

Psychosocial Barriers to Home Dialysis: A Literature Review

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This review of 35 research and anecdotal reports discussing psychosocial barriers to home dialysis explores the challenges and successes of home dialysis from the viewpoints of both patients and nephrology professionals. The literature identified multiple psychosocial barriers to successful home dialysis: physical ability, cognition, patient attitudes toward home dialysis, emotional impact on the patient, emotional impact on the family, support from family, whether patient or caregiver is responsible for treatment, time constraints, patient personality and mental health, safety and patient's adherence with procedures, suitability of patient's home and willingness to change it, cultural issues, language barriers, unplanned start on dialysis, policy differences between modalities, loss of relationships with staff and other patients, support from staff for home dialysis, knowledge barriers, cost to hospital/staff availability to train and maintain home dialysis patients, and cost to the patient. Assessment tools already exist. The Jo-Pre-training Assessment Tool (JPAT) is a screening instrument which assesses the suitability of candidates for home dialysis, either peritoneal dialysis (PD) or home hemodialysis (HHD). It is designed to identify health-related problems; candidates are then referred to the appropriate professionals among the multidisciplinary team for assessment and care before starting training. The Method to Assess Treatment Choices for Home Dialysis (MATCH-D) was also developed to assess patients' suitability for home dialysis (PD or HHD), screening for medical and social barriers. However, we were not able to find a comprehensive tool specific to psychosocial barriers experienced by patients and their families. Based on the literature review, we concluded that psychosocial aspects are significant factors influencing the patients' ability to maintain home dialysis. To this end, the authors are developing a new tool: the Psychosocial Assessment Tool for Home Dialysis (PATH-D).

INTRODUCTION

We limited our search to articles discussing psychosocial barriers to home treatment modalities. Home hemodialysis (HHD) has been in use since the 1960s, and peritoneal dialysis (PD) since the mid-70s, and are used extensively around the world with varying rates of success. In Australia and New Zealand, data from 2008 revealed that between 30% and 40% of dialysis patients performed their treatments at home (Agar, 2008); in the UK, 25% of dialysis patients were on PD (Lindley, 2006) while HHD was not being widely offered; and in Finland, the rate of home dialysis was 24% in 2007 (Honkanen & Rauta, 2008). Comparatively, the United States, had a home dialysis rate of less than 8% (Jennette, Derebail, Baldwin, & Cameron, 2009; Schatell, 2007), and in Canada the rate of home dialysis in 2008 was 12.9% (Canadian Institute for Health Information (CIHI), 2010).

In Ontario, Canada, The Provincial PD Joint Initiative Committee in 2006 had set a goal of increasing the rate of PD from 14.7% in 2008 to 30% by 2010 (CIHI, 2010). Data supports that there are physiological benefits to home dialysis, such as improved patient survival and a reduction in cardiovascular risk, as well as advantages pertaining to quality of life, and social and economic aspects (Masterson, 2008). Masterson (2008) indicates that these benefits outweigh the disadvantages associated with the application and time commitment required for training, the potential for relationship strain, and reluctance to "hospitalize" the home (p. S16).

Medical contraindications for PD include abdominal adhesions from past surgeries, severe peripheral neuropathy which involves progressive deterioration of nerve endings, and in some cases, severe polycystic kidney disease (Brey & Jarvis, 1983). Other than medical appropriateness, Schatell (2007) suggests that many patients may succeed with PD or HHD, such as those who drive a car and use many abilities similar to the ones required to perform these treatments: "hand-eye coordination, doing steps in sequence, feeling overwhelmed at first and then adjusting to the routine, and the life-and-death nature of the task" (p. 44). Agar (2008) reports that such "simplistic approaches" (p. S27) as answering positively to "do you drive?" may be helpful, but adds that some non-drivers who use comparable skills, for instance people who operate a sewing machine, would also be suitable. These approaches ignore the complex psychological and social impact on individuals and families assuming responsibility for rigorous medical procedures. While they could be used for initial screening, further assessment is required.

Medical treatment does not happen in a neutral setting. While there is a tendency to focus on medical outcomes in determining the "best" treatment modality, a patient-centered assessment will also explore potential outcomes related to work, family, and social life. Raphael (2009) states that the social determinants of health ("...the economic and social conditions that influence the health of individuals...") are reliable indicators of successful health outcomes. As such, it is incumbent upon us to acknowledge the nonmedical factors influencing a patient's ability to succeed on home dialysis, and to attempt to improve the patient's situation.

BARRIERS

Barriers Linked to Physical Ability

Assessments of the patient's physical ability should take into account manual dexterity as well as the need to lift, move, and dispose of the dialysis supplies. Hodge (2008) acknowledges the importance of considering the physical abilities of HHD candidates. Brown (2008) states, "The problem is to determine if frail elderly, who often have considerable comorbidity such as impaired vision or hearing, poor mobility, arthritis and cognitive problems, can cope with the rigors of a home treatment.

"Data from Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD) [<http://www.necosad.nl/xcms/text/id/279>] show that the main reasons for not choosing PD were age, being female, and living alone. Patients 70 years or older were six times more likely to choose in-center HD than those aged 18–40 years..." (Brown, 2008, p. S70).

If a patient does not have the physical ability to manage either PD or HHD themselves, then a support system is needed to enable home dialysis. For those who have a good support system, family members in particular are often willing to help with all or part of the procedure. The increased use of community nurses enables frail patients to be on PD in their own homes (Brown, 2008, S69). In Canada, some provinces provide funding for home care nurses to assist PD patients as a way of promoting PD. We recognize that government-funded home care support may not be available in other countries.

Cognitive Barriers

Loos-Ayav, Frimat, Kessler, Chanliau, Durand, and Briançon (2008) find that one of the main factors limiting patient education is impaired cognitive function. Home dialysis requires the ability to learn and consistently perform a complex task, along with the ability to problem solve. Hemodialysis is generally acknowledged to be more demanding than PD. Hodge (2008) acknowledges the need to consider the mental status and skills of the patient when HHD is offered, and estimates that 50% of patients could successfully perform hemodialysis at home (p. 1). Robert Lockridge, MD, maintains that "active drug and alcohol abuse, and severe mental retardation" are the only exclusion criteria for HHD (Munasque, 2010). This may be the case in home dialysis programs which require the availability of a trained helper, but for patients who self-administer their dialysis treatments, a thorough assessment of the patient's cognitive abilities is necessary.

When memory problems are evident, the patient does not necessarily have to be excluded from home dialysis. The training nurses can adapt the teaching process by providing extra help and repeating procedures many times (Palmer, 1978).

Teaching patients presents its own challenges, as the mental and physical manifestations of illness affect the ability to learn during training (Wong, Migram, Halifax, Eakin, Cafazzo, & Chan, 2009). "Learning problems and emotional resistance may impede...[the] educational process" and the social worker can become a resource person for the nurses and technicians who are training the patients, indicates Palmer (1978, p. 365).

Attitudinal Barriers

McLaughlin, Manns, Mortis, Hons, and Taub (2003) examine the reasons why patients do not select self-care dialysis. Their definition of self-care dialysis includes HHD, PD, and self-care in-center hemodialysis. They identify knowledge barriers (lack of a satisfactory explanation of the various techniques); attitudinal barriers (belief that patients should not dialyze without direct supervision; fear of failure to perform self-care dialysis adequately; and fear of social isolation); and skill barriers (needle phobia and lack of space at home). They note that attitudinal barriers are generally considered the most difficult to overcome.

Cafazzo, Leonard, Easty, Rossos, and Chan (2009) studied patient-perceived barriers to nocturnal home hemodialysis (NHHD). The major barriers identified by chronic hemodialysis patients were lack of self-efficacy (estimation of one's capacity to engage in behaviors that contribute to desired health outcomes in performing the therapy (p. 787)), lack of confidence in self-cannulation, and length of time on current therapy. From the qualitative analysis, similar themes were found: burden on family members and fear of a catastrophic event without nurses' support, which patients perceived as loss of safety (pp. 786–787). The patients' belief that hemodialysis was too demanding or too dangerous to be performed outside a medical center was a significant obstacle. The authors found that, despite significant potential improvements in overall health, cardiovascular health, and sleep quality, as well as elimination of dietary restrictions, the adoption of NHHD was limited (p. 784). PD patients found the regimen demanding and difficult to balance with other daily activities, yet some felt empowered through greater involvement in their health care (Lehoux, 2004).

Van Eps, Jeffries, Johnson, Campbell, Isbel, Mudge, and Hawley's 2010 study on quality of life and alternating treatments of NHHD enumerates the benefits of frequent HHD; yet, patient preference and motivation are intrinsically linked to psychosocial supports. Increasing patient motivation was found to be the key to success in self-care by nephrology professionals. Creating a thorough understanding of the pros and cons of different therapy alternatives should be the foundation for increasing motivation, although the physicians felt that simplification of the dialysis procedure was more important (Ledebro, 2008).

Patients who experience secondary gains from their dependence on staff and family members, or their role as “the chronically ill person” may be reluctant to switch to home therapy offering the possibility of increased independence (Brey & Jarvis, 1983).

Emotional Impact on the Patient

Jennette, Derebail, Baldwin, and Cameron (2009) find that patient choice of treatment modality is heavily influenced by the perceived impact on lifestyle and schedule. Palmer (1978) mentions that anxiety in home dialysis is aggravated by the fact that the patient and partner are expected to administer their own “traumatic and complicated” treatment away from a medical center (p. 368). She adds that for patients who are depressed from the repercussions of dialysis on their lifestyle and/or their self-image (loss of body function and increased dependency on others), treatment should begin before patients are entrenched in the “sick” role and overwhelmed by the pessimism that feeds their depression (p. 371).

Wong, Migram, Halifax, Eakin, Cafazzo, and Chan (2009) indicate that educators need to be attentive to self-treatment being a socially situated activity. They anticipate that the primary factor determining whether or not the patient could take on the responsibility of self-care would be the challenge of managing complex medical technology. However, they conclude that psychosocial dimensions of home dialysis (e.g., family responsibilities, coping skills, life style) also determine whether home dialysis is viable. Loos-Ayav et al. (2008) also find that a certain psychological competence is required in order to perform self-care dialysis (PD or HHD unassisted by a nurse).

Patients’ adjustment to the impact of dialysis on their social and recreational activities will have a significant influence on their compliance with medical procedures (Peterson, 1984, p. 34). Peterson (1984) explains that dialysis patients may experience fatigue due to anemia, stress related to eating and drinking, and sexual difficulties such as impotence.

“The nephrology social worker is the only member of the treatment team whose professional orientation is geared towards the psychosocial management of chronic renal failure” (Peterson, 1984, p. 42). Therefore, the social worker’s role should include the facilitation of communication between disciplines, and between the patient and the team. Peterson also adds the need for social workers to teach the staff about “the importance of the interaction between their responses to the patients, the medical management of the illness, and the patient’s long-term psychosocial adjustment” (Peterson, 1984, p. 43).

For HHD, responsibility for operating the dialysis machine and fear of self-needling can seem overwhelming for some patients (Cafazzo et al., 2009; Masterson, 2008; Wong et al., 2009), both of which can cause anxiety and problems with sleep (Masterson, 2008). Fear of self-needling was

also identified as a common barrier by Bessie Young, MD, MPH (Munasque, 2010). Cafazzo et al. (2009) report that the loss of nursing support in critical situations was perceived by patients as a loss of safety (p. 787), and patients feared a catastrophic event.

Emotional barriers to PD include: fear of infection, peer experiences with peritonitis, fear of isolation, and lack of supervision, as well as having small children in the home (Jennette et al., 2009). Wong et al. (2009) mention anxiety related to uncertainty over the training period and the shift of medical responsibility from practitioner to patient. According to Hodge (2008), the convenience of not having to travel to the dialysis unit, and having a flexible schedule when performing hemodialysis at home is often outweighed by different fears (self-needling, technology, impact on a relationship with a caregiver, inability to function while ill, inability to handle emergencies, and giving up a dependency relationship with staff from the center or social support from other patients). The author believes that the physician should prescribe the modality that will provide the best probability of longer and better quality of life, and give the patient the facts about the differences in outcomes between the different modalities, with nocturnal hemodialysis providing the best outcomes. Hodge suggests that fears can be overcome if the patients participate in a short in-center frequent dialysis trial as they will experience the benefits of more frequent dialysis.

Courts and Boyette (1998) conducted a comparative descriptive study exploring the anxiety, depression, and psychosocial adjustment of male patients on three types of dialysis—HHD, in-center hemodialysis, and PD, with 5 patients from each modality. They state that chronic illnesses challenge the coping mechanisms of patients and their families and demand behavioral and emotional changes. Patients on dialysis have unique problems because they may not appear to be ill, therefore, they often feel pressured to live normally. Other problems include lifestyle changes required to perform dialysis, inability to work due to dialysis time constraints, as well as loss of status, social position, family roles, and independence. By using the Clinical Anxiety Scale (Corcoran & Fischer, 1987), the Generalized Contentment Scale (Hudson & Proctor, 1977), the Hemodialysis Stressor Scale (Baldree, Murphy, & Powers, 1982), and the Psychosocial Adjustment to Illness Scale—Self-Report (Derogatis & Lopes, 1983), Courts and Boyette (1998) observe that the patients on HHD had the highest level of psychosocial adjustment to illness, the lowest anxiety scores, and the lowest depression scores. The PD patients had the highest anxiety scores, while the highest depression scores were for the in-center HD group. These authors conclude that HHD patients fare much better than their counterparts, largely due to their ability to control scheduling and length of treatments, an increased sense of overall control, and the ability to use dialysis time for a variety of activities in the home. PD patients share similar experiences with those on HHD, and might be expected to

experience high psychosocial adjustment to illness. The difference in this study may be that the HHD patients had dialysis partners, while the PD patients generally performed their own treatments.

Altered body image is identified as one factor which influences patient acceptance of the treatment (Lehoux, 2004). Lehoux's research underlines the importance of the individual patient's values (e.g., ability to accept the merging of their physical body with medical technology; valuing independence and autonomy) and self-image (e.g., image of self as capable of technical competency, body image) in determining who will successfully integrate home therapy into their life.

Results of a study by Buss (2008) show improved quality of life (QOL) in HHD patients, particularly in the role-physical (limitations in usual role activities because of physical health problems), vitality (energy and fatigue) and social functioning (limitations in social activities because of physical and emotional problems) domains of the Medical Outcomes Survey Short Form (SF)-36. This study also revealed that "an overall sense of well-being is indicated with benefits of increased energy, strength, and endurance, which is a most desirable outcome from a social work perspective" (p. 14). This is of importance to social workers, who advocate for the best QOL possible for patients. Buss adds that the patients who were trained for HHD but returned to other modalities had found the experience overwhelming (30% dialyzed without a partner), had complicated medical issues, or had an assistant who had difficulty (13% of them dialyzed with their partner doing all of the procedures) (p. 14). From that article, HHD patients consistently reported feeling much better after entering the HHD program, and most valued the freedom in scheduling their own dialysis, and the opportunity to be involved in other activities, such as continuing to work, volunteering, and being more involved with their families (p. 15).

Impact on the Family

Cafazzo et al.'s 2009 study found that, in multiple instances, family members who were primary caregivers recognized their lack of appreciation of the extent of patients' conditions until therapy was administered at home. The authors conclude that family members might be fearful of complex home therapy, and that there would be additional patient care responsibilities (p. 786). For some patients, needing a helper made HHD unappealing (Jennette et al., 2009).

Partner or helper burnout was identified as a potential issue by Bessie Young, MD, MPH (Munasque, 2010). Masterson (2008) indicates that there is potential for relationship strain or "burnout," especially when the person providing the assistance with dialysis has employment that requires traveling or shift work. When partners are assuming the major responsibility of the treatment, the social worker, who is trained in problem solving, can help the team deal with difficult family dynamics, as well as assist the family and patient in accepting the new situation and the feelings

of dependency brought on by the continued necessity of treatment (Palmer, 1978).

Polaschek (2005) reports patients acknowledging that, in general, their family, especially their wives, now provide increased support for them and this comes at a cost to these family members, not only through limiting their own activities to the house during treatment, but also increased stress from sharing responsibility for treatment.

"Several small studies and anecdotal reports have found that the added responsibility of home hemodialysis can generate fear, hostility, anxiety, and fatigue in caregivers, and negatively affects family and other social relationships" (Van Eps et al., 2010, p. 36). In a letter from Bernheim and Korzets (1999), the authors report that helpers and/or other family members of patients on HHD were often affected psychologically, namely with insomnia and nightmares often related to the dialysis procedure, as well as extreme anxiety affecting their functional ability. Van Eps et al. (2010) also note, in their study as well as others, that the majority of successful caregivers for HHD patients are female and that fewer female dialysis patients enjoy the benefits of home-based dialysis therapy as a result of lack of family support. "Increasing numbers of women are now juggling paid employment in addition to household chores and family responsibilities. This leaves them little time for meeting their own health and leisure needs. These observations have important implications for patient recruitment [to home hemodialysis], as well as social support provided by home hemodialysis units' staff to patients and their families" (p. 37). Improving our understanding of the impact of family dynamics on home dialysis may also assist in expanding the patient population that can be successfully maintained with home therapies (p. 37).

A literature review conducted by Brunier and McKeever (1993) clearly revealed that the majority of family members assisting or carrying out HHD were female. They conclude that the majority of women work outside the home and that, "as heads of household[s], home dialysis may place an even bigger physical and emotional burden on female caregivers" (p. 658).

Support from Family

Van Eps et al. (2010) emphasize the importance of a good social support network, as it has been shown to improve compliance and outcomes in hemodialysis patients and is often critical for the success of home-based dialysis therapies, although "home-base[d] dialysis may place an extra load of responsibility upon family and friends" (p. 35).

For Hodge (2008), not having a helper constitutes one of the three exclusion criteria for HHD. The Method to Assess Treatment Choices for Home Dialysis (MATCH-D) (Schatell & Witten, 2009) also screens out potential HHD candidates who do not have a helper at home. Lack of support for home care from families was one of the two most common barriers to self-care identified by the volunteers from the European Dialysis and Transplant Nursing

Association/European Renal Care Association (EDTNA/ERCA), the other being language barriers (Lindley, 2006). At the authors' Ottawa Hospital, patients can perform HHD on their own, provided they are linked with a personal alarm system.

Patient versus Caregiver Responsibility for Performing Dialysis

Agar (2008) indicates that caregiver fatigue is often identified as the cause for stopping HHD, especially in North America, whereas in Australia and New Zealand, there is an effort to ensure that the responsibility for care falls on the patient. In one study, it was found that dialysis partners often felt too great a responsibility, and this led to stress situations (Lindley, 2006). In Lehoux's 2004 study, a patient's wife "found the manual PD a burden—four times a day... it's like being in jail, you can't go anywhere" (p. 6). Agar (2008) reports that when patients take responsibility for their own care, the caregivers experience less emotional and psychological stress. The caregivers can then take a support role regarding dialysis instead of being the facilitators. In addition, Lindley (2006) notes that when patients attend training knowing that they cannot rely on anyone else, they seem to concentrate better, increasing their chances of becoming more self-sufficient.

There is recognition that even when partners need to take some responsibility for a home treatment modality, the burden might be less than some of the responsibilities associated with in-center dialysis, i.e., arranging and paying for transportation three times per week for in-center hemodialysis, and preparing meals that take into account a more restrictive diet and a more vigilant monitoring of fluid intake (Schatell, 2007).

In some countries, automated PD is used as the preferred modality when patients need assistance, with two visits from the nurse to connect and disconnect from the machine. PD patients from the Ottawa Hospital can receive this type of home support, which makes home dialysis a viable option for many elderly patients. The patient or caregiver only needs to be able to respond to alarms from theycler, and/or contact the nurse on call who can guide them.

Courts (2000, May) conducted a study investigating the psychosocial reactions of patients on HHD and their dialysis partners, how decisions were made to choose HHD, and the patients' perceptions of HHD stressors. She studied 14 patients and their partners. Of the sample group, only 2 patients actually participated in the dialysis process; the other 12 patients had a caregiver perform their dialysis. Results showed that patients enjoyed not needing to depend on dialysis technicians and appreciated the freedom to dialyze at their convenience, which increased their sense of control over their lives. The dialysis partners found HHD stressful, although this stress decreased over time. Anxiety and depression scores were low for both patients and their partners, compared to other dialysis patients. Courts emphasizes the need to assess patients and their partners

carefully, and recommends time with each to talk separately about their concerns and wishes. She also recommends providing relief for the dialysis partner. At the Ottawa Hospital, HHD patients can receive "respite" in the form of a few treatments in-center when they or their partners need time off from the responsibilities associated with performing hemodialysis at home. Patients on HHD must switch to in-center HD permanently when they can no longer manage their treatment at home and no family assistance is possible, as there is no community assistance coverage for HHD.

Loos-Ayav et al. (2008) found that after one year of being on HHD, autonomous patients had better health-related quality of life scores than in-center dialysis patients for the dimensions "burden of kidney disease, role-emotional, cognitive function and effects of kidney disease" (p. 6). The authors attribute higher quality of life scores to lesser dependence on others and a more positive outlook regarding the effects of kidney disease on their daily activities. They also found that the autonomous patients were more active than the in-center patients, more frequently having an occupation or doing leisure activities. They conclude that even though some patients had limited autonomy due to age, comorbid factors or disabilities, their participation in self-care hemodialysis is to be encouraged.

Cafazzo et al.'s (2009) qualitative research reveals that patient concerns about the burden on family members were a barrier to choosing NHD. Munasque (2010) confirms this: "The partner needs to be treated like a living donor. They need a full explanation of what they're committing themselves to. They need a chance to say 'no' in private."

The social worker can help with communication between the patient and the dialysis partner. It is important to assist the patient and the dialysis partner in understanding their roles and responsibilities, and to problem solve communication issues. For example, Palmer (1978) reports that frustrations and resentment can arise when the patient dominates the partner and has little appreciation for their efforts, or when the dialysis partner takes too much responsibility for the patient's treatment.

Time Required

Training time for HHD was found to be a barrier by Agar (2008). Lindley (2006) also finds that the training period for HHD (8 to 10 weeks, compared to 4 to 5 days for PD) was a major drawback. Masterson (2008) also reports this as being an issue, even though the study sample's training time for HHD was 3 to 6 weeks, and was considered especially difficult for people working full-time or for those living in rural areas who had to relocate temporarily during training.

Time constraints are also identified by Jennette et al. (2009) as a reason why PD is less desirable. All of Lehoux's (2004) subjects experienced major obstacles with employment because of the frequency and/or duration of treatment.

Female patients often do not consider HHD because of their other responsibilities within the family (Lindley, 2006; Palmer, 1978). In Spain, the number of HHD patients declined, in part due to the difficulty of recruiting female patients (Lindley, 2006).

Patient Personality and Mental Health

Of the articles reviewed, only a few, such as Kaplan, De-Nour, and Czaczkes (1976), mention that personality traits and psychological condition can be contraindications to home therapies. Depression is mentioned frequently (Courts 2000; Courts & Boyette 1998; Kaplan, De-Nour & Czaczkes, 1976; Palmer, 1978; Schatell 2007) as a by-product of ESRD, so while it is clear that a degree of depression might be a contraindication to home dialysis, it is not clear what weight is placed on the patient's overall mental health.

Kaplan, De-Nour and Czaczkes (1976) identify personality traits and mental health issues that can be assessed prior to starting dialysis, such as frustration tolerance, obsessive-compulsive tendencies, acting out aggressively, depression or suicidal ideation, denial of sick role or excessive gains from the sick role, rejection of dependency needs, and satisfaction with work as potentially predicting the person's behavior during treatment. These authors mention that clinicians have a "tendency to over-rate patients' potential for adjustments, i.e., to under-rate the stressfulness of the situation" (p. 330). Personality traits such as irresponsible behavior from the patient or assistant (e.g., excessive alcohol consumption) can interfere with home dialysis due to the responsibility involved (Palmer, 1978), although patients who are depressed, angry, or disruptive in-center may actually do better at home (Schatell, 2007).

It seems evident that patients who cannot reliably act in their own best interests would be at greater risk for harm if given responsibility for their own dialysis.

Safety and Patient Ability/ Willingness to Follow Recommended Procedures

Giles (2003) discusses observing unsafe working/living conditions, such as HHD patients storing blood in the kitchen refrigerator. The author states that this highlights the need for the development of health and safety protocols for dialysis within the home environment.

In Australia and New Zealand (ANZ), home visits are made by nursing and/or medical staff, and technicians do machine maintenance in the home on a regular basis, but contrary to "service calls," some patients don't want intrusions in their home (Agar, 2008). At the Ottawa Hospital, the patients on PD are visited at home by nurses, and the HHD patients are also visited by technicians.

Wong et al. (2009) emphasize the need to ensure patients have the capability of administering their own therapies using complex medical technology safely and without clinic supervision (p. 28).

Suitability of the Home/ Patient's Willingness to Change the Home

Not all dialysis patients have accommodations that are suitable for home dialysis. Giles (2003) points out that renters, people who live in shelters, and those who pursue various other forms of shelter will experience severe obstacles to receiving home dialysis.

In some countries, such as Australia, New Zealand, and Canada, plumbing and electrical alterations to the home are necessary to install the HHD equipment. For potential HHD patients who rent, approval from the renting agency or property owner must be received, and some assurance must be provided that the patient doesn't intend to relocate in the near future. Proper power circuits, water sources, and water quality must be adequate, and waste disposal systems with backflow protection must be in place (Agar, 2008).

Jennette et al. (2009) find that changes to the home water system and needing a room big enough for the machine and supplies were identified as barriers for HHD. Storage space for PD supplies can be an issue for some patients, since deliveries are rarely feasible more than monthly (Agar, 2008). Hodge (2008) also views inadequate home environment (also reported by Lindley (2006)) as one of the 3 exclusion criteria for HHD, another being unacceptable utility services.

Lehoux (2004) states that dialysis technology does not always fit neatly in the home setting, and describes one PD patient who planned to have an evacuation system installed so he would not have to dispose of the solution from his peritoneal cavity through the toilet anymore. Some patients are reluctant to make changes to their home or make space for supplies, as they don't want to "hospitalize" the home (Giles, 2003; Masterson, 2008, p. S16; Munasque, 2010).

Patients in long-term care facilities (nursing homes) may not be eligible for home therapy due to lack of staff support. In Ottawa, there are no long-term care (LTC) facilities willing to accept patients on PD. PD patients who require admission to a LTC facility have to secure a bed in one of the few PD-friendly facilities outside the city limits, or switch to in-center hemodialysis.

Cultural Issues

Some cultural differences between families and staff regarding expectations can occur. For example, Palmer notes cultural differences in "meeting the standards of time and measurements involved in dialysis, as these were not important considerations in their own society" (1978, p. 377). Palmer explains that "...families might learn the regime easily, but follow it casually, in keeping with the easygoing and fatalistic orientation of their own culture" (p. 377). Social workers can help mediate conflicts between patients' needs or values and medical expectations. Other patients may find the need to dispose of waste products to

be disagreeable because of their backgrounds or cultures. The expectation that home dialysis patients will have a stable, long-term residency runs counter to some cultural traditions where frequent changes in residence and fluidity of the family constellation are the norm.

Language Barriers

Lindley (2006) reports that language problems were identified as a barrier to self-care. Cafazzo et al. (2009) report that the patient's level of educational attainment does not appear to be a factor in adoption of NHHD, and that English as a second language does not appear to be a barrier. The barriers occur when the patient's grasp of English (and, in many parts of Canada, French) is minimal. Interpreters and family members or friends can assist in the training process. The bigger barrier is the ability to communicate with on-call staff when patients require urgent assistance with problems at home.

Unplanned Start on Dialysis

A significant number of dialysis patients begin treatment on an urgent basis, with little or no education about kidney disease and treatment modalities. At the Ottawa Hospital in 2010, only 8% of patients receiving their first dialysis treatment had a planned start. While a significant number of these patients were no longer on dialysis at the 3 month marker (due to recovery of kidney function or mortality), the 34% who remained on dialysis were all receiving in-center hemodialysis (The Ottawa Hospital, 2011).

Given that an urgent start almost always entails hemodialysis with a CV line, it is no surprise that "an unplanned start to dialysis seems to be the greatest barrier to the uptake of self-care therapies" (Lindley, 2006), as patients quickly become dependent on dialysis center staff. One solution is a more aggressive approach to educating health professionals about the symptoms of kidney disease, promoting early referrals to nephrology specialists, and enabling quick integration of home dialysis programs.

In-center Dialysis versus "Home First" Policy

In Finland, the pre-dialysis program started in Helsinki made a fundamental change in promoting the ideology of self-care by developing a "home first" policy. The role of the patient changed from passive patient to care provider, and arranged for centralized HHD training that also serves more remote hospitals, report Honkanen and Rauta (2008). They explain that patients prefer to start dialysis directly in the training unit. If there are no contraindications and patients accept, they are directed to either PD or HHD, which are the first-line therapies of choice. The authors also discuss considerations for the future, as the patients starting dialysis are getting older and increasingly have various comorbidities, which means that training times may need to be extended and that patients may need to utilize the backup of dialysis units. Therefore, these authors report,

there is a need to put more emphasis on developing systems for assisted treatments, not only for PD, but for HHD as well.

The Ottawa Hospital has an in-center nocturnal hemodialysis program and is starting a self-care hemodialysis unit, where patients can take most of the responsibility for their treatment, yet enjoy the security of nursing support. It is hoped that hemodialysis patients can then transition more easily from hospital-based self-care treatment to home dialysis.

Loss of Relationship with Staff and Other Patients

An issue for patients who start hemodialysis in-center is that after having adjusted to a dependent role, switching to PD or HHD may bring another period of adjustment—this time to a more independent lifestyle (Brey & Jarvis, 1983). Patients who dialyze in-center have the opportunity to socialize a number of times a week, and those who have been on hemodialysis five or more years have spent so much time in the dialysis unit that "contact with [other or outside] friends and family will have filtered away" (p. 204). Masterson (2008) indicates that some patients may feel socially isolated on home dialysis if they have had the experience of in-center dialysis, as they will miss the companionship and support of other patients. In contrast, Agar (2008) finds that patients do adjust, and that they rarely go back to in-center dialysis due to loss of relationships.

Peer support is identified by Wong et al. (2009) as very important during training for NHHD, due to the desire to learn from other patients. These authors state that watching others struggle and achieve their goals helped motivate patients in training, reassured them that they were normal, and reassured them that feeling overwhelmed during their transition to nocturnal HHD was common. This speaks to the importance of early intervention to identify and support potential home therapy candidates.

Support from Staff for Home Dialysis

Jennette et al. (2009) report a finding from Bernadini in 2004 that both patients and dialysis center staff believed myths about PD, including perceptions that PD is inappropriate for patients who are noncompliant or obese, that it demands that patients be totally independent, has poor survival rates, and high infection risks.

Research has found biases in selection criteria, meaning some individuals who could do well at home—or are doing poorly on in-center treatment—are never given the option (Schatell, 2007). Schatell (2007) identifies that patients who are married, of higher socioeconomic status and more educated were more likely to be given modality choices. Schatell discusses the importance of patient-led modality choice, and states that it significantly predicts longer survival and a better chance for transplant than a team-led or even a joint decision. However, the decision about suitability for

home dialysis is often made by health professionals without patient consultation. It is important to provide information in an unbiased way, “giving the pros and cons for both PD and HD relevant to their age and comorbidities” states Brown (2008, p. S70). This author adds that most education occurs during the pre-dialysis phase when mild cognitive impairment and uremia may make it difficult for patients to understand the implications of information, and those starting dialysis urgently may never receive this information at all. “It may be appropriate to offer choice of modality 2–3 months after starting dialysis, once patients know more about the ups and downs of life on dialysis” (Brown, 2008, p. S70). This advice contradicts Palmer (1978) who warns about patients becoming “entrenched in the sick role” and reluctant to consider home dialysis.

Empathy from the clinician was found to impact the ability to persevere when learning how to perform NHD while also dealing with family responsibilities, state Wong et al. (2009). They emphasize the importance of understanding patients’ learning styles, as patients distinguish between understanding and memorizing what they were taught. Patients want to gain understanding of why they are required to learn particular concepts and their importance, which Wong et al. (2009) think could be driven by their need for reassurance. They report that different techniques may be required in order to achieve the best learning outcomes, due to the different learning styles. For example, some patients are visual learners and want video material, while others need a varied delivery, such as video coupled with hands-on learning. “Complex and multidimensional learning is challenging, even under ideal conditions, but the challenge is exacerbated by the added responsibilities of coping with an illness and dealing with increased levels of anxiety,” which is important to consider when planning patient education and training (p. 32).

Additionally, “a multidisciplinary team approach allowing the patients access to psychosocial counseling may be beneficial in providing support to patients and to their families, while adapting to the training process for home self-treatment. The need for support may become more pervasive as patients and their families assume more responsibility for administering their own treatments” (Wong et al., p. 32).

Knowledge Barriers

Cafazzo et al. (2009) note that “pre-dialysis patients had difficulty articulating their opinions on modality choice as they had little knowledge of the specifics of the various dialysis options. Their lack of experience and knowledge of the different therapies limited their participation in the qualitative study” (p. 788).

The way in which information about HHD is delivered to patients and families can make a difference, which points to the need to have well-trained staff capable of using simple explanatory language devoid of medical terminology as much as possible, states Agar (2008). The author also

reports that patients who are secure with dialyzing at home can be a valuable resource to a home dialysis education program. At the Ottawa Hospital, home dialysis patients are being recruited to participate in the education of pre-dialysis patients. In addition, the hospital has a dedicated nurse-educator who meets with in-center hemodialysis patients as well as their families to discuss the option of home dialysis, and admits patients who require an acute start.

Hodge (2008) states that physician-patient discussion should focus on expected clinical outcomes and health benefits, not patient convenience or “lifestyle” (p. 1). The author explains that the “financial health of dialysis centers will be enhanced by shifting continually inflating costs from the center to the patients and home caregivers.” This sounds simplistic as it does not consider the psychosocial aspects involved in performing dialysis at home, which are crucial to patient satisfaction and adherence to the home dialysis program. However, we must acknowledge that patients and family members who have more information about the health benefits of more frequent dialysis may then be willing to make some changes to their lives to accommodate home dialysis.

Lehoux (2004) conducted a qualitative study documenting patients’ perspectives on how the user-friendliness of home care technology influences its integration into their private lives. Lehoux studied four types of home care interventions, one of which was PD (sample size = 3 patients). The conclusion by this author is that patients rarely perceived home care technology to be user-friendly, and user acceptance was closely linked to user competence. Therefore it is important to consider lengthening the training period until the patients have more confidence in being able to master the machine.

Cost to Hospital/Availability of Staff to Train and Maintain Home Dialysis Patients

Hodge (2008) proposes a trial during which patients dialyze more frequently in-center to demonstrate whether patients have enough self-discipline to justify the expense of training. In some centers, identified barriers to home dialysis are: lack of time for training and monitoring patients, lack of space for training, lack of support from doctors, as well as economic pressure to keep the hemodialysis center running to capacity (Lindley, 2006). In fact, Kalirao and Kaplan (2009) discuss the higher direct cost of nocturnal home hemodialysis for centers in Canada. Reimbursement is established for conventional hemodialysis at three times per week. However, significant savings were shown in many other areas: staff, medications, support, hospital admissions, and procedures—with the projected annual saving of \$10,000 less per patient than in-center HD (p. 259). The lack of dedicated resources is one of the main barriers to the growth of home dialysis, especially when converting patients who are used to full-time care, despite simplification of the dialysis procedures and evidence of

improved outcomes (Ledebor, 2008). The author states that organizational expectations for the number of patients using home dialysis should be based on patient capabilities, not organizational shortcomings.

Cost to the Patient

“In some Australia and New Zealand states, an annual reimbursement from the state assists patients with any costs incurred through the provision and use of standard utilities—particularly water and power costs [in the home]” (Agar, 2008).

At the Ottawa Hospital, the home dialysis team assisted in advocating for an annual water bill rebate from the city of Ottawa, which is now available to all HHD patients living within city limits. As of this writing, the city of Ottawa and a municipality on Vancouver Island are the only areas in Canada that have established an annual water rebate for patients on HHD. To date, there is no assistance with power costs.

Agar also mentions that training for both PD and HHD is less developed in the U.S. due to the cost burden to patients, whereas it is fully funded by the state in ANZ. This is also the case in Canada, where there is universal health care and access to a federal program of unemployment health insurance benefits.

REVIEW OF TOOLS

The Jo-Pre-training Assessment Tool (JPAT) was developed in 1996 (Chow & Bennett, 2001). It is a quantitative assessment of a person’s suitability for HHD or PD. Prior to developing this tool, the authors had not found another tool purposely designed to assess potential candidates before they start training for home dialysis. They felt that it was important to assess the person prior to starting training, so he or she would be in a better position to make informed decisions about health care. The content of the JPAT was determined from a consensus of a focus group (expert opinion), a literature review, a telephone survey, and a 1996 national survey of 36 renal units and a review of their pre-dialysis training assessment methods. A pilot study served to refine the instrument before its use in ESRD programs.

The JPAT is primarily focused on identifying health-related problems (e.g., bowel problems, hypertension, nutritional status, and physical stability) that may affect home dialysis therapy, but also addresses some psychosocial issues (e.g., living arrangements, mental status, motivation, and sense of control). Interviews are conducted with patients based on 38 assessment items in 6 domains: Physical Stability, Nutritional Status, Communication Ability, Ability to Maintain Self-Care, Social Support, and Psychological Suitability.

The tool is based on the Medical Outcomes Study Short Form 36-Item Health Survey (SF-36[®]), by McHorney, Ware, and Sherbourne (1994). Guided by the SF-36, Chow and Bennett (2001) looked at items, such as the section

entitled “Physical Functioning and Role Limitation Due to Physical Health,” which may partially apply to assessing a person’s ability to maintain self-care, e.g., lifting, carrying groceries, climbing stairs, bending, bathing, and dressing. The interviewers are also required to observe activities such as hand-eye coordination. Results from the pilot study showed that patients who currently worked around the house were likely to be home therapy candidates. The JPAT has proven to be a reliable tool for use with ESRD patients in Australia, “identifying patients with the greatest chance of learning to manage the program” (Chow, 2005, p. 19). Chow & Bennett (2001) also found that it was useful in assessing patient conditions and needs before starting the dialysis training, as well as for ongoing assessment of current dialysis patients’ physical and mental status.

Agar (2008) references the Method to Assess Treatment Choices for Home Dialysis (MATCH-D), which was developed by Schatell and Witten in 2007 with the input of American, Canadian and Australian home dialysis experts. The author indicates that a valid approach is to consider that people with the skills to drive or use a sewing machine should be, by definition, potential HHD candidates. Schatell (2007) explains the rationale for the MATCH-D tool, which was designed to standardize the selection criteria and avoid biases in patient selection for referral, as identified in research. The author mentions the characteristics of the ideal home dialysis candidate: working or in school, caring for loved ones, traveling actively, having issues with transportation to in-center treatments, having trouble following the in-center diet and fluid limits, and being unhappy because of lack of control. This tool recognizes that patients who are depressed, angry, or disruptive in-center may actually do better at home. In addition, this tool recognizes the importance of patient motivation. However, patients who don’t have a dialysis partner are considered unsuitable for HHD and referred to PD.

Schatell (2007) explains that the MATCH-D tool does not have a point system, as the information is gathered to promote discussion between the patient, family, and care team for the patient to choose the treatment modality that is most appropriate for his or her lifestyle and capabilities. This tool also lists some of the barriers and solutions. MATCH-D helps the care staff identify patients who can succeed at home more independently, those for whom more consideration is needed to overcome barriers, and those who need a helper to take primary responsibility.

CONCLUSION

Throughout this review, we developed an understanding of many reasons why medically eligible patients may decline or never be offered home dialysis, and more importantly, why patients may start and then quit home dialysis. The barriers facing patients on home modalities can easily be taken for granted. Lehoux (2008) points out the need for a “smooth fit” between the technical and human barriers that affect patient compliance. Lehoux indicates that

with a growing elderly population and limited health care resources, promoting self-management will become a major issue in most industrialized countries. Home treatment involves more than simply transferring a particular technology from the hospital to the home; it requires transferring knowledge and skills to lay people, and making sure that the home and social environments enable a safe, effective, appropriate, and personally satisfying use of technology (Lehoux, 2004, p. 8).

Improving our understanding of the challenges faced by home dialysis patients and their families can help increase the number of patients using home dialysis. As Wong et al. (2009) note "...it was widely assumed that technology-related fears and concerns posed the greatest potential barrier to the training of patients and caregivers to self-administer HHD. However... [the primary barriers] were psychosocial in nature rather than technological, as originally anticipated" (p. 31). The importance of understanding and ameliorating the very real emotional and social challenges faced by both patients and their families is key to increasing the home dialysis rates.

The point of assessment is to not only gather information about the patient, but also to engage the patient and caregiver in additional learning about the practicalities of performing dialysis at home. The assessor is provided with an opportunity to gain insight into the patient's values and priorities, and to engage in problem solving with the family and the medical team. Social workers have a very important role to play in assessing and preparing patients for home dialysis, and communicating patients' concerns to the health care team. As Peterson (1984) states: "The nephrology social worker is the only member of the treatment team whose professional orientation is geared towards the psychosocial management of chronic renal failure" (p. 42). With knowledge of the social stressors faced by patients and families, and skills at facilitating patient empowerment, social workers can help patients transition from passive recipients of medical care to active participants in the kidney health care team.

The literature indicates that a patient's ability to manage the psychosocial aspects of home dialysis is a significant predictor of success (Peterson, 1984; Wong et al., 2009). While the JPAT and MATCH-D tools address some of the psychosocial elements of home dialysis, the authors ask if a more in-depth psychosocial assessment could improve patient selection and patient readiness for home dialysis. To this end, we are developing a psychosocial assessment tool for patients with no medical contraindications to PD or HHD: the Psychosocial Assessment Tool for Home Dialysis (PATH-D). We see the need for a tool developed by social workers with the specific intention of assessing social or attitudinal barriers which can prevent seemingly ideal candidates from succeeding with home dialysis. The PATH-D is still under development, but we hope further study validates that a thorough psychosocial assessment can assist in developing strategies to reduce social barriers, bet-

ter preparing patients for the realities of home dialysis, and matching patients to the most sustainable treatment modality according to their abilities, lifestyles, and social support.

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