Longitudinal Changes in the Use of PD Assistance for Patients Maintained on Peritoneal Dialysis

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Abstract

Background Home dialysis therapies, such as peritoneal dialysis (PD), offer flexibility and improved well-being, particularly for older individuals. However, a substantial proportion require assistance with personal care and health care-related tasks. We hypothesized that patients and families would require less PD assistance as they became more familiar with PD-related tasks. The study objective was to assess whether the nature of, and need for, PD assistance decreased over time.

Methods Using a multicentered, prospective, observational study design, patients aged ≥50 years were recruited from those starting PD. Patients underwent formal evaluation using validated components of a Comprehensive Geriatric Assessment at baseline, and they were followed monthly and administered a questionnaire about the need for assistance with PD-related tasks.

Results A total of 111 patients (age 69 ± 10 years, 68% men, and 56% diabetic) were followed for a total of 609 patient-months. Of those who needed help, 40% had help from a family member, and 33% were helped by nurses. Both the quantity and nature of help received by patients remained generally stable throughout follow-up and did not vary according to age, frailty, functional dependence, or cognitive impairment (P = 0.93). The proportion of patients needing help varied widely across the 13 different tasks but appeared relatively stable across time. The paid-unpaid caregiver ratio for the different tasks did not change over time.

Conclusions Older patients initiating PD in the outpatient setting have a high need for assistance with PD-related tasks, which seems to persist over the initial 6-month period.

Key Points

- Nearly three quarters of patients aged ≥50y starting peritoneal dialysis need help with treatment-related tasks.
- The degree of assistance for peritoneal dialysis-related tasks does not change over the initial six-months of treatment.
- Information about the ongoing need for assistance with treatment-related tasks should be included in shared decision-making discussions.

Introduction

Home dialysis therapies, such as peritoneal dialysis (PD), offer flexibility, symptom control, and improved well-being, particularly for older individuals (1–5). Until recently, home dialysis was largely performed by the patients themselves in their own home environment. Assisted PD has proven to be an efficient and safe modality (6). Patients on PD have variable degrees of functional impairment (7), so over the past decade, there has been increased awareness of the need to help patients in managing PD-related tasks at home to increase access and improve outcomes. Consequently, several models of care have emerged across the world (3,8–10), and patients often receive support from both paid and unpaid caregivers for a number of treatment-related activities. Within Ontario, the health care funding system includes nurse-assisted PD. We previously found that almost half of those patients who initiate dialysis with baseline evidence of frailty, functional decline, or cognitive impairment require assistance during the first month of treatment for several tasks associated with PD (11). In this study, we sought to follow up with these patients’ needs for assistance over time. We hypothesized, on the basis of our understanding of the clinical trajectory of patients initiating dialysis (12), that several individuals would become more able to independently perform PD-related tasks, whereas others would require more support over time.

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Materials and Methods

Population and Study Design

Recruitment of patients and baseline assessments have been previously described in detail (11). In brief, all patients aged 50 years or more initiating PD between December 2012 and March 2014 at one of three Ontario centers were approached for participation. Patients were eligible if they were planning to undergo routine PD in their own home environment, as opposed to a nursing home or long-term care. Informed consent was obtained as per research ethics guidelines. Participants were asked to identify individuals who supported them and may potentially assist with their dialysis care. Permission was sought to contact caregivers directly. Patients (or caregivers) were contacted monthly over a period of 6 months and asked, using a structured questionnaire, about what assistance was being given for each of 13 tasks (11). As in the previous study, tasks included core PD activities (handwashing, exit site care, assessment of BP and weight, documentation, bag selection, lifting bags, connecting and disconnecting, and discarding materials safely and troubleshooting) and instrumental PD activities (ordering supplies, organizing and managing clinic appointments, and organizing and managing medications and adding medications to dialysate). For the purposes of the study, we defined assistance as having any form of help for the specific task, including verbal prompting, to ensure that the task was being done correctly. Respondents were also asked how much time, in minutes, help was received on an average day to assess if the amount of time that help was needed changed through follow-up. For those with longer hospitalization periods (>2 weeks), patients were considered to be receiving full PD assistance for all 13 tasks.

We categorized patients as receiving help if they answered “sometimes,” “often,” or “always” (as compared with “rarely” or “never”) when asked if they received help for each activity. Details of who most commonly provided the assistance were categorized for each task into two groups: friend/family member (abbreviated to “family”) or help received from a paid caregiver or nurse (abbreviated to “nurse”).

Statistical Methods

Demographic data were analyzed and reported descriptively using percentages for categorical variables and means (with SDs) or medians (with interquartile ranges) as appropriate for continuous variables. Imputation was performed (n=35 values) using the last observation carried forward methodology for patients who were temporarily unreachable but otherwise had stable results (excluding those censored because of death, transplant, temporary transfer to hemodialysis [HD], or transfer out of center). For values that were missing in the first follow-up month, the value collected from the second month of follow-up was used. Imputation on a second time point was not performed if data were missing on more than two consecutive time points. Although this method of deterministically filling in missing data is not generally recommended, the stability of outcomes over time within the patient was felt to give good approximation to model-based imputation.

Trends over time were assessed by summarizing the number of the 13 tasks on which patients required help at each time point. Help received was categorized as none (help with no tasks), minimal (help with one to four tasks), moderate (help with five to nine tasks), or significant (help with ten to 13 tasks). Changes in this grouped ordinal variable (none, minimal, moderate, or significant) were assessed using a mixed effects proportional odds model (using the package mixor [13], which included a random effect for patient and fixed effects for time). Both summary plots and data analysis used the same datasets for trend analysis; patients who were temporarily off PD, hospitalized, or switched to HD at the time of assessment did not contribute data. Odds ratios from this model estimate whether there is a change in the level of help at a follow-up time compared with baseline. A Wald test was used to assess the overall effect of time. Analyses were done using R version 4.0.2 (R Core Team [2020], Vienna, Austria; https://www.R-project.org/); a statistical significance threshold of 0.05 was applied.

Results

Demographic details of the participating patients have been previously reported (11). Of 143 eligible patients, 121 agreed to participate. Of the initial 121 participants, only 111 entered the longitudinal study (Figure 1). Nine of the ten patients excluded from the longitudinal study did not start home PD and therefore, did not enter the longitudinal follow-up study (one renal recovery, seven early technique failure and permanent switch to HD, and one hospitalized for the full 6-month study period). One participant was unreachable throughout the study period. This patient was maintained in the home setting on PD but was living in Europe and therefore, not contactable.

Longitudinal data were collected for 111 patients to a total of 609 patient months. Of those who contributed longitudinal data, 68% were men, with a mean age of 68.9±10.2 years (Table 1). A total of 16 of 111 (14%) patients

![Figure 1. Study flow diagram. HD, hemodialysis; PD, peritoneal dialysis.](image-url)
The number of tasks with which patients received help, either from family or nurse, remained stable from month 1 through month 6 for the majority of patients (Figure 2). No differences were seen in the stability of help received over time for patients identified at baseline as having cognitive impairment, frailty, and/or functional decline (Figures 3 and 4). An average of 73% of patients received help for at least one task during the study period, of whom 40% had help from a family member and 33% had help from nurses (Figure 5). As previously noted, the amount of help needed was variable among the 13 different tasks, but the proportions of patients receiving help for each task remained relatively stable across time (Figure 2). Overall, patients received more help with tasks such as lifting bags (55%), ordering and discarding supplies (54% and 54%, respectively), and adding medication to the bags when required (53%). Help was least often required for handwashing (overall 7%) and medication management (23.5%). Nursing help was more commonly required for tasks such as adding medications to the bags, cycler setup, and ordering supplies (Figure 2).

Results of the ordinal model reporting trends over time showed little evidence of change between categories (P=0.93). A total of six (5.7%) patients had a change in assistance of more than two categories, and four (3.8%) changed from the highest (significant assistance) to the lowest (mild assistance) category over their follow-up (Figure 6). The odds ratios representing the change between month 1 and each other month were all close to one and

### Table 1. Demographic details of the study population at the time of dialysis initiation

| Variable                        | Total, n=111 | Any Assistance, n=82 | No Assistance, n=29 | P Value |
|---------------------------------|--------------|-----------------------|---------------------|---------|
| Age, yr                         | 68.9±10.2    | 69.8±10.1             | 66.3±10.3           | 0.10    |
| Men                             | 75 (68%)     | 54 (66%)              | 21 (72%)            | 0.51    |
| Employment                      |              |                       |                     |         |
| Full time                       | 12 (11%)     | 4 (5%)                | 8 (28%)             | <0.001  |
| Part time                       | 9 (8%)       | 6 (7%)                | 3 (10%)             | 0.60    |
| Not employed                    | 87 (78%)     | 69 (84%)              | 18 (62%)            | 0.01    |
| Unknown                         | 3 (3%)       | 3 (4%)                | 0 (0%)              | —       |
| Education                       |              |                       |                     |         |
| Did not complete grade school   | 14 (13%)     | 13 (16%)              | 1 (3%)              | 0.08    |
| Grade school                    | 24 (22%)     | 21 (26%)              | 3 (10%)             | 0.08    |
| High school                     | 19 (17%)     | 12 (15%)              | 7 (24%)             | 0.24    |
| College/trade                   | 22 (20%)     | 13 (16%)              | 9 (31%)             | 0.07    |
| University degree               | 29 (26%)     | 20 (24%)              | 9 (31%)             | 0.48    |
| Unknown                         | 3 (3%)       | 3 (4%)                | 0 (0%)              | —       |
| Lives alone                     | 22 (20%) (n=108) | 12 (15%) (n=79) | 10 (35%)            | 0.02    |
| Started dialysis as inpatient   | 18 (16%)     | 13 (16%)              | 5 (17%)             | 0.86    |
| Transferred from HD             | 23 (21%)     | 18 (22%)              | 5 (17%)             | 0.59    |
| Comorbidities                   |              |                       |                     |         |
| Diabetes                        | 62 (56%)     | 54 (66%)              | 8 (27%)             | <0.001  |
| Coronary artery disease         | 25 (23%)     | 20 (24%)              | 5 (17%)             | 0.42    |
| Congestive heart failure        | 25 (23%)     | 21 (26%)              | 4 (14%)             | 0.19    |
| Other cardiac disease           | 46 (41%)     | 33 (40%)              | 13 (45%)            | 0.66    |
| Peripheral vascular disease     | 11 (10%)     | 9 (11%)               | 2 (7%)              | 0.52    |
| Cerebrovascular disease         | 9 (8%)       | 9 (11%)               | 0 (0%)              | —       |
| Cancer                          | 15 (14%)     | 10 (12%)              | 5 (17%)             | 0.46    |
| Gastrointestinal bleed          | 5 (5%)       | 4 (5%)                | 1 (3%)              | 0.75    |
| Chronic pulmonary disease       | 8 (7%)       | 6 (7.3%)              | 2 (7%)              | 0.94    |
| Laboratory values               |              |                       |                     |         |
| Creatinine, mg/dL, median (IQR) | 5.67 (5.09–8.81) | 6.39 (4.94–7.44) | 8.25 (6.04–11.00) | 0.005   |
| Urea, mg/dL                     | 78.4±26.0 (n=108) | 77.9±26.8 (n=78) | 89±22.7             | 0.05    |
| Albumin, g/L                    | 3.5±0.5 (n=108) | 3.49±0.5 (n=79) | 3.57±0.53           | 0.43    |
| Hemoglobin, g/L                 | 9.80±1.42     | 9.78±1.38             | 9.93±1.58           | 0.61    |
| Disabilities                    |              |                       |                     |         |
| Functional                      | 72 (66%) (n=110) | 59 (72.8%) (n=81) | 13 (45%)            | 0.006   |
| Cognitive                       | 63 (59%) (n=106) | 55 (71.4%) (n=77) | 8 (28%)             | <0.001  |
| Fraility                        | 65 (64%) (n=101) | 50 (68.5%) (n=73) | 15 (54%) (n=28)    | 0.16    |
| No. of tasks needing assistance, median (IQR) | — | 6.5 (3–10) | N/A |
ranged from a minimum of 0.88 (*i.e.*, a slight decrease in need for assistance) at months 2 and 6 to a maximum of 1.08 at month 3. The time spent receiving assistance remained stable over the follow-up period, with the median per-patient time being 17 min/d (interquartile range, 2–47 min/d; \( P = 0.62 \)).

**Discussion**

In this longitudinal study, we observed that there was a relatively stable trajectory in the degree of PD-related assistance required by patients, regardless of age, frailty, or functional or cognitive impairment, over the initial 6-month period after starting PD. Similarly, assistance required for all 13 core and instrumental PD-related tasks appeared to be stable over time. We observed that the need for assistance depended on the task being performed and that nurses were more likely to help with specific tasks, such as adding medication to PD bags, cycler setup, and handwashing. Assistance in our population was equally often provided by family members as by paid caregivers, and only in rare cases did the responsibility for providing help with one particular task transfer from one to the other (data available on request).

Our data are important on several fronts. For families and caregivers, these data provide information around what the commitment and care burden is likely to be after dialysis initiation. In the true spirit of advanced care planning, this allows for more realistic expectations for the patient, and it may help set caregiver expectations and mitigate any negative effect on caregivers’ quality of life. For health care practitioners, these data allow for improved future planning, robust budgeting, and staff training in accordance with regional differences in the demographics of patients initiating onto PD, particularly those related to functional dependence, cognitive impairment, or frailty. This information can complement current planning and inform new policies in different regions trying to expand home-based therapies (14).

One of the main limitations of our study is that data were collected only within three programs limited to Ontario, Canada, where health care is provided through a socialized universal health care system to all citizens and the government finances nursing support for PD. In Ontario, assistance is provided at the discretion of the PD program and community home care services. There are no strict criteria or standards for re-evaluation intervals. This model applies across much of Canada but does not directly translate across other regions and countries of the world. To mitigate this, where possible, we included all patients aged 50 years or more at the time of starting dialysis and recruited widely.
across large units in Ontario. The use of protocols that measured a number of aspects of geriatric functioning provides a detailed description of our patients at baseline, potentially allowing for more meaningful comparisons across the populations in different countries and regions.

Our data only partly explain why patients need PD assistance and what factors prevent their need from reducing over time as we had initially expected. Our observation, for example, that there is incomplete concordance between the presence of frailty or functional or cognitive impairment and assistance emphasizes how the individual clinical scenario is important. Impairments, both physical and cognitive, do not always translate in practice into disability, and individuals can continue to function in their own environment despite noticeable impairments with the right supports and strategies (15). We anticipated and did not observe a decrease in need for assistance on the basis of previous studies (12) and the expectation that patients would have increased independence with skill acquisition and mastery over time. It is possible that patients and/or their caregivers become acclimatized to receiving and giving assistance, and caregiver-patient pairs align their expectations with a “sick-role” model. Also likely is the high risk that patients starting onto PD accumulate new or worsening comorbid conditions that lead to a decline in their personal functioning and their ability to partake in daily activities. Previous findings about PD assistance vary and are incomplete. A pilot PD assistance program from British Columbia included both respite and long-term PD assistance. Of those offered temporary respite PD assistance, 73% returned to unassisted PD within 3 months (17). In contrast, the majority who started onto long-term PD assistance remained on assisted PD at the end of follow-up, with only five of 53 having transitioned to unassisted PD after 12 months. Recent data from the Ontario Renal Network show that approximately 25% of all patients on prevalent PD in Ontario receive paid assistance at any given time point and that 35% have received it at some time during the prior 12 months (M. Oliver, personal communication); however, these data likely include in-home nursing help provided transiently to administer intraperitoneal antibiotic therapy for acute peritonitis. In other studies, the number of visits from health care professionals was reported by patients to be stable over time, whereas those using administrative data noted a reduction in visits for PD assistance (3,12). Although differences in study methodology, the patient or caregiver perspective, and population and data sources may contribute to the observed variations, we believe that the results presented in this study do accurately estimate the needs over time particularly as data were collected directly from patient or caregiver sources. Nevertheless, this should continue to be an active area of research.

In summary, we have identified that a substantial number of patients starting PD when aged 50 years or older require assistance for PD-related tasks and that this proportion declines little over the initial 6 months. It emphasizes the
importance of starting discussions early and introducing advance care plans, goals, and most importantly, expectations as patients approach dialysis initiation.

Disclosures
A. Jain reports research funding from Baxter Healthcare; and honoraria from Baxter Healthcare and AWAK Technologies. S.V. Jassal reports honoraria from Otsaka (April 2020); and other interests/relationships with Alexion, Janssen Ortho, and Sanofi (provision of unrestricted educational grants for educational meetings in which S.V. Jassal participated). M.J. Oliver reports ownership interest as the sole owner of Oliver Medical Management Inc., which is a private corporation that licenses the Dialysis Measurement Analysis and Reporting (DMAR) software system; research funding from Baxter Healthcare and Medtronic (provision of funding support to create a PD catheter registry for the International Society of Peritoneal Dialysis); honoraria from Amgen, Baxter Healthcare, and Janssen; and patents and inventions as Oliver Medical Management Inc. is co-owner of a Canadian patent for DMAR systems. All remaining authors have nothing to disclose.

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Author Contributions
S.V. Jassal and M.J. Oliver conceptualized the study; J.F. Farragher, J.I. Fonseca-Correa, and A. Jain were responsible for investigation; J.F. Farragher, S. Flanagan, S.V. Jassal, and K. Koyke were responsible for data curation; J.F. Farragher and S.V. Jassal were responsible for project administration; S.V. Jassal and G. Tomlinson were responsible for formal analysis; S.V. Jassal and M.J. Oliver were responsible for funding acquisition; S.V. Jassal and M.J. Oliver were responsible for

Figure 4. | Change in PD assistance received by study patients over time categorized into four groups according to baseline assessment results. (A) frailty (n=65 of 101), (B) functional impairment (n=72 of 110), (C) cognitive impairment (n=63 of 106), or (D) any of the three impairments (n=99 of 111). Each horizontal line represents one individual followed over the study period.
Figure 5. | Proportion of patients receiving help from a nurse (light gray) or family member (dark gray) for one or more PD-related activities over the 6-month study period. The black shaded areas represent the proportions of patients independent with all tasks.

Figure 6. | Alluvial plot showing participants’ trends in degree of assistance over time.
methodology; S.V. Jassal provided supervision; J.I. Fonseca-Correa wrote the original draft; and J.F. Farragher, J. I. Fonseca-Correa, S. Flanagan, A. Jain, S.V. Jassal, K. Koyle, M.J. Oliver, and G. Tomlinson reviewed and edited the manuscript.

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