



## Patient and Caregiver Perspectives on Home Hemodialysis: A Systematic Review

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**Background:** Although home hemodialysis (HD) is associated with better survival compared with hospital HD, the burden of treatment may be intensified for patients and their caregivers and deter patients from this treatment choice. We describe patient and caregiver perspectives and experiences of home HD to inform home HD programs that align with patient preferences.

**Study Design:** Systematic review of qualitative studies.

**Setting & Population:** Adults with chronic kidney disease and caregivers of both home and hospital dialysis patients who expressed opinions about home HD.

**Search Strategy & Sources:** MEDLINE, EMBASE, PsycINFO, CINAHL, and reference lists were searched to October 2013.

**Analytical Approach:** Thematic synthesis.

**Results:** 24 studies involving 221 patients (home HD [n = 109], hospital HD [n = 97], and predialysis [n = 15]) and 121 caregivers were eligible. We identified 5 themes: vulnerability of dialyzing independently (fear of self-needling, feeling unqualified, and anticipating catastrophic complications), fear of being alone (social isolation and medical disconnection), concern of family burden (emotional demands on caregivers, imposing responsibility, family involvement, and medicalizing the home), opportunity to thrive (re-establishing a healthy self-identity, gaining control and freedom, strengthening relationships, experiencing improved health, and ownership of decision), and appreciating medical responsiveness (attentive monitoring and communication, depending on learning and support, developing readiness, and clinician validation).

**Limitations:** Non-English articles were excluded.

**Conclusions:** Patients and caregivers perceive that home HD offers the opportunity to thrive; improves freedom, flexibility, and well-being; and strengthens relationships. However, some voice anxiety and fear about starting home HD due to the confronting nature of the treatment and isolation from medical and social support. Acknowledging and addressing these apprehensions can improve the delivery of predialysis and home HD programs to better support patients and caregivers considering home HD.

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**INDEX WORDS:** Home hemodialysis; chronic kidney disease (CKD); qualitative research; thematic synthesis; hemodialysis (HD); quotidian dialysis; patients; quality of life; caregiver burden; renal replacement therapy (RRT) modality; end-stage renal disease (ESRD).

The global dialysis population is increasing by ~7% annually<sup>1</sup> and accounts for at least 1% of the health expenditure in the United States, the United Kingdom, Australia, and New Zealand.<sup>2-5</sup> People treated with hemodialysis (HD) frequently experience severe symptoms, including fatigue, sleep abnormalities, anxiety, and anorexia.<sup>6</sup>

Compared to in-center or hospital-based long-term HD therapy, home HD is associated with survival approaching that of deceased donor kidney transplantation,<sup>7</sup> improved quality of life,<sup>8</sup> and cost savings.<sup>9</sup> These factors and the growing body of evidence suggest possible benefits of longer hours and quotidian HD and potential for improving patient-centered outcomes.<sup>10-12</sup> Clinical practice guidelines recommend that patients suitable for home dialysis should have the option to choose it.<sup>13</sup>

Despite the potential for home HD to offer improved well-being, many patients are anxious about self-cannulation, dialyzing alone, the risk of catastrophic events during dialysis, and not having immediate

medical or social support and are concerned about caregiver burden.<sup>14-16</sup> These fears may limit patient uptake of home HD, especially if combined with system barriers such as clinician bias and resource constraints.<sup>15,17-19</sup> Rates of home HD use vary

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Table 1. Characteristics of the Included Studies

Study	Country	No. of Pts	No. of Caregivers	Age Range (y)	CKD Stage & Modality	Conceptual Methodological Framework	Data Collection	Analysis	Topic
Blogg <sup>27</sup> (2008)	AU	—	5	42-65	—	Ethnography	F2F semistructured interviews	Thematic content analysis	Role of caregiver; impact on personal relationships, lifestyle, health, emotional well-being, and freedom
Cases <sup>28</sup> (2011)	UK	6	—	48-78	HHD (n = 6)	Phenomenology	F2F semistructured interviews	Interpretive phenomenology	Experience starting HHD, impact on lifestyle, health care support systems
Cafazzo <sup>25</sup> (2008)	CA	20	—	22-70	NHD (n = 7), ICHD (n = 6), NDD (n = 7)	Health belief model, ethnography	F2F in-depth interviews	Inductive	Barriers to NHD
Cafazzo <sup>26</sup> (2009) <sup>a</sup>	CA	20	—	22-70	NHD (n = 7), ICHD (n = 6), NDD (n = 7)	Health belief model, ethnography	F2F in-depth interviews	Inductive	Barriers to NHD
Cafazzo <sup>44</sup> (2010) <sup>a</sup>	CA	20	—	22-70	NHD (n = 7), ICHD (n = 6), NDD (n = 7)	Health belief model, ethnography	F2F in-depth interviews	Inductive	Barriers to NHD
Courts <sup>34</sup> (2000)	US	14	14	22-75	HHD (n = 14)	Mixed methods	F2F semistructured interviews	—	Decision making
Fex <sup>41</sup> (2011)	SE	—	11	57-72	—	Mixed methods, hermeneutical	Semistructured interviews	Hermeneutical	Living with an adult receiving advanced medical technologies
Flaherty <sup>51</sup> (1992)	US	—	50	29-82	—	Mixed methods	Semistructured interviews	Thematic content analysis	Impact of dialysis on family coping style
Giles <sup>40</sup> (2003)	CA	4	—	—	NHHD (n = 3), DHHD (n = 1)	Phenomenology	Semistructured interviews	Phenomenology	Life experiences
Giles <sup>49</sup> (2005)	CA	4	—	—	NHHD (n = 3), DHHD (n = 1)	Phenomenology	Semistructured interviews	Phenomenology	Experiences of HHD
Luk <sup>31</sup> (2002)	CN	—	30	45-78	—	Phenomenology	F2F semistructured interviews	Thematic content analysis	Impact of HHD on family life and relationships
Morton <sup>42</sup> (2010)	AU	95	—	—	HHD (n = 4), SHD (n = 52), ICHD (n = 8), PD (n = 13), Tx (n = 18)	—	Semistructured interviews	Thematic analysis	Treatment choices, satisfaction
Morton <sup>32</sup> (2011)	AU	17	17	30-86	HHD (n = 3), SHD (n = 3), PD (n = 3), predialysis (n = 8)	Mixed methods	Focus groups	Thematic analysis	Identify and rank most important characteristics of dialysis choice for patients and caregivers

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