



The Potential Burden of Home Dialysis on Patients and Caregivers: A Narrative Review

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Abstract

Purpose of review: Home dialysis modalities offer several benefits for patients with end-stage kidney disease when compared with facility-based thrice-weekly hemodialysis. To increase uptake of home dialysis, many centers are encouraging a “home-first” approach. However, it is important to appreciate that “one size may not fit all” and that dialysis modality selection is a complex decision that needs to be individualized. The purpose of this review was to explore aspects associated with home dialysis that may be associated with burden for patients and their caregivers and to discuss strategies to alleviate these concerns.

Sources of information: Original research articles were identified from PubMed using search terms “peritoneal dialysis,” “home hemodialysis,” “home dialysis,” “barriers,” “quality of life” and “burden.”

Methods: We performed a focused narrative review examining potential sources of burden with home dialysis therapies after conducting a critical appraisal of the literature and identifying the major recurring themes.

Key findings: Home dialysis is associated with burden for certain patients. Indeed, some patients may experience ongoing concerns regarding the risks of adverse events and of inadequately performing dialysis on their own. Psychosocial issues affecting quality of life may also arise and include fear of social isolation, sleep disturbances, perceived financial burden, anxiety, and fatigue. Patients who depend on a caregiver may worry about creating a stressful home environment for their close ones. Furthermore, the demands associated with being a caregiver may lead to psychosocial distress in the caregivers themselves. All these factors may lead to burnout and consequently, therapy discontinuation necessitating an unplanned transition to in-center hemodialysis leading to adverse outcomes. However, certain strategies may help alleviate burden especially if concerns are identified early on.

Limitations: As we did not apply any formal tool to assess the quality of the studies included, selection bias may have occurred. Nonetheless, we have attempted to provide a comprehensive review on the topic using numerous diverse studies and extensive review of the literature.

Implications: Future studies should focus on better identifying patient priorities and strategies to facilitate dialysis modality selection and improve quality of life.

Abrégé

Justification: Les modalités de dialyse à domicile présentent plusieurs avantages pour les patients atteints d'insuffisance rénale terminale comparativement à l'hémodialyse trois fois par semaine en centre. Pour accroître l'adhésion des patients à la dialyse à domicile, plusieurs centres privilégient une approche «à domicile d'abord». Cette approche n'est toutefois pas universelle, et le choix de la modalité de dialyse est une décision complexe qui doit être personnalisée. Cette revue de la littérature avait pour but d'explorer les aspects de la dialyse à domicile susceptibles de représenter un fardeau pour les patients et leurs soignants, et de discuter de stratégies pour les atténuer.

Sources: Les articles ont été répertoriés dans PUBMED à l'aide des termes de recherche *peritoneal dialysis* (dialyse péritonéale), *home hemodialysis* (hémodialyse à domicile), *home dialysis* (dialyse à domicile), *barriers* (entraves), *quality of life* (qualité de vie) et *burden* (fardeau).

Méthodologie: Après avoir fait une évaluation critique de la documentation et dégagé les principaux termes récurrents, nous avons procédé à une revue narrative ciblée examinant les éléments susceptibles d'alourdir le fardeau lié à la dialyse à domicile.

Principaux résultats: Certains patients perçoivent la dialyse à domicile comme un fardeau, certains sont préoccupés par les risques d'événements indésirables et s'inquiètent de ne pas être en mesure de la pratiquer adéquatement. Des enjeux psychosociaux affectant la qualité de vie, notamment la peur de l'isolement social, des troubles du sommeil, la perception



d'un fardeau financier, l'anxiété et la fatigue pourraient survenir. De plus, les patients qui dépendent d'un soignant pourraient s'inquiéter de créer un environnement stressant pour leurs proches. Du côté des soignants, les exigences associées à leur rôle peuvent entraîner une détresse psychosociale. Tous ces facteurs sont susceptibles de conduire à l'épuisement et ultimement, à l'interruption du traitement, ce qui nécessite alors une transition non planifiée vers l'hémodialyse en centre et entraîne des issues indésirables. Néanmoins, certaines stratégies pourraient atténuer le fardeau perçu, en particulier si ces préoccupations sont décelées à un stade précoce.

Limites: Les résultats pourraient comporter un biais de sélection puisque nous n'avons pas utilisé d'outils formels pour évaluer la qualité des études retenues. Nous avons néanmoins tenté de procéder à une revue exhaustive du sujet grâce à un examen approfondi de la documentation et à un échantillon de plusieurs études différentes.

Conclusion: Les études à venir devraient se concentrer sur une meilleure définition des priorités des patients et des stratégies pour faciliter le choix de la modalité de dialyse et améliorer la qualité de vie.

Keywords

peritoneal dialysis, home hemodialysis, home dialysis, burden, quality of life

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Why is this review important?

Home dialysis modalities offer several benefits for patients with end-stage kidney disease when compared with facility-based thrice-weekly hemodialysis. To increase uptake of home dialysis, many centers are encouraging a “home-first” approach. However, it is important to appreciate that dialysis modality selection is a complex decision that needs to be individualized by weighing the risks and benefits of each modality.

What are the key messages?

This review elaborates on the sources of potential burden with home dialysis including fear of adverse events, psychosocial issues, caregiver burden, and risks of technique failure. Strategies to alleviate these concerns are addressed and the importance of having a transparent discussion about the advantages and disadvantages of home dialysis modalities is emphasized.

Introduction

Utilization of home dialysis has grown in recent years. Undeniably, there is significant evidence of clinical and quality of life benefits with home dialysis modalities. Peritoneal dialysis (PD) and home hemodialysis (HHD) are both associated with increased patient autonomy and allow patients the flexibility of directing their own treatment while avoiding the time constraints of frequent travel to a dialysis center.¹⁻⁴ Studies have also consistently demonstrated significant lower costs with home dialysis compared to in-center hemodialysis.⁵

Furthermore, in HHD patients, studies have shown improvement in blood pressure, fluid overload, left ventricular hypertrophy, hyperphosphatemia, sleep quality, and fertility compared to conventional in-center hemodialysis.^{2,6-8} In contrast, in PD patients, there is better preservation of residual kidney function with improved hemodynamic stability compared to conventional hemodialysis. Moreover, PD obviates the need for a vascular access with its associated complications.^{9,10}

Despite demonstrated benefits with home dialysis, facility-based thrice-weekly hemodialysis still remains the form of renal replacement therapy in the great majority of patients.¹¹ In Canada, home dialysis is achieved only in 20% to 25% of patients, with significant variation between centers.¹¹ With efforts to increase home dialysis uptake, many centers are encouraging a “home first” approach. However, it is important to recognize that “one size may not fit all” and that dialysis modality selection is a complex decision that needs to be individualized. Certainly, some patients may feel empowered by performing dialysis independently at home. On the other hand, home dialysis may place a strain on certain patients and create unnecessary burden and stress. This may be especially true for those who are not convinced that home dialysis is the best option for them.

In this paper, we will explore aspects associated with home dialysis that are often overlooked and that may be associated with burden. These include fear of adverse events, psychosocial issues associated with changes in quality of life, caregiver burden, and the risks associated with therapy discontinuation. Strategies to alleviate these potential concerns are addressed.

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Fear of Adverse Events

The potential complexity of home dialysis therapies and uncertainty as to the ability to adequately perform dialysis at home can be major sources of apprehension and anxiety for some patients and their caregivers.¹² These fears are highest at the training stage, but may persist even once established on the therapy. Moreover, the constant responsibility and time required for preparation and completion may be an important cause of burden.¹³

For HHD, patients may fear machine complications with alarms, maintenance responsibilities, and possible catastrophic events such as needles dislodgement, catheter disconnection, or air embolism.¹⁴ Difficulties with vascular access self-cannulation may also cause significant burden. This may be aggravated even further by the need for more frequent hospital visits related to vascular access complications. Indeed, risks of vascular complications appear to be higher with frequent hemodialysis. In the Frequent Hemodialysis Network (FHN) trial, nocturnal home dialysis was associated with a significantly increased risk of first access event (hazard ratio [HR]: 3.23, 95% confidence interval [CI]: 1.07-10.34) in the subgroup of patients with an arteriovenous fistula or graft.¹⁵ These events may be time-consuming and discouraging for patients and their caregivers. Furthermore, the necessity to self-adjust ultrafiltration and other dialysis parameters may also contribute to anxiety in patients who are concerned with making errors.¹⁶⁻¹⁸ Conversely, in PD, patients may have concerns dealing with PD catheter dysfunction, adequacy of technique, cyclor alarms or malfunction, and fear of the development of peritonitis.¹⁹ As such, some patients may experience ongoing concerns regarding the risks of adverse events and of inadequately performing dialysis on their own. This may potentially lead to psychosocial distress, poor compliance, and even therapy discontinuation, which may all negatively impact clinical outcomes and quality of life.

Psychosocial Issues Arising With Home Dialysis

While psychosocial factors weigh heavily in the choice of a home modality, they are also major causes of apprehension and discontinuation of therapy.²⁰⁻²³ Home dialysis patients may experience a feeling of social isolation, anxiety, and fatigue leading to burnout.^{16,24} Home dialysis may also be associated with perceived financial burden.

While some patients may enjoy the freedom and flexibility of performing dialysis at home, others may fear being less frequently monitored and feel socially isolated.^{25,26} Home dialysis patients may also experience illness intrusiveness resulting from the time and energy required to perform dialysis at home in addition to the constant physical presence of the dialysis apparatus and supplies.²⁴ Patients may be concerned about how home dialysis fits into their

daily schedule and this may require adjustments of their daily activities such as employment, scholarly activities, social engagements, or hobbies. Moreover, in patients performing dialysis at night, whether PD or HHD, machine alarms or malfunction may lead to sleep disturbances, and poor sleep quality.²⁷ Other psychosocial issues that should not be understated are body image issues associated with vascular access or PD catheters.²⁸ The development of weight gain and perceived abdominal distension with PD may also be challenging for patients.²⁹ Furthermore, although overall costs to the healthcare system are decreased, home dialysis modalities may be associated with direct financial stress to patients. In fact, higher water, electricity costs, and need for home renovations can be of concern for patients, especially those on HHD.¹⁴ All these factors may lead to anxiety, fatigue or even burnout and may negatively impact quality of life.

Caregiver Burden

Home dialysis patients may require help from a family member or caregiver. While increased support from family members or close persons has been associated with improved survival, better treatment adherence, and quality of life in dialysis patients, the risk of caregiver burden should not be ignored.³⁰⁻³² Depending on a caregiver to help perform dialysis at home or with other health-related issues may lead to patients feeling like a burden. Patients may indeed worry about bringing their illness into their home and creating a stressful environment for their close ones. In a study including 66 nocturnal HHD from the University Health Center in Toronto, most patients were aware that a decision to adopt HHD would have a significant impact on their caregivers.³³ In a cross-sectional survey of patients enrolled in the FHN trial, more than half of 236 patients on HHD with caregivers worried that their caregivers were overextended and felt guilty about the demands their illness had on their caregivers. It was also noticed that the highest perception of burden was in patients with unpaid caregivers, and this increased with deterioration in the functional ability of patients. This overall perceived burden by patients on their caregivers was associated with worse depression and quality of life.³⁴

Furthermore, the demands associated with being a caregiver may lead to psychosocial issues in the caregivers themselves. A review of the literature focusing on the caregivers' perspective showed that caregivers commonly felt stressed and overwhelmed, which led to a burden on families.^{35,36} Caregiver burden may increase with frequency or intensity of treatment. In fact, the FHN trial showed that caregiver burden was higher after 12 months with intensive versus conventional home HD with a difference in change in Cousineau perceived burden score of 19.4 (95% CI: 10.6-118.3).³⁷ However, studies have not demonstrated any significant difference in burden level for those caring for patients treated with HHD compared with PD.³⁸ It should

also be noted that caregivers may experience a deterioration in their own health and may have insufficient time for their own self-care activities.^{39,40} Nonetheless, despite potential strain, caregivers mostly highlight that one of the many advantages of taking care of their loved ones is the way it can strengthen the character and lead to development of a sense of self-worth.⁴¹

Risks of Therapy Discontinuation

All the above-mentioned aspects may lead to burnout and consequently, therapy discontinuation necessitating an unplanned transition to in-center HD. Indeed, psychosocial factors contribute to technique failure in a large proportion of home dialysis patients.^{42,43} Some of the reported psychosocial factors associated with discontinuation have included inability to cope with the burden of doing dialysis at home, inappropriate home situation, patient burnout, caregiver burnout, and patient choice.^{42,43} The transition period from home dialysis to facility-based hemodialysis is a particularly vulnerable time for patients that is associated with higher mortality and morbidity.^{43,44} It is well recognized that there is a higher mortality associated with unplanned HD initiation, especially with catheter use and its associated higher infectious risks.⁴⁴⁻⁴⁷ Indeed, with an unplanned transition from PD, patients will often initiate HD with a central venous catheter. Comparatively, with a transition from HHD to facility-based HD, modality change is also associated with poor outcomes. In a study by Shah et al comparing 23 patients who experienced technique failure to 60 patients who remained on HHD and/or were transplanted, the 90-day mortality in patients who experienced HHD technique failure was significantly higher (6 of 23 patients – 26%) compared to patients who remained on HHD.⁴³ This transition period may also be associated with psychosocial distress and changes in quality of life.

In order to prevent therapy discontinuation, it is crucial to choose the right patients for home dialysis. The same study by Shah et al highlighted the fact that before starting HHD, 14 of 22 (64%) patients that were flagged by the multidisciplinary team as higher risk for future failure experienced death or program exit in the next 18 months after starting the modality.⁴³ Thus, directing a patient to a home dialysis modality without adequate education and a thorough psychosocial evaluation may lead to burnout, technique discontinuation, and poor outcomes.

Strategies to Alleviate Potential Burden

The selection of an appropriate dialysis modality is complex and needs to be individualized by taking into account degree of comorbidity, cognitive function, psychosocial and socioeconomic factors. While home dialysis is associated with many benefits, home dialysis may be associated with burden

in certain patients. Directing a patient toward home dialysis without adequately addressing these concerns may negatively impact their quality of life and lead to worse clinical outcomes. These concerns need to be addressed at the pre-dialysis stage and regularly thereafter.

It is imperative to well inform patients not only about the numerous benefits with home dialysis, but also on potential risks. This should be done as early as possible at the pre-dialysis stage with the help of a multidisciplinary team. It is important to gather as much information as possible about patients including their level of functioning, social support, employment and workplace, financial aspects, and social activities. Patients should be encouraged to bring their family members to follow-up visits to participate in the discussion about modality selection. This will permit the observation of the dynamics between the patients and their close ones. Patient concerns and priorities need to be identified and addressed as early as possible, thus facilitating a patient-centered approach to dialysis modality selection. Indeed, priorities likely differ significantly between patients. A focus on the priorities of an individual patient allows the healthcare team to adapt discussion tone and topics in order to provide better individualized education. Tennankore et al highlighted that an in-depth discussion addressing patients' concerns and fears such as self-cannulation or fear of isolation may hopefully decrease the associated anxiety and better direct patients' expectations.⁴⁸ Balancing the discussion with the added numerous benefits with home dialysis modalities from a clinical perspective, but also with a focus on quality of life, may appeal to patients. Situations where help from a caregiver may be needed should also be identified early and addressed appropriately.

Several strategies may help alleviate patient concerns (Table 1). These include meeting with other patients who have done well on home dialysis, reassuring patients that support will be available throughout the process, providing adequate resources that specifically address psychosocial stress (social worker, psychologist, psychiatrist), proposing extra training if deemed necessary, or offering the possibility of remote monitoring. Indeed, remote monitoring technologies can be used to validate the knowledge of certain vulnerable patients and prevent significant medical status deterioration.⁴⁹ The use of assisted dialysis, in PD and potentially also in HHD, may also alleviate anxiety for patients who do not feel confident in their abilities to perform dialysis independently at home.⁵⁰ Furthermore, in certain situations, the option of a paid helper can be considered. Paid helpers can also contribute to alleviate the burden of primary caregivers.⁵¹ Short-term respite dialysis care is another option that may help give patients or their caregivers time off if needed.⁵² A well-established support structure is needed for home dialysis patients to aid particularly in crisis situations.⁴⁸ Other solutions to maintain patients on home modalities could be in flexibility with the treatment prescription itself. In certain patients, allowing for more flexible treatment targets may allow

Table 1. Strategies to Alleviate Burden in Home Dialysis Patients and Their Caregivers.

Sources of burden	Strategies to overcome burden
Fear of adverse events Complexity of therapies ^{12,19} Responsibility and time required for preparation ¹³ Fear of machine complications ¹⁴ Difficulties with vascular access ¹⁵	Early education of risks and benefits with home dialysis Early identification of concerns and fears by a multidisciplinary team ⁴⁸ Involving family members and/or close ones in modality education and discussion ⁴⁸ Propose extra training time if necessary Meeting with other home dialysis patients Consideration for home visits or remote monitoring ⁴⁹
Psychosocial issues ^{16,20-24} Anxiety Social isolation ^{25,26} Interaction with daily activities Sleep disturbances ²⁷ Financial stress ¹⁴ Body image issues ²⁹	Multidisciplinary evaluation Identification of individual patient concerns and priorities ⁴⁸ Focus discussion on quality of life Adequate resources that specifically address psychological stress
Caregiver burden Patient's perception as a burden ^{30-32,34} Caregiver burnout ³⁰⁻³³	Early identification of support structure Consideration for assisted dialysis ⁵⁰ Short-term respite care ⁵² Flexibility in treatment prescription ⁵⁰

patients to remain on a home dialysis modality while decreasing burden. Shafi and Jaar suggested starting patients with incremental HHD to help with patient or caregiver burnout, frequently linked to treatment frequency or length.⁵⁰ After thorough review and education, if patients are not altogether convinced that home dialysis is the best option for them, perhaps home dialysis should not be pushed further as there may be risks of significant psychosocial stress and burden.

Conclusion

Encouraging a home-first approach without recognizing the potential burden caused by home dialysis modalities may lead to poor outcomes. This review elaborated on the sources of potential burden with home dialysis including fear of adverse events, psychosocial issues, caregiver burden, and risks of technique failure. Patients and caregivers perceptions and experience of home dialysis are key determinants to the success of these treatment modalities and should be one of the main focuses in a home dialysis program. The importance of having a transparent discussion about the advantages and disadvantages of home dialysis modalities in the pre-dialysis period is emphasized.

Future Direction

The majority of dialysis studies have focused on clinical outcomes including mortality, adverse events, and biomarkers. Conversely, less is known on what outcomes matter most to patients. In a survey directly involving patients, and their caregivers by Manns et al, outcomes that were considered priorities included fatigue, coping skills, ability to travel, free time, impact on family, employment, and sleep.⁵³ Thus,

it appears that what matters most to patients is how dialysis affects their quality of life. Future studies should place more emphasis on patient-centered care by helping identify higher risk patients and strategies to improve patient-reported outcomes. In order to identify patient priorities, patients need to be actively involved in the research process. An example of a promising patient-oriented initiative is the Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) network, which directly involves patients, health-care providers, policy makers and researchers across Canada. This will help elucidate what priorities are important to patients and will allow us to optimize how we deliver care. Once identified, it is also imperative to find strategies to deal with these issues and alleviate burden in order to improve quality of life.

Ethics Approval and Consent to Participate

No patient consent or ethics approval was required for this narrative review.

Consent for Publication

The authors have consented to publication of this review.

Availability of Data and Materials

No data or materials are available for this review.

Declaration of Conflicting Interests

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