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# Psychosocial Aspects in Home Hemodialysis: A Review

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**Implementing  
Hemodialysis in the Home**  
A Global Perspective

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# Psychosocial Aspects in Home Hemodialysis: A Review

## Abstract

Psychosocial aspects related to home hemodialysis (HD) play an important role in the success of home HD programs. Once patients commence HD at home, unique psychosocial issues related to patient and care partner burden can emerge. Proactive professional support, peer support, respite care, travel support, and financial support from the home HD healthcare team must be a priority for patient care. If the psychosocial aspects are not proactively addressed, patients receiving HD at home may return to in-center HD and the program may struggle as a result. This review provides a psychosocial guide for new start-up home HD programs.

## Introduction

Home hemodialysis (HD) is far more than a medical treatment: it is a lifestyle. Home HD delivers the physical requirements needed for patients with end-stage renal disease (ESRD) to prolong their lives at a higher quality while they perform treatments in their homes. The impact of performing therapy at home and the ability of both patients and care partners (when present) to take an active part in productive day-to-day life activities requires psychosocial support from family, friends, peer groups, and the center to ensure success. There needs to be a clarification of dialysis roles for both patients and care partners through effective communication and education, with an understanding of the financial impact of performing home HD.<sup>1,4</sup> Appropriate support from a multidisciplinary team, including nephrologists, nurses, health psychologists, and social workers, must be a priority to ensure that patients and care partners receive the psychosocial care they need.<sup>3,5</sup> This review provides a psychosocial guide for new start-up home HD programs.

## Professional Psychosocial Support

Patients who have any chronic disease, and those who use dialysis, in particular, are at a high risk of depression and anxiety. The Dialysis Outcomes and Practice Patterns Study (DOPPS), using the Center for Epidemiological Screening – Depression (CES-D) index, identified depression in 43% of 9382 standard in-center HD patients from 12 countries compared to nephrologists who suggested only 13.9%.<sup>6</sup> Diagnosing and treating depression is vital, as its presence has been strongly associated with mortality.<sup>7</sup> Depressed HD patients tend not to follow their treatment plans,<sup>8</sup> and depression among patients on HD predicts the decision to withdraw from therapy.<sup>9</sup>

Depression has been found to be significantly less prevalent in the home HD population (8%) than among in-center HD patients (42.3%).<sup>10</sup> Results from the Rehabilitation, Economics, and Everyday-Dialysis Outcomes Measurements (FREEDOM) study, indicated that 128 participants who completed 12 months of short daily home HD had a significant decrease in their depressive symptoms over the course of the study, from 41% to 27%.<sup>11</sup> Patients enrolled in the Frequent Hemodialysis Network (FHN) trial who received short daily HD in-center did not experience an improvement in depression.<sup>12</sup> While the nocturnal

HD branch of the FHN trial did not find a significant difference in depression vs conventional home HD therapy, it is important to note that this study was underpowered, and that home HD of any sort may convey enough benefit that there is insufficient separation between home HD options.<sup>13</sup>

It is important to formally assess all HD patients, in-center and home, for depression upon initiating treatment and periodically thereafter, particularly if symptoms are observed or the patient has a change in life status (divorce, death in the family, loss of a job, hospitalization, etc.). However, many countries may not have the capacity to formally assess patients and thus a cheaper, more efficient screening process may be an option. In the United States, the Kidney Disease Quality of Life survey (KDQOL-36) is required for adult dialysis patients annually for use in care planning. More specific depression scales can also be used as a preliminary screener for depression such as the Mental Component Summary (MCS), the Patient Health Questionnaire -2 (PHQ-2), and the Beck inventory.<sup>14</sup> Because home HD has been found to improve health-related quality of life (HRQOL) –including mental functioning<sup>15, 16</sup>– and better HRQOL scores predict lower morbidity and mortality,<sup>17</sup> dialysis programs can consider home HD as an intervention for medically appropriate patients with failure to thrive or depression who are at risk for poor outcomes.

Patients undergoing home HD also experience mental health concerns that are not typically experienced by patients undergoing other dialysis modalities,<sup>18</sup> and these distinct problems are not always considered or recognized by the treatment team. It is important to proactively involve a psychologist or counselor at the beginning of training and at regular intervals of treatment to ensure that a patient's potential for anxiety and depression is explored. This approach may help keep the patient from withdrawing from home HD completely. Depression and other psychological assessment tools have been used to assess those patients considering home HD<sup>10</sup> and may be useful instruments to use in developing a successful start-up home HD program.

## Peer Psychosocial Support

A feeling of isolation can be an issue for those patients who dialyze at home.<sup>19</sup> Group peer support or time spent with others who dialyze at home can help reduce isolation among home HD patients and care partners.<sup>19, 20</sup> Home HD training teams must acknowledge a patient's need for peer support, given the higher potential for isolation for these patients compared with patients undergoing in-center dialysis where on-site social networks develop naturally.<sup>21</sup> Several options for peer support are available, for example, local support groups, web-based groups, or "buddy" support from fellow patients.

### Local support groups

Consumer networks and face-to-face peer support groups for patients on home HD and their care partners are increasingly more accessible. Such support groups can offer understanding and friendship from others facing similar life challenges, and can be led by healthcare professionals or other home HD patients. There may be challenges in motivating patients to attend a professionally run group, however, as patients may not welcome professionals as guest speakers or facilitators and would prefer socializing with dialysis patients going through challenges similar to their own. Peer-run groups that meet away from the dialysis clinics in more social settings, such as a restaurant, library, place of worship, or home, may be more acceptable to patients and

thus better attended. The most engaging support groups will be those that are driven by the members of each group, with nephrology staff providing encouragement and support to sustain the activities and initiatives that arise.

### Web-based support

Increasing numbers of dialysis patients are using the Internet for information and support.<sup>22-24</sup> Internet-based support and information is available 24 hours a day anywhere in the world in the form of social media discussion groups, message boards, email distribution lists, chat rooms, and others. It is important that healthcare professionals are aware of these options and encourage patients to share their stories and offer others virtual support. The Internet-based method of accessing a wide variety of information and support increases healthcare professional responsibility to ensure that patients are provided with appropriate, accurate, and evidence-based information.<sup>22</sup>

### Individual support

One-on-one interaction between home HD patients, including care partners (if present), can lend emotional support, and get-togethers can be logistically easier to arrange than group gatherings. Such support can take place face to face or via telephone or the Internet. The center's home HD team can advocate this "buddy" system by encouraging current home HD patients and care partners to provide support to others.

Contact information and basic demographic data (eg, age, gender, work status) can be recorded (with permission) to enable patients with similar situations and interests to be matched. A patient who has expressed interest in being a support "buddy" previously but has not immediately been serving in this role should be contacted again before his or her name is given to a patient; this ensures that the prospective support patient is still interested in participating in the buddy program. Background information about the patient who needs support should also be communicated to the potential buddy at this time. Buddies should be cautioned to divert all specific medical questions a patient may have to the care team as each patient's treatment and prescriptions are different. This buddy system can be easily set up within each dialysis program, region, or country.

## Dialysis Partner or Solo?

A patient can dialyze independently or with the assistance of a care partner who may be a spouse, parent, child, sibling, friend, or neighbor. There is a range of care partner involvement, from a self-dialyzing patient with no partner<sup>25</sup>—a model that is encouraged or required in some countries,<sup>26,27</sup> but discouraged or forbidden in others—to full care in those cases where a patient requires total assistance with all activities of daily living, including management of home HD.<sup>3,25</sup> Any time a care partner is present for home HD, his or her involvement can fall anywhere along this care continuum. A partner's level of participation in care may also vary over time, as the patient becomes more confident and adept or if a health setback reduces the patient's physical or cognitive abilities. Nephrologists, nurses, social workers, and especially home HD training staff who encourage the maximal degree of patient independence for self-care may help minimize dialysis care partner burnout.<sup>28</sup> In particular, cannulation can be extremely stressful for dialysis care partners. It is best that patients learn to self-cannulate, if possible, to minimize care partner burnout associated with this task.<sup>29</sup> If a care partner becomes unable or unwilling to provide care, a patient on home HD who requires care partner assistance may be unable to continue treatment at home.

The chances for home HD success may improve if dialysis patients and partners offer social and emotional support to each other and clearly define their healthcare roles.<sup>30</sup> Center staff who create

an expectation that self-dialysis is the norm and provide positive feedback for each step along this path goes a long way toward helping patients and dialysis care partners succeed. A study conducted by Wise et al<sup>3</sup> identified four dialysis partner-patient team types: "thriving", "surviving", "martyrdom", and "seeking [other options]". Home HD with thriving and surviving teams was more successful than home HD with the martyrdom and seeking partnerships team types. Observing warning signs of martyrdom and looking for other options may mean that psychosocial support may be needed to reduce the potential for home HD burnout and withdrawal.<sup>3</sup>

Care partners who show an interest in home HD, who are encouraging and express open communication about expectations, and who urge the patient to do as much as he or she is able to do independently are strategies that can improve the success rate of the program. It is wise to confront the issue of care partner burnout up front during training and explain how it can be addressed (eg, shifting of care tasks onto the patient, identifying backup care partners, and using respite services).<sup>31</sup> This way, patients will not be surprised if one day the therapy becomes untenable for the care partner.

## Dialysis Care Partner Considerations

It is important that patients and their care partners are educated regarding all aspects of home HD. Ensuring that dialysis care partners learn how to access respite and relevant resources is a critical part of a home HD program that involves or requires care partners.<sup>32</sup> Proactive monitoring of patients by the overseeing unit and identifying potential stressors early may help eliminate care partner fatigue and assuage a partner's feelings of guilt about wanting, or needing, to take a break.<sup>19,33</sup> Comprehensive resources may be of benefit to those care partners who are responsible for coping with a home HD patient's activities of daily living (i.e., feeding, bathing, toileting, etc) and performing medical tasks (suctioning, cannulating, supply monitoring and ordering, etc.). Intermittent respite care by dialysis professionals can relieve care partner burden and may make the difference between a patient's remaining in home HD or withdrawing from this modality entirely.

Care partners, regardless of level of involvement with home HD treatments, may benefit from peer support from other home dialysis partners to help them to reduce their own feelings of isolation. Just as for patients, centers should develop local face-to-face and online support options for care partners.<sup>20</sup> Good communication between patients on home HD and their respective dialysis care partners (if involved) is vital. The home dialysis team needs to develop strategies to identify

the early signs of isolation, poor partner communication, and partner-patient friction, and provide the necessary support tools to address these problems.

The term “care partner” (not “caregiver” or “carer”) has been deliberately used in this module. “Caregiver” and “carer” imply an individual who is deeply immersed in and feels responsible for the patient’s day-to-day home HD treatments, including machine set-up, cannulation, monitoring, clean-up, reporting, and supply ordering. While assistance from a care partner may be a necessity for some patients, without appropriate support mechanisms, this is a recipe for burnout and is, at least anecdotally, a substantial cause of patient withdrawal from the home HD program. The “patient-does-most” model has achieved the greatest success, as long as patients are capable of learning and performing home HD safely and independently.<sup>26</sup>

## Respite Care for Home HD

Proactive respite for patients and dialysis care partners may make the difference between home HD success and failure. Both patients and partners should be informed about the availability of respite care during and after training, and ensure that they know how to access these services when it is wanted or needed (ie, due to a sudden illness or travel of a care partner). Respite programs may offer a nurse or other paid respite care provider who could visit the home on a temporary basis to perform the designated care partner’s dialysis tasks, allowing the designated care partner to take time off from the role.<sup>33</sup> This respite model is likely to be preferred by both patients and care partners, as the patient’s setting and dialysis prescription will not change, and the respite care provider may be trusted by both individuals (particularly important when the patient does not self-cannulate). Program respite may also require access to a dialysis machine at a local satellite unit or other home training unit that can offer this service.<sup>34</sup> This in-center respite model may be much less appealing, particularly if patients who use frequent and/or extended home HD must switch to conventional, thrice-weekly treatments and also use an unknown cannulator. Respite care could be automatically planned for 1 to 4 weeks per year in the home HD program. The type of respite required will be determined by the patient and dialysis care partner to fit their own unique situation.

## Trained dialysis assistance

In some countries, professionals who are trained in dialysis may come to the home and assist the patient with dialysis treatments. Government-sponsored financial support is available in some regions, but it is not common.<sup>35</sup> So-called staff-assisted home HD could be a convenient alternative for patients who do not have a dialysis care partner, who do not want to do dialysis-related activities by themselves, and who can afford to pay a salary or a per-treatment fee to a helper.<sup>36</sup> However, there is a danger that patients may rely on these assistants too heavily<sup>37</sup>; therefore, appropriately vigilant management of this role by the home HD team is required to prevent overreliance.

## Travel and Holidays

Travel and holidays are an important part of many patients' lives and, depending on the machine used, can be a great challenge to those on home HD.<sup>38,39</sup> Although there may be an increased risk of complications such as infection,<sup>40</sup> assisting and encouraging home HD patients to enjoy a holiday may provide them with some normality, improve their quality of life, and keep them on home HD longer.<sup>41</sup> Because some patients may believe that travel is not possible while they undergo dialysis, it is vital that healthcare professionals make every effort to help patients to see the possibilities.<sup>42</sup> Independent or organized holidays<sup>43</sup> can improve quality of life, self-image, and self-confidence.

Newer, smaller home HD machines specifically designed to be more mobile can enable patients to travel more independently.<sup>44</sup> Many international airlines now accept these smaller machines as essential medical equipment at no charge. Typically, supplies must be shipped to the patient's travel destination, and there may or may not be a fee the patient must pay, depending on distance and location. Regional travel in caravans or recreational vehicles fitted with a hemodialysis machine is possible.<sup>44,45</sup> It is necessary for the home HD team to advise patients to research and identify clinics at their destinations that can support them if necessary during their trips.<sup>43</sup>

To travel safely can be a logistical challenge that can be mitigated with help from the home HD team. Home HD patients who want to travel may need to plan for holidays from several months to as much as a year in advance.<sup>46</sup> Home HD staff can assist patients with travel dialysis bookings, review the administration tasks involved during travel, revisit blood test requirements, provide medication storage information as patients travel, and deliver specific nutrition education. Those home HD patients wanting to travel who switch from frequent and nocturnal home HD treatments to thrice weekly dialysis sessions to accommodate their travel plans may need to consider the increased dietary restrictions required for this regimen. This may mean that patients should schedule a renal dietitian consult before a trip<sup>43</sup> as a refresher to review the importance of restricting potassium in the diet to eliminate the chance of lethal high serum potassium levels and to review the symptoms of hyperkalemia. Furthermore, if patients will be away for an extended period, they should be encouraged to undergo blood testing at a clinic at their destination.

## Financial Consideration

Home HD is considered more cost-effective than hospital or community satellite hemodialysis.<sup>47</sup> Some costs, however, may shift from the center to the patient, and these costs are perceived by some patients as a barrier to home HD.<sup>48</sup> It is vital that patients who choose home HD not be financially burdened. Considering the unique financial issues to home HD care is particularly important for those centers establishing new home HD programs. Reimbursement models may not take into consideration the cost shifting associated with home HD care. Costs beyond the machine and water treatment systems include ongoing dialysis partner payments (country dependent); disability pensions; electricity and water usage; medications; dialysis consumables; dialysis chairs; dressings; and equipment for health monitoring, such as scales and blood pressure machines.<sup>49</sup> Assistance with these costs through reimbursement can be facilitated by the home HD team to avoid financial burden, however small it may appear, and help maintain patients on home HD.

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Dialysis care partner costs may include accommodation or travel during training. In some countries, care partners may be eligible for a Carer's Pension or other financial support through local or regional government sources. In some countries, government-supported Social Security or pension systems may make annual payments to patients whose home energy costs increase due to the use of essential medical equipment for a disability or health condition, and these payments may apply to home HD therapies. In other countries, there is minimal government or insurance company support for home HD; patients may pay out of pocket.<sup>50</sup> Some providers have begun to offer home HD programs where patients pay a monthly equipment rental fee and do not have to purchase the equipment. In such cases, insurance companies may pay the equivalent of an in-center HD session, while the rest of the cost is borne by the patient. Such programs mainly offer staff-assisted HD. There are still cost hurdles to overcome in many countries and these need to be explored thoroughly before attempting to develop a home HD program.

## Summary

Psychosocial aspects for patients and care partners in home HD are an important component to consider when starting a new home HD program. Many patients around the world who perform home HD have been able to fit dialysis into their lifestyles rather than allowing the restrictions of dialysis to dominate their lives. Although the improved lifestyle aspects associated with home HD are appealing, healthcare teams must monitor each patient and care partner to ensure the therapy does not increase their psychosocial burden. Strategies to prevent increased burden include initiating proactive professional support, peer support, respite support, travel support, and financial support, all of which contribute to a sustainable home HD program.

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