, heavy weight on you...I feel like I've got a big, heavy load on me and I'm just so tired."⁶	6,7,10,15,16, 21-25,27,31,33,34,38,79,84,90,91,96,101,104,106,108,109,111
Trapped in a vicious cycle of post dialysis exhaustion	"You get off the machines ...The rest of the day is trying to recover, get that energy back that you lose to this machine."²² "Sometimes...it just drains you, you know? You can't get up, do nothing same day (as treatment), next day at that you finally get better then turn around and you gotta go right back the next day (laughter)."³⁰ "It depends again if they take more than...two kilos of fluid out of me, it happens a lot. I get cramps and then I feel a lot more tired afterwards. But if it's anything under two then I feel fine,...no effects."²⁷ "And usually when I come from dialysis I'm a little bit wiped out and then Yeah, I'd be kind of drained after dialysis."²⁴	6,10,14-16,21-24,26-28,30,31,33,34,36,38,43,45,46,79,82,85,88,90-92,98,99,104,107
Rest inhibited by vigilance and worry	"I do NOT (emphasis) sleep during my treatment. I would NEVER (emphasis) sleep during my treatment, it is potentially a life threatening treatment."³² "I could not close my eyes, I was watching everybody and I was the monitor in that room. I was so tired when I came out of there... I was afraid to close my eyes..."³²	6,22,32,34,45
Tiresome and agonizing regimen	"It seems like a treadmill, like I'm going every day when I don't really get no break in that one day in between, you know, cause I still be tired from the day before, you know. On the weekends the only time I get fresh, a breath cause I get two days off in a row . . . and then like I say, I feel refreshed. Now I got to go right back tomorrow. Like I say, back to the treadmill."³¹ "Because sometimes you're so tired, worn out, that you don't want it no more, you know what I mean? You get tired of it."²² "Sometimes I ask 'how long can this last? When is the end of this lifestyle?' Of course, I'm hoping that something can solve this. I still live with stress, we're still trying to slowly improve the quality of life. How to arrange the schedule so it's not too tiring, but you can still see your friends. If I tell you I'm happy about it, I'm lying."²⁹ "[Fatigue] is just like, imagine working 12 h and then having to go home and do all the house stuff."¹⁰⁰	6,10,14,15,21,22,27,29-31,33,35,36,38,39,46,83,88,89,92,94,95,99,100,102
Without remedy and relief	"I'm sick and tired of being sick and tired. I wanted to feel that energy that that gentleman [patient on dialysis] showed that he had after his exercise ... and that he felt, even not just physically, but mentally. Changed his whole outlook. And that's what ... I wanted."⁹⁵ "I don't think it [a psychological therapy] can help. Not with the fatigue anyway . . . I can't see how talking can help it?"⁶ "Participants focused heavily on those that were the most bothersome and challenging to manage: muscle cramping, fatigue, itching, and depression."^{27*}	6,7,10,27,95,100
Restricted life participation		

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24	Deprived of time	_"In reality I only have a 4-day week because the dialysis days don't count because I am too tired to do anything." ³⁵	7,14,16,35,36
25		"I find that it aggravates me to have to go to dialysis because it kills four hours of my time that I can't do anything ... I'm stuck over there with needles in my arm ... you got another two hours you have to rest so there's six hours. So there's half a day gone." ¹⁴	,91
26		"It just sort of comes over you. Sitting here, and I don't even know when it is going to happen ... I usually take something to read, but sometimes, I am sitting there, people watching, and I fall off to sleep. They come to check on something, and they wake me up ... I did not even know I had fallen asleep. You just sort of feel like you lost time; you missed out." ¹⁴	
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29	Managing energy reserves	"And I guess to an extent I still feel great. But I am not able to do the things that I used to do....I'll tire out quicker nowBut I mean, if I pace myself, I can go all day." ³²	6,14-16,21-24,31,36-
30		"I had more energy and it's all to do with... organisation... you've got to organise yourself. Dialysis treatment's like going to work... that's how I get my head around it. I make myself a packed lunch I make myself a flask and I'm going to work for 6 hours that's how I get my head around it... if some things got to be done do it, get on with it." ³⁸	38,42,43,81,87,92,103
31		"I take the things that are more important. I have priorities in my life now I save my energy for going to the mall to buy my little girl a dress, or I save my energy to go to the grocery or something like that instead of just always being on the go and going to fiestas." ³⁶	
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35	Frustrating need to rest	"It's really tiresome changing bed sheets ... I have to do it in turns ... because it's heavy enough just to manage the duvet ... it drives me crazy not having the strength." ²³	6,10,16,21,23,24,26,27,36,
36		"And you sit there and get angry ... because you don't have the strength ... it makes you angry when you plan to hurry up and get it over with... and instead you have to sit down." ²³	45,81,96,100,108
37		"My life changed 100%. One hundred percent! ... I might as well have died and been reborn, everything changed so much! I feel so powerless because there are so many things I can't do. Like for example, I can't sweep, I can't mop, I can't vacuum because I get so tired and I can't breathe ... I get very depressed when I can't do things. Oh! I feel like screaming and crying at not being able to do anything. And I want to! I try! I try to make myself strong and I can't!... My strength just runs out." ³⁶	
38		"I have a hard time sleeping. I think a lot of it is because I'm sleeping in the daytime so I have a hard time sleeping at night....a lot of times I've got to take a sleeping pill to go to sleep at night." ²⁷	
39		"If I'm folding laundry, I get really exhausted, so I have to stop and lay down." ²⁷	
40		"I would sleep at the facility for 4 hours and I would sleep when I get home." ¹⁰	
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45	Joys foregone	'My greatest interest was travelling, and that's just over now.... I sit here and long to go somewhere'. ³⁹	10,14-
46		"We always used to go out dancing and visit friends, but I don't have the strength any longer. I tell my husband that he may go out alone but... I miss it very much." ²⁸	16,22,25,28,31,36,38-
47		"I used to get out and be active with them [daughters]. We would go to the mall, even if we just had lunch and split it between the three of us, you know, we would do that, and, you know, just walk around and look at things or, you know, go to the park or, you know. Now I can't really do that because I get tired quick." ³¹	42,45,46,80,81,84,92,95,107
48		"It can also be a detriment to what you enjoy in life." ¹⁰	
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52	Diminishing capacities to fulfil relationship roles		
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54	Loss of ability to work and provide for family	"I used to work . . . I enjoy working and it's a big difference when you can't work to jumping to disability.... I feel bad sometime when my daughters ask me for something and I tell them I have to wait 'til I done paid the bills or bought the groceries to see what's basically left over...that makes me feel horrible. If they even come to me and ask me for a dollar and I don't have that dollar [silent pause]...". ³¹	6,7,10,15,16,27,29-
55		"That's one major thing to me, because I feel if I'm working, I'm being productive, I'm being like everyone else. _you know...I started working when I was 14 years old and it's in my life, it's something that's under my skin...." ⁴¹	31,36,37,41,42,45,81,84,91,92,111
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24	Failing as a parent	"The days I do go to dialysis I just don't feel like I'm that particular person [all man] because I be drained. I can't get up and play with my son. He wants to play basketball, throw the ball around. I'm not able to do that because I be too tired..." ³¹	6,10,16,21,27
25		"I don't do things with my kids like I used to. Like go out with them shopping, like go to a movie, you know, go out to the park. I just like to stay home and just ... lie down...especially after dialysis. I feel real exhausted!...they understand, on the dialysis days they do, but like today and tomorrow [non-dialysis days], you know, sometimes I don't like to do anything. They start saying, "But why Mom? Come on, you didn't go to dialysis today." ³⁶	,31,36,38-40,42
26		"Cause the girls want to go out sometimes, and I can't do it, because I just don't have the energy to do it." ⁶	
27			
28			
29			
30	Lacking stamina for sexual intimacy	"My desire is mostly dampened by the fact that you're tired all the time. Occasionally [I have the] desire...It's hard to get enthusiastic about it because I'm so tired." ⁴³	31,43,44,93
31		"I mean, to have sex takes a lot of energy and sometimes you need some concentration and I'm so drained, I can't perform...By night time, I go to bed, I...have no energy. On dialysis days I feel terrible." ⁴³	
32			
33	Relying on others	"If my wife would get sick, then I wouldn't manage. That's what's worrying me most actually, 'you can't get sick,' I tell her." ³⁹	10,14,16,21,2
34		"No matter how much I tell myself that it's not my fault that my children have to take on a lot of the responsibilities around the house, I feel guilty." ²¹	7,36,39,42,44
35			,45,80,82,88,89
36			
37	Vulnerable to criticism misunderstanding		
38	Being criticized	".. people need to be understood, it's not that we don't want to work, it's not that we don't want to be like everyone else, we struggle to be like everybody else and we need to be understood." ⁴¹	21,35,41,42,4
39	judged for the need to rest	"I lie down, but I can't sleep. My family thinks I'm sleeping and expects me to be refreshed when I get up. But I feel just as sleepy and tired. I try to get involved with my extended family but it's still difficult for me." ²¹	4,80
40			
41	Failing to meet expectations	"Some days you aren't going to feel on top of the world. But my wife just said, I'm sorry, I don't accept that. That was her way of dealing with it. I think that may have contributed to what happened (divorce). Technically you have a walking handicap, and yet when they see you walking around — in my case, playing racquetball, playing tennis — they look at you and say, this must be a piece of cake. They don't know that some days I don't feel good and some days my legs cramp so badly you can literally see the muscles. I don't tell people that because it is really none of their business. " ⁴⁴	21,31,35,44,4
42		"I have two women friends at dialysis. They give me motivation and they've been on dialysis longer than I have and they know what I'm going through since I'm just starting dialysis . . . my sister said, well we understand you're sick. You know, we sick too. But they're not sick to the point that they have to go to dialysis three days a week or feel fatigue or... " ³¹	6
43			

*Quote from the authors summarizing or paraphrasing participant quotations

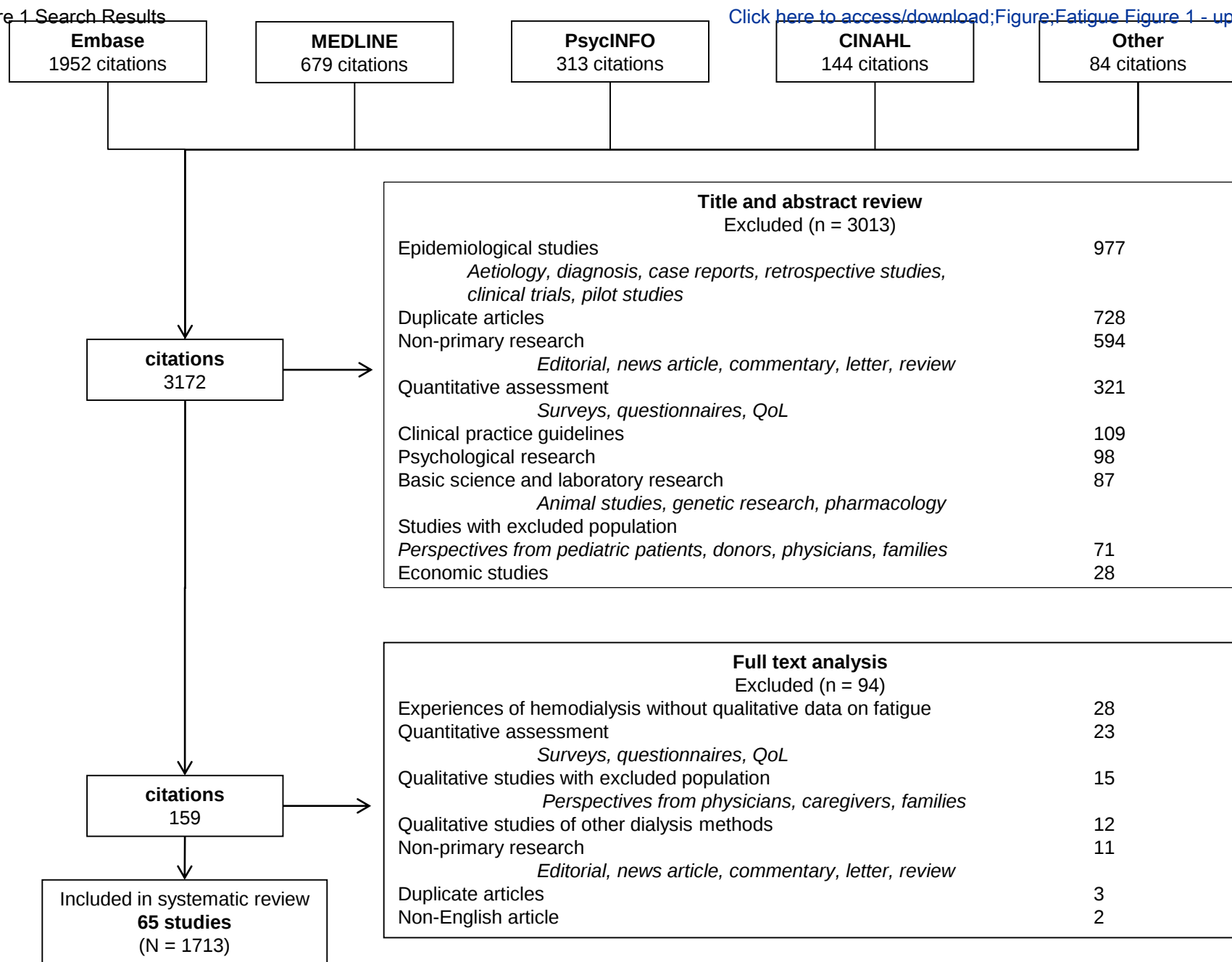
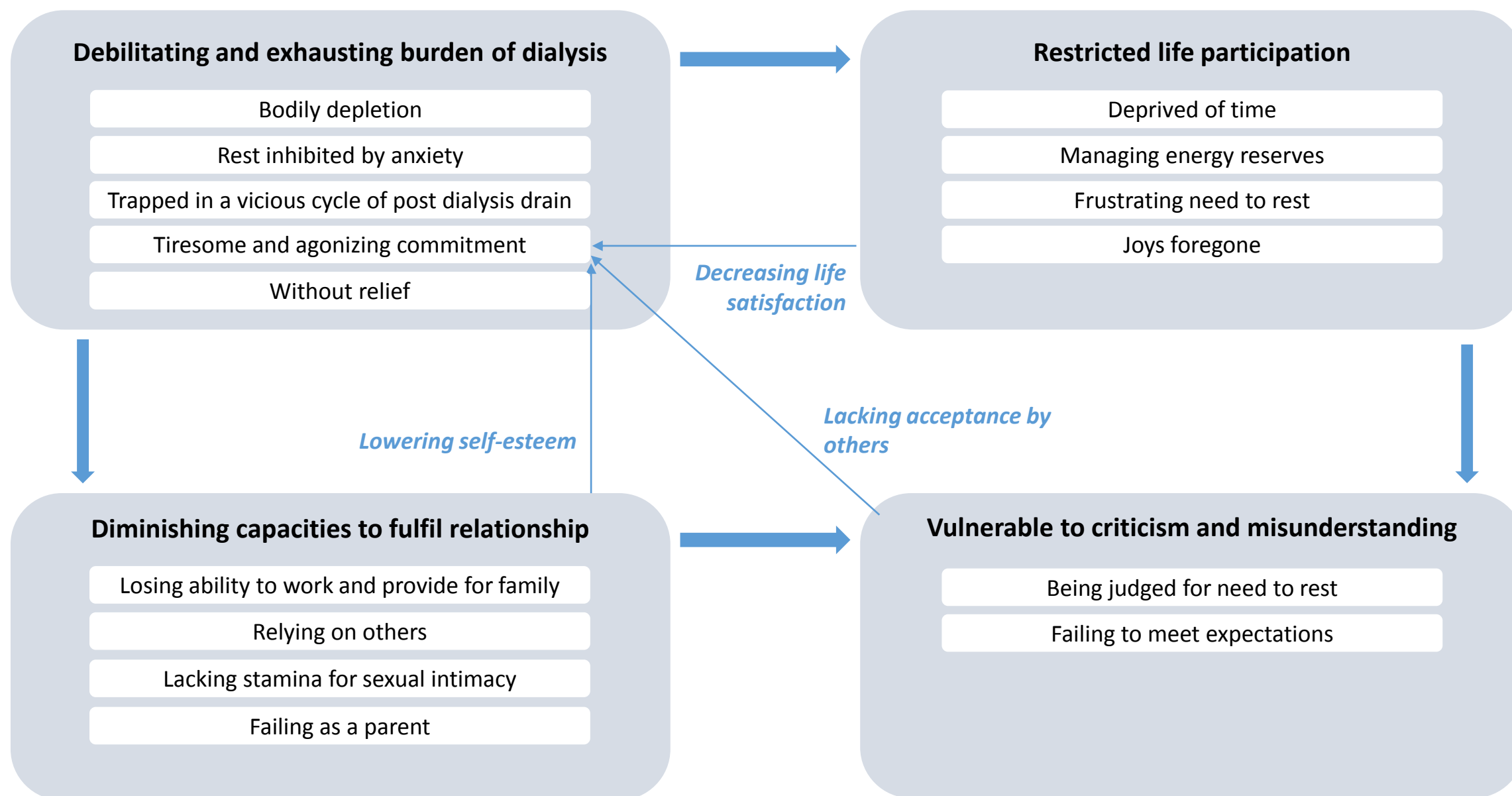
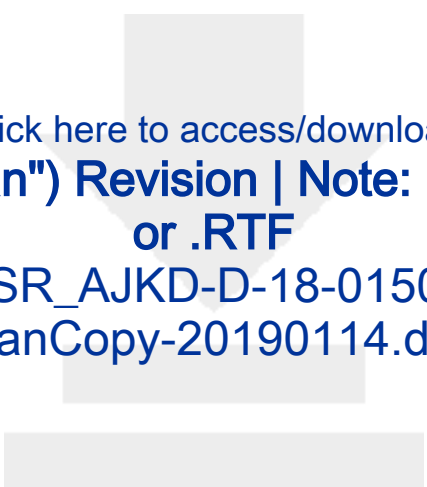


Figure 1: Search process and results.





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**Unmarked ("Clean") Revision | Note: must be .DOC(X)
or .RTF**

AJKDFatigueSR_AJKD-D-18-01509R1-vFINAL-
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Supplementary Files

Supplementary Table 1: Search strategies

Medline 1946 to 23rd October 2018

- 1 (hemodialysis or haemodialysis).tw.
- 2 Renal Dialysis/
- 3 end stage kidney disease.mp. or exp Kidney Failure, Chronic/
- 4 dialysis.tw.
- 5 (end-stage kidney or end-stage renal or endstage kidney or endstage renal).tw.
- 6 (ESKD or ESRD).tw.
- 7 Renal Replacement Therapy/
- 8 or/1-7
- 9 exp fatigue/
- 10 fatigue.tw.
- 11 chronic fatigue syndrome.tw.
- 12 exp Mental Fatigue/
- 13 (weary or weariness or exhaust\$).tw.
- 14 (lacklustre or lackluster).tw.
- 15 letharg\$.tw.
- 16 lassitude.tw.
- 17 tired.tw.
- 18 (energy\$ or vigor\$ or vigour\$).tw.
- 19 sleep/ or sleep\$.tw.
- 20 astheni\$.tw.
- 21 (weak\$ or vitality).tw.
- 22 Physical Exertion/
- 23 or/9-22
- 24 exp qualitative research/
- 25 qualitative.tw.
- 26 interview\$.tw.
- 27 focus group\$.tw.
- 28 (thematic\$ or theme\$).tw.
- 29 grounded theory.tw.
- 30 phenomenol\$.tw.
- 31 content analysis.tw.
- 32 ethnograph\$.tw.
- 33 exp Illness Behavior/
- 34 exp Knowledge/ or Health Knowledge, Attitudes, Practice/
- 35 symbolic interact\$.tw.

36 Psychology, Social/
37 quality of life/
38 Adaptation, Psychological/
39 communication/
40 emotions/
41 or/24-40
42 8 and 23 and 41

Embase 1980 to 23rd October 2018

1 (hemodialysis or haemodialysis).tw.
2 exp hemodialysis patient/
3 exp hemodialysis/
4 renal replacement therapy/
5 kidney failure/
6 chronic kidney failure/
7 (end-stage kidney or end-stage renal or endstage kidney or endstage
renal).tw.
8 (ESKD or ESRD).tw.
9 or/1-8
10 exp fatigue/
11 fatigue\$.tw.
12 dysthymia/
13 (weary or weariness or exhaust\$).tw.
14 (lacklustre or lackluster).tw.
15 letharg\$.tw.
16 lassitude.tw.
17 tired.tw.
18 (energy\$ or vigor\$ or vigour\$).tw.
19 sleep/ or sleep\$.tw.
20 astheni\$.tw.
21 (weak\$ or vitality).tw.
22 chronic fatigue syndrome/
23 or/10-22
24 exp qualitative research/
25 qualitative\$.tw.
26 interview\$.tw.
27 focus group\$.tw.
28 "Quality of Life"/
29 social psychology/
30 adaptation/ or adaptive behavior/
31 social aspect/ or social support/
32 mental stress/
33 self esteem/
34 life satisfaction/ or satisfaction/ or patient satisfaction/
35 family/
36 employment/
37 lifestyle/ or lifestyle modification/
38 life event/
39 (thematic\$ or theme\$).tw.

40 grounded theory.tw.
 41 phenomenol\$.tw.
 42 content analysis.tw.
 43 ethnograph\$.tw.
 44 interpret\$.tw.
 45 (narrative\$ or discourse\$).tw.
 46 or/24-45
 47 9 and 23 and 46

PsycINFO 1806 to 23rd October 2018

1 exp HEMODIALYSIS/
 2 (haemodialysis\$ or hemodialysis\$).tw.
 3 dialysis.tw.
 4 exp Kidney Diseases/
 5 or/1-4
 6 exp CHRONIC FATIGUE SYNDROME/ or exp FATIGUE/
 7 fatigue\$.tw.
 8 (weary or weariness or exhaust\$).tw.
 9 (lacklustre or lackluster).tw.
 10 letharg\$.tw.
 11 lassitude.tw.
 12 tired.tw.
 13 (energy\$ or vigor\$ or vigour\$).tw.
 14 sleep/ or sleep\$.tw.
 15 astheni\$.tw.
 16 (weak\$ or vitality).tw.
 17 or/7-16
 18 5 and 17

CINAHL

Search ID#	Search Terms
S1 and S4	Search modes - Boolean/Phrase
S4	S2 or S3
S3	TX ("fatigue") or TX ("vitality") or TX ("lethargy")
S2	(MH "Fatigue+") OR (MH "Fatigue Syndrome, Chronic") OR (MH "Muscle Fatigue") OR (MH "Mental Fatigue")
S1	(MH "Hemodialysis+") OR (MH "Dialysis Patients")

Supplementary Table 2: Characteristics of the included studies

Study	Country	N	Age range (y)	M:F	Ethnicity	Conceptual Methodological Framework	Qualitative Data Collection	Analysis	Topic
Al Arabi (2003) ¹	US	80	25-78	39:41	African American, Caucasian, Hispanic	Lazarus and Folkman's cognitive theory of stress	Semi-structured interviews and questionnaire	Thematic analysis	Coping with HD
Artinian (1990) ²	US	45	18-30	NS	NS	Grounded theory	Serial semi-structured interviews	Constant comparative method	Changing marital role with dialysis
Axelsson (2012) ^{a3}	SW	8	66-87	5:3	NS	Phenomenology	Serial face-to-face interviews	Phenomenologic hermeneutical method	Meanings of being severely ill and nearing end of life
Bass (1999) ⁴	US	8	24-62	5:3	Mixed	Qualitative Design	Focus group	Content analysis	HD and quality of life
Beanlands (2001) ⁵	CA	47	18-70	33:17	NS	Mixed methods	Semi-structured interviews	Content and thematic analysis	Engulfment
Berzoff (2008) ^{b6}	US	36d	NS	NS	NS	Grounded theory	Semi-structured focus groups	Grounded theory	Developing renal supportive care teams
Bordelon (1997) ⁷	US	20	NS	9:11	Caucasian, Native American, Hispanic	Case study method	Semi-structured interviews	Content analysis	Empowerment with HD
Breckenridge (1995) ⁸	US	22	29-69	NS	NS	Grounded theory	Semi-structured interviews	Constant comparative method	Choice of dialysis modality
Clarkson (2010) ⁹	US	10	26-85	NS	NS	Qualitative design	Face-to-face semi-structured interviews	Thematic analysis	Experience of dialysis
Costello (1999) ¹⁰	US	7	45-78	11:0	African American, Caucasian, Hispanic	Developmental conceptions of illness	Focus groups	Thematic analysis	Adaptation to ESRD
Cox (2017) ¹¹	US	50	NS	26:24	Native American, African American, Caucasian, Hispanic	Interpretive qualitative design	Semi-structured interviews	Thematic analysis	Symptoms of HD
Curren (1997) ¹²	US	30	27-76	12:18	African American, Caucasian, Hispanic	Narrative theory and Adult Development Theory	Semi-structured interviews	Narrative and grounded theory analysis	Coping with HD
Ekelund (2007) ¹²	SW	73	18-84	51:22	NS	N/A	Open-ended questionnaire	Factor Analysis	Patient Stressors

Evangelidis (2017) ¹³	AU	161	NS	NS	Mixed	Delphi Method (with open text response)	Delphi Survey (with open text response)	NS	Developing core outcomes for HD
Fatani (2008) ¹⁴	SA	50	24-59	0:50	Saudi	Grounded theory	Two semi-structured interviews	Grounded theory analysis	Impact of ESRD on cultural roles
Fetherstonhaugh (2007) ¹⁵	AU	10	68-86	5:5	NS	Longitudinal qualitative design	Serial semi-structured interviews	Thematic analysis	Transitioning to HD
Flythe (2018) ¹⁶	US	119	25-74	58:61	African American, Caucasian, Hispanic, Asian, Native American	Mixed methods	Focus groups and open-ended questionnaire	Thematic analysis	Prioritizing symptoms of HD
Ghimire (2017) ¹⁷	AU	30	44-84	23:7	NS	Exploratory qualitative design	Semi-structured interviews	Thematic analysis	Perspectives of medication adherence in HD
Gibson (1995) ¹⁸	US	20	34-80	11:9	Caucasian, African American	George & Bearon's Dimensions of Quality of Life	Semi-structured interviews	Manifest and latent content analysis	Quality of life
Gordon (2001) ¹⁹	US	16	28-62	8:8	Caucasian, African American	Grounded theory	Unstructured interviews	Grounded theory analysis	Uncertainty after kidney transplant
Gregory (1998) ²⁰	US	36	19-87	18:18	NS	Qualitative design	Two semi-structured interviews	Constant comparative method	Perceptions of HD
Hagren (2005) ²¹	SW	41	29-86	26:15	NS	Interpretative qualitative design	Semi-structured interviews	Content analysis	Experience of HD
Hagren (2001) ²²	SW	15	50-86	7:8	NS	Interpretative qualitative design	Semi-structured interviews	Content analysis	Suffering and HD
Hanson (2017) ²³	AU	20	31-77	14:6	Mixed	Mixed methods	Serial face-to-face interviews	Thematic analysis	Home HD training
Harkness (2000) ²⁴	CA	10	20-76	0:10	NS	Phenomenology	Two face-to-face interviews	Giorgi's psychological phenomenological method	Women's sexuality and HD
Heiwe (2003) ²⁵	SW	16	NS	NS	NS	Phenomenography	Single face-to-face interview	Not stated	Functioning with CRF
Horigan (2016) ^c	US	14	<50-80-89	7:7	Caucasian, African American	Qualitative design	Two semi-structured interviews and 36hr fatigue diary	Content analysis (manifest and latent)	Temporal patterns of fatigue in HD

Horigan (2013) ^{c26}	US	14	<50; 80-89	7:7	Caucasian, African American	Qualitative design	Serial face-to-face interviews	Content analysis (manifest and latent)	Fatigue in HD
Humphreys (2011) ²⁷	US	10	39-64	5:5	African American	Grounded theory	Two semi-structured interviews	Grounded theory analysis	Dialysis patient's experience with transplant evaluation
Jhamb (2016) ²⁸	US	16	NS	8:8	African American, Caucasian	Grounded theory	Semi-structured interviews	Grounded theory analysis	Exercise and HD
Johnson (2001) ²⁹	US	6	48-72	2:4	NS	Phenomenology	Semi-structured interviews	Colaizzi method	HD experience and diabetes
Ju (2018) ³⁰	AU	15	NS	NS	Mixed	Qualitative design	Consensus workshop	Thematic analysis	Core outcome measure for fatigue in HD
Kaufman (2006) ³¹	US	43	70-93	77:55	African American, Caucasian, Chinese, Japanese, Hispanic, Filipino, Samoan, Afghan, Vietnamese	Ethnography	Semi-structured interviews and participant observation in clinic	Ethnographic analysis	Choice about life extending procedures
Kazemi (2011) ³²	IR	21	NS	12:9	Iranian	Qualitative design	Semi-structured interviews	Thematic analysis	Experience of HD
Kontos (2018) ³³	CA	10	65:89	8:2	NS	Qualitative design	Three serial semi-structured interviews	Thematic analysis	Exercise promotion in HD
Landry (2002) ³⁴	CA	9	61-88	0:9	Caucasian, African American	Grounded theory	Semi-structured interviews	Grounded theory analysis	Experience of HD
Lee (2007) ³⁴	TA	14	26-72	4:10	NS	Phenomenology	Serial, semi-structured interviews	Colaizzi method	Fatigue in HD
Lindberg (2012) ³⁵	US	9	26-59	5:4	Caucasian, African American	Qualitative design	Semi-structured interviews	Thematic analysis	Reasons to discontinue HD
Lindquist (2000) ³⁶	SW	30	29-86	20:10	NS	Qualitative design	Unstructured interviews	Content analysis	Consequences of renal failure
Monaro (2014) ³⁷	AU	11	33-84	5:6	NS	Phenomenology	Semi-structured interviews	Phenomenologic hermeneutical method	Acceptance of HD
Partsiopoulou (2017) ³⁸	GR	12	30-79	6:6	NS	Qualitative design	Single interviews	Content analysis	Quality of life and HD

Picariello (2018) ³⁹	UK	25	33-83	15:10	Caucasian, Black, Asian	Pluralist	Semi-structured interviews	Thematic analysis	Fatigue in ESKD
Piyasut (2010) ⁴⁰	TH	30	26-75	15:15	Thai	Grounded theory	Semi-structured interviews	Theoretical sampling	Experience of ESRD
Polaschek (2003) ⁴¹	NZ	6	20-69	6:0	Caucasian	Critical interpretive methodology	Three semi-structured interviews	Foucauldian analysis	Concerns about HD
Preece (2010) ⁴²	AU	14	20-69	6:8	Aboriginal Australian and Torres Strait Islander	Qualitative design	Single semi-structured interviews	Thematic and content analysis	Care model to improve wellbeing and HD
Rezaei (2018) ⁴³	IR	12	19-65	10:2	NS	Qualitative design	Semi-structured interviews	Content analysis	Psychological problems and fatigue in HD
Richard (2008) ⁴⁴	US	14	23-87	7:7	Caucasian, African American, Hispanic	Ethnography	Serial, semi-structured interviews	Thematic analysis	AV fistula for HD
Rudini (2017) ⁴⁵	ID	6	52-66	3:3	NS	Phenomenology	Face-to-face interviews	Colaizzi method	Psychosocial impact of HD
Russ (2005) ^a	US	43	70-93	17:23	Caucasian, African American, Asian, Hispanic	Ethnography	Face-to-face interviews	Ethnographic analysis	Aging on HD
Salimena (2016) ⁴⁶	BR	9	34-64	0:9	Black, Hispanic, Caucasian	Qualitative design	Face-to-face interviews	Critical discourse analysis	Experiences of HD
Schaumburg (1993) ⁴⁷	US	15	40-69	7:8	Caucasian, Native American	Ethnography	Semi-structured interviews and patient observation	Constant comparison analysis	Quality of life
Seabrook (2011) ⁴⁸	UK	6	30-49	6:0	NS	Phenomenology	Semi-structured interviews	Interpretive phenomenological analysis	Experiences of ESKD
Soto (2009) ⁴⁹	US	30	37-72	20:10	Hispanic	Qualitative design	Interview and open-ended questionnaire	Thematic analysis	Medical compliance with HD
Spigolon (2016) ⁵⁰	BR	63	NS	NS	NS	Collective subject discourse	Face-to-face interviews	Collective subject discourse analysis	Perceptions of health on HD
Stevenson (2018) ⁵¹	AU	35	NS	19:16	Caucasian, Aboriginal Australian and Torres Strait Islander, Polynesian, Asian, Middle-Eastern and North African	Grounded theory	Semi-structured interviews	Grounded theory analysis	Dietary management and HD

Stewart (2010) ⁵²	US	19	37-59	12:7	NS	Qualitative design	Semi-structured interviews	Thematic analysis	Perceptions of sexuality on HD
Suwaileh (1996) ⁵³	BA	60	22-82	38:32	Bahrani	Descriptive, Correlational design	Semi-structured interviews and questionnaire	Content analysis	Coping with HD
Tarp (2017) ⁵⁴	DK	15	32-86	9:6	NS	Phenomenological-hermeneutic	Semi-structured interviews	Systematic text condensation	Uremic pruritus in HD
Thompson (2016) ⁵⁵	CA	25	B	19:6	Caucasian, Aboriginal Canadian, African, Hispanic	Interpretative qualitative design	Semi-structured interviews	Thematic analysis	Exercise and HD
Tljerina (2000) ⁵⁶	US	30	30-56	0:30	Hispanic	Phenomenology	Semi-structured interviews	Template style analysis	Compliance and perspectives regarding HD
Viegas (2017) ⁵⁷	BR	8	NS	NS	NS	Exploratory qualitative design	Narrative interviews and observations	Narrative analysis	Young adults' experiences of HD
Warrior (2015) ⁵⁸	US	6	38-68	3:3	Native American	Transcendental phenomenological design	Semi-structured interviews	Colaizzi method	Emotional experience of HD
Wells (2009) ⁵⁹	US	15	NS	8:7	Hispanic	Qualitative design	Semi-structured interviews and observations	Qualitative content analysis	Occupation and HD
Yngman-Uhlin (2016) ⁶⁰	SW	8	33-53	7:1	NS	Qualitative design	Semi-structured interviews	Content analysis	Experiences of kidney transplant waiting lists
Yodchai (2011) ⁶¹	TH	5	24-66	3:2	Thai	Grounded theory	Single face-to-face interviews	Grounded theory analysis	Adaptation to HD

Abbreviations and definitions: AU, Australia; BA, Bahrain; BR, Brazil; CA, Canada; CKD, Chronic kidney disease; DK, Denmark; ESRD, End-stage renal disease; GR, Greece; HD, Hemodialysis; ID, Indonesia; IR, Iran; NZ, New Zealand; SA, Saudi Arabia; SW, Sweden; TA, Taiwan; TH, Thailand; UK, United Kingdom; US, United States. N refers to number of patients on HD included in the qualitative study

^a The same participants were enrolled in Axelsson 2012 and Russ 2005.

^b In Berzoff (2008) the number of participants given includes patients, family and staff.

^c Horigan (2016) and (2013) used data from the same sample

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