

10

Psychosocial Guide for Healthcare Professionals

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CONTENTS

- 3 Introduction
- 3 Psychosocial Support
- 4 Dialysis Partner or Solo?
- 6 Respite Care for Home HD
- 7 Depression
- 7 Travel and Holidays/Vacations
- 8 Financial and Cost Considerations
- 9 Infrastructure Support
- 9 Summary
- 10 References

Introduction

Home hemodialysis (HD) is far more than a medical treatment: it is a *lifestyle*. For patients and dialysis care partners* (when present) to succeed, we must pay attention to such psychosocial aspects of care as the impact of therapy on day-to-day life, including offering support for patients and care partners, gaining social support from peers, defining partner roles, opening lines of communication, addressing depression, taking advantage of opportunities to travel, and considering the financial impact of home HD. Psychosocial factors are significant in a home HD program,¹ and psychosocial support from nephrologists, nurses, health psychologists, and social workers should thus be a priority for patient care.



Care Partner

A care partner is someone who assists a patient with home HD treatment, often a family member or friend, but not all home HD patients require a care partner. Please note the deliberate use of the term “care partner”—not “caregiver.” While in the United States there is a regrettable tendency to turn a care partner into a de facto dialysis technician who undertakes machine set-up, cannulation, monitoring, clean-up, reporting, and even supply ordering, this model is not the case in most of the rest of the world, nor is it ideal. Rather, it is best for each patient to take on as many of the responsibilities for dialysis treatment as she or he is capable of learning and performing safely and independently, with the partner present for emotional support. (The amount of self-care a patient can do is likely to change over time.) The term “caregiver” implies an individual who is deeply immersed in the patient’s day-to-day home HD treatments, which is a recipe for burnout and, at least anecdotally, a substantial cause of home HD dropout.

Psychosocial Support

Isolation can be an issue for those who dialyze at home and their care partners. Group peer support or time spent with individual “buddies” can help reduce isolation among home HD patients and partners. It is wise for home training teams to acknowledge the need for peer support, given the numbers of patients who may stay in-center because they have no other social outlet. Several options for peer support are described below.

Local Support Groups

Your country may have consumer networks and face-to-face peer support groups for people on dialysis, and perhaps even specifically for home HD. Such groups can offer understanding and friendship to others who are faced with similar life challenges. If there is a local group near your clinic, provide the contact information to patients and encourage them to attend.

If your area does not have these types of support groups, interested home HD patients and/or dialysis care partners may wish to start one of their own. Clinics often report challenges getting patients to attend clinic- or professional-run groups. Peer-run groups that meet outside of the dialysis clinic in a social setting such as a restaurant, library, place of worship, or home may be more acceptable to patients, and thus better attended.

Patient groups may—or may not—welcome professionals as guest speakers or facilitators. Each group may differ, and the choice of speakers needs to belong to the members. Patients and dialysis care partners may benefit from having separate groups so members of each group can speak freely without worrying about upsetting a loved one.

Web-based Support

For Internet-savvy patients, online support is available 24 hours a day anywhere in the world, in the form of social media discussion groups, message boards, email listservs, chat rooms, and others. For example, a Facebook discussion group that includes patients undergoing home HD can be found [here](#), and other groups are available online in Google+, Yahoo, etc. Because each person's treatment and prescriptions are different, caution patients not to follow medical advice of any kind discussed in these groups without first checking with their own care teams.

Buddy Support

One-on-one “buddy” support can help patients and/or dialysis partners, and can be logistically easier to arrange than group support. Such support can be face-to-face or via telephone or the Internet. Talk to patients and dialysis partners and see if they would like to provide support to others. If so, keep their contact information and basic demographics (age, gender, work status, cause of kidney disease, etc), so you can attempt to match like

individuals. It may be wise to recontact a potential buddy before giving out his or her name to a patient, to protect the buddy's privacy and ensure that he or she is still available and interested in participating. It is important to provide participating buddies with some general nonmedical background information about the patient who needs support. Caution buddies to divert all medical questions to the care team, as each person's treatment and prescriptions are different.

Useful Resources

For those who want to start a peer support group.

- » [The Community Toolbox. Creating and Facilitating Peer Support Groups](#)
- » [Manuals and Workbooks for Starting and Running Support Groups](#)

Practice Tip

An example of a buddy support system can be found at <http://homedialyzorsunited.org/hdu-buddies/>. This system could be set up in your own program, region, or country.

Dialysis Partner or Solo?

The patient is always involved in home HD as the recipient of treatment. However, there is a continuum of care partner involvement, from 0% (self-dialyzing patient with no partner; a model that is encouraged or required in some countries, but discouraged or forbidden in others) to 100% (severely disabled patient who requires total care for all activities of daily living as well as home HD). Dialysis care partners are most often spouses or significant others. However, some are parents, children, siblings, friends, or neighbors. Any time a partner is present for home HD, his or her involvement can fall anywhere along the 0% to 100% continuum, and the level of care partner participation in care may vary over time, either as a patient becomes more confident and adept, or if a health setback reduces his or her 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 partner burnout. In particular, cannulation can be extremely stressful for dialysis partners and is best undertaken by the patients themselves, if possible (See “The Care and Keeping of Vascular Access for Home Hemodialysis Patients” module). If a partner becomes unable or unwilling to provide care, a patient on home HD who requires partner assistance is unlikely to be able to continue at home.

Psychosocial Guide for Healthcare Professionals

The chances for home HD success may improve if dialysis care partners (when present) offer social and emotional support to the able patient, while taking on as few of the instrumental tasks as possible.² Creating an expectation that self-dialysis is the norm and providing positive feedback for each step along this path can go a long way toward helping patients and dialysis care partners succeed. A study conducted by Wise et al identified 4 dialysis partner/patient team types, 2 of which in the study appeared, at least in the short run, to be far more successful than the others.²

1. **Thriving** – Both the patient and dialysis partner flourish with the new challenge they face together. They work as a team and use the HD time as couple time to strengthen their relationship.
2. **Surviving** – Home HD does not make a patient and the dialysis partner stronger, but they successfully adjust to the challenges and succeed.
3. **Martyrdom** – A patient expects support from a dialysis partner who provides it resentfully. Research suggests that burdening a partner is associated with home HD failure.
4. **Seeking Other Options** – A patient may insist that his or her home treatment is burdening the dialysis partner—even though the care partner may not agree. The patient plans to switch to in-center care.

Dialysis Partner Considerations

Ensuring that dialysis partners learn how to access relevant resources is a critical part of a home HD program that involves or requires partners. Dialysis partners who are moderately or highly involved in day-to-day home HD treatments need to feel that their questions will be answered by a very patient home dialysis staff at any time of the day or night. Dialysis partners may need to take time off to refresh themselves and renew their energy by socializing with friends or family or pursuing a hobby, even if only for a few hours at a time. (And they need to hear from dialysis staff that time away will not only help the patient, but also themselves, and that partners should not feel guilty about wanting a break.) Partners also need to know that they or the patient can get short- or longer-term respite care when and if it is needed.

Generic care partner resources may be of benefit to those partners whose role in home HD and other activities of daily living and medical tasks is all encompassing (ie, feeding, bathing, toileting, suctioning, etc). Given the high degree of dialysis care partner burnout, support for both patients and care partners is vital to ensure home HD program success.

All care partners, regardless of level of involvement with home HD treatments, may benefit from peer support from other home HD partners. Tell them about local face-to-face and online support options that may help them to reduce their own isolation. Good communication between patients on home HD and dialysis partners is vital. Encouraging patients and dialysis partners to work as a team can bring them closer together (Table 1).



Practice Tip

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



Useful Resources

- » [Caregiving Basics: Tips for Caregivers](#)
- » [Caregiver.com](#)
- » [Caring for Caregivers](#)
- » [Family Caregiver Support Network](#)
- » [US Administration on Aging – What states are required to do to help caregivers](#)
- » [Carers UK](#)
- » [Carers Support UK](#)

Table 1. Communication Strategies for Trainers to Share with Patients and Care Partners

Make eye contact—look at your partner

Tell your partner that you appreciate things he or she does

Use forms of touch that you are both comfortable with (eg, a pat on the back or hug)

Celebrate milestones (ie, each year on dialysis as 1 year more of life together)

Negotiate home dialysis task changes if your situation changes

Talk about your goals and dreams, and steps you'll take to reach them

Respite Care for Home HD

Respite care is the provision of temporary or part-time care by healthcare professionals and provides relief to the patient and their care partner from having to perform HD at home. Proactive respite care for patients and dialysis partners may make the difference between home HD success and failure, although there are no studies in adults that examine this premise. Encourage both partners to exercise, get out socially, support others, engage in hobbies, and be active in a community. Life should NOT be about dialysis! Alert both patients and partners to the availability of respite care during training and afterward, and ensure that they know how to access the service 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 care assistance who could visit the home on a temporary basis to take on the chosen care partner's dialysis tasks, providing the partner with time off from the role. 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. This 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 individual as the cannulator.

Plan to include 1 to 4 weeks per year of respite care in your renal program. The type of respite required will be determined by the patient and dialysis partner and their own unique situation.

Trained Dialysis Assistance

In some countries, professionals who are trained in dialysis may come to the home and assist with dialysis treatments. So-called "staff-assisted" home HD could be a convenient alternative for patients who do not have a dialysis partner, do not want to do everything by themselves, and can afford to pay a monthly salary or a per-treatment fee to a helper. The salary or fee would vary depending on the tasks a helper would need to do.

Depression

In a small study of nocturnal home HD (N = 67) participants and care partners, depression criteria were met by 47% of patients and 25% of care partners.³ Other research has found that depression will not subside without treatment,⁴ and can substantially reduce the ability of an individual to follow the treatment plan. The Kidney Disease Quality of Life survey (KDQOL-36; required to be performed at least annually in the United States) can be used as an initial assessment tool for determining depression, with a mental functioning score of 42 or less suggesting that additional screening is needed. The Center for Epidemiologic Studies Depression Scale Revised (CESD-R) is a valid, reliable, 20-question tool to assess for clinical depression that is easily scored by hand. You can access the CES-D in English [here](#).

Proactively involving a psychologist at the beginning of training and at regular intervals of treatment can ensure that the potential for anxiety and depression for both patients and care partners are explored, and may help keep patients from withdrawing from home HD unnecessarily (Table 2).

Table 2. Informal Questions to Detect Anxiety and Depression

Are you often struggling to get out of bed and do daily activities?
Do you cry often?
Do you feel angry easily for no reason?
Have you stopped paying attention to how you look?
Are you eating for comfort or refusing to eat at all?
Are you thinking of harming yourself?

Travel and Holidays/ Vacations

Travel and holidays/vacations are an important part of many peoples' lives. Assisting and encouraging home HD patients to enjoy a holiday/vacation may provide them with some normality, improve their quality of life, and keep them on home HD longer. Because some patients may believe that travel is not possible while they are undergoing dialysis, it is vital that health professionals make every effort to help patients to see the possibilities. Patients on home HD can indeed travel, but may require staff assistance, depending on the machine. Machines that are more portable allow the patient to bring the machine along in a carrier in a car, plane, ship, or train. Many international airlines now accept the machines as essential medical equipment at no charge, and some allow 2-days' worth of dialysate to accompany the machine as long as the dialysate is in the original packaging. Supplies must be shipped to the travel destination, for which there may or may not be a fee the patient must pay, depending on distance and location. A hotel may charge a package receiving fee; it is worth asking if this fee

can be waived due to the lifesaving nature of the delivery. Advise patients who bring their own machines along for travel to identify a clinic at their destination that can support them if necessary during the trip. Dialysis travel checklists and information can be found at:

- <http://www.davita.com/services/travel-support/travel-tips-and-articles/travel-checklist-for-people-on-dialysis/s/5734>
- <http://www.nwkidney.org/dialysis/traveling/checklist.html>
- <http://www.kidney.org.au/ForPatients/DialysisandTravel/tabid/608/Default.aspx>

For those patients with a non-portable machine, planning for holidays/vacations may be required from several months to as much as a year in advance. Clinic staff must assist with travel dialysis bookings and the administration that is involved (blood tests, treatment information).

Travel can change dialysis logistics. The food at another location may be different, as may the treatment schedules, so patients will need to be flexible regarding their own self-care. Further, blood pressure may change with travel, so dose adjustment of antihypertensive medications may be necessary. Special medication storage may be required for drugs such as erythropoietin and insulin that must be kept within a certain temperature range.

Financial and Cost Considerations

Real and perceived costs may determine the success of maintaining people on home HD. People who choose home HD should not be financially burdened by it. If in-center HD incurs minimal or no cost to the patient, home HD must provide a comparable cost structure, or cost will be a disincentive. Sharing the cost implications with interested patients may dispel myths and make home HD more appealing. In some countries, patients wrongly believe that they must buy a home HD machine, and many do not know that their government-funded healthcare helps pay for most dialysis, dialysis partners, utility costs, and equipment (see “Funding and Planning: What You Need to Know for Starting or Expanding a Home Hemodialysis Program” module).



Practice Tip

Patients who switch from nocturnal and home HD treatments to standard ones during travel risk lethal hyperkalemia if they do not adapt their diets. A visit with a renal dietitian or at least a revisiting of the need to restrict potassium (and reexamining which foods and beverages contain it) and discussing the symptoms of hyperkalemia before a trip can help avert high serum potassium. Blood tests are encouraged at the destination clinic if patients will be away for an extended period.

Costs for dialysis care partners may include accommodation or travel during training. In some countries (not the United States), care partners may be eligible for a Carer’s Pension or other financial support through local or regional government sources. Examples of funding support in Australia can be found [here](#).

Healthcare financing systems vary by country, and in some cases within regions of the same country. For home HD, costs beyond the machine and water treatment include ongoing dialysis partner payments (country-dependent), disability pensions, electricity and water usage, medications, dialysis consumables, dialysis chairs, medications, dressings, and equipment for health monitoring, such as scales and blood pressure machines.

In some countries, the social security/pension system may make annual payments to people 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, such as India, there is currently minimal government or insurance company support for home HD; patients must pay out of pocket. Some providers have started to offer home HD programs where patients pay a monthly equipment rental fee and do not have to buy 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.

Infrastructure Support

In countries that have infrastructure support in place for home HD, it may be hard to imagine its absence. However, in some parts of the world where home HD is relatively new, there may not be adequate infrastructure in place to fully support home HD (eg, telephone backup for home patients and technicians to make electrical and water updates for a home HD machine). It is important to acknowledge that patients who lack such support may feel even more anxious and isolated than they already would at the prospect of having to dialyze at home. Providing answers to questions like, “What do I do if I have a problem?” is vital to allow these patients to succeed at home. In these cases, online peer support may make the difference between success and failure (see “Patient Safety in Home Hemodialysis” module).

Summary

In this module, we have provided you with information regarding the psychosocial aspects related to home hemodialysis. Although there are many other important facets to consider, many people 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. We wish you all the best with the development of your program and encourage you to consider the information we have provided above.

References

1. Nearhos J, Van Eps C, Connor J. Psychological factors associated with successful outcomes in home haemodialysis. *Nephrology (Carlton)*. 2013;18:505-509.
2. Wise M, Schatell D, Klicko K, Burdan A, Showers M. Successful daily home hemodialysis patient-care partner dyads: benefits outweigh burdens. *Hemodial Int*. 2010;14:278-288.
3. Rioux JP, Narayanan R, Chan CT. Caregiver burden among nocturnal home hemodialysis patients. *Hemodial Int*. 2012;16:214-219.
4. Soykan A, Boztas H, Kutlay S, et al. Depression and its 6-month course in untreated hemodialysis patients: a preliminary prospective follow-up study in Turkey. *Int J Behav Med*. 2004;11:243-246.