ARTICLE

The value of patient and provider reported experiences in evaluating home-based assisted peritoneal dialysis

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Abstract

Rationale, aims and objectives: Assisted peritoneal dialysis (PD) is a proven intervention to support patients with functional limitations in performing home-based PD. Previous research has focused on clinical outcomes, but experiences with assisted PD have not been explored from the perspective of patients and providers. Through a 12-month pilot program called PD Assist (PDA), this study elicited these perspectives to improve the program.

Methods: A 12-month pilot of PDA delivered by a contracted health service provider delivered across multiple PD units in British Columbia, Canada, was evaluated. A multi-source evaluation model was used, including the semi-structured qualitative feedback in this report. Patients and their families, PD staff and caregiver stakeholders involved in the PDA pilot project, participated in the feedback process. Qualitative feedback was codified and analyzed via a thematic approach to identify values, enablers, barriers and suggestions for PDA program improvement from the perspective of patients and providers involved in PDA.

Results: All stakeholder groups advocated for continuation of PDA services. Key reported values were patient independence, enhanced psychosocial support and relief of treatment-associated burden. Consistency and communication between involved parties were reported as enablers of success, while scheduling conflicts, geographic challenges and staffing inconsistency were viewed as barriers. Areas for program improvement included the need for more personalized services.

Conclusions: Semi-structured qualitative feedback provided meaningful insights into the experiences of PDA among patients and providers that were an instrumental part of a successful pilot project and identified opportunities for further program improvement.

Keywords
Barriers, caregivers, chronic disease management, clinical communication, decision-making, enables, patient-centered care, patient experience, peritoneal dialysis, person-centered healthcare, provider experience, psychological support, values

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Introduction

In Canada, as in many other developed countries, rates of end-stage renal disease (ESRD) are increasing [1]. For patients who wish to pursue active treatment of their ESRD, the options are transplantation, hemodialysis or peritoneal dialysis (PD). In recent years, many jurisdictions have made efforts to promote home-based dialysis modalities such as PD [2] because it allows patients to remain independent, is cost effective [3,4] and is associated with favourable outcomes when compared to other dialysis modalities [5-7]. Many patients reach ESRD with high levels of frailty and physical or functional dependence [8-11] which limits their ability to
independently perform PD at home [12-15]. One method to support these patients is assisted PD which refers to the use of hired caregivers to support patients who are unable to perform PD independently [12,16]; assisted PD has been shown to yield acceptable and cost-effective clinical outcomes [12,17-25].

To explore the impact of assisted PD in the province of British Columbia, Canada, a 12-month pilot project of assisted PD service was implemented; this program was known as PD Assist (PDA). Quantitative results from this project were favorable, the results of which are reported in a separate paper [26]. The planned evaluation of this pilot followed a mixed-methods design and included an exploratory qualitative evaluation of the perspectives of patients and families who required PDA, as well as the healthcare professionals who supported them. Qualitative evaluation results are reported here and highlight important insights from these multiple perspectives as well as the recommendations for PDA program improvement that were informed by this stakeholder feedback.

A literature review of the Medline and CINAHL databases identified 16 original reports of assisted PD that were reviewed [17-32]. Of note, there is substantial variation in reported assisted PD programs; caregivers can either be volunteers such as family and friends or paid caregivers that are either privately or publicly funded [12,16,33].

Of the studies that compared assisted PD patients to other dialysis modality patients, all but one study found similar or lower rates of overall survival and PD technique survival (duration the patient remains on PD), as well as higher rates of hospitalization amongst assisted PD patients [18,19,21,22,24,26,28]. The accepted opinion is that rather than being an effect of the assistance provided, assisted PD patients have higher levels of comorbidity and frailty than their self-care PD counterparts and poorer outcomes are typically observed in these non-randomized studies [12]. One report described a competing risks approach and found higher PD technique survival but lower overall survival [25], a finding which highlights the goal of assisted PD to support patients on their chosen treatment modality up to and including end-of-life care.

Two evaluations of assisted PD focused on quality of life [27,33] and employed multiple validated quality of life assessment tools. While there was no difference in overall quality of life in assisted PD patients, there was a greater treatment satisfaction among patients on assisted PD [27] compared to other dialysis modalities.

British Columbia (BC), Canada, has higher rates of PD than any other Canadian province [1], but has found it challenging to further increase PD utilization, especially among patients with functional limitations [34]. With direction from senior renal healthcare leaders, a pilot program was initiated to determine long-term viability and feasibility of PDA as a means to address this challenge and support patients to perform PD at home.

The PDA pilot program was offered between July 2014 to August 2015 and involved four PD programs in BC. Whereas other PDA programs have been limited to smaller areas or utilized staff employed by the renal program [12,17-23,25], that solution was not possible across the multiple health authorities in BC and so an external care provider was contracted to provide this service. As the PDA program involved multiple stakeholders, it was vital to engage them early in the process to ensure program goals were satisfactory.

The clinical team at the PD units assessed patient eligibility through a standardized referral questionnaire that was designed to identify functional limitations. All patients who met eligibility criteria were offered PDA. Once enrolled in PDA, trained caregivers provided once daily home visits of up to one hour, up to seven days a week. While caregivers assisted in PD-specific tasks, PDA patients or their families made treatment decisions and managed other medical comorbidities. The supervising PD program remained responsible for clinical oversight of the dialysis treatment. This arrangement to manage PDA in the home resulted in a new set of relationships between PD patients and healthcare providers (Figure 1).

**Figure 1 PDA Pilot Stakeholders and Relationships**

![Figure 1](image-url)

The purpose of the qualitative component of this evaluation study was to assess the value of PDA from the perspective of the participating patients, family/caregivers, PD staff and external PDA service providers and to identify enablers and challenges associated with PDA that could inform optimization of PDA service delivery. A modified version of the Framework for Program Evaluation [35] was used to determine if the program provided appropriate and acceptable care, as well as to determine the value of PDA for PD clinicians and external service providers. To this end, the evaluation design
incorporated qualitative data collection methods to gather credible evidence surrounding the quality and value of the program. Figure 2 highlights six key steps that were undertaken to design, implement and evaluate the PDA pilot program.

**Figure 2 CDC Framework for Program Evaluation [35]**

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**Methods**

This semi-structured qualitative program evaluation method incorporated multiple perspectives, including patient, program and provider feedback.

**Ethical Considerations**

Participation in the interviews and focus groups was voluntary and confidentiality was maintained. The study was exempt from formal institutional ethics review under the Tri-Council Policy Statement on Ethical Research Involving Humans [36] because of its program evaluation and quality improvement nature.

**Participants & Data Collection**

Semi-structured interviews with the patient/family caregiver participants were conducted by telephone and were approximately 45 minutes in duration. Sample questions asked of patients and family members/caregivers during the interview included: (1) “How did you find out about getting some help in doing dialysis at home or some assistance with the cycler?” (2) “Can you tell me about your experience with this service of getting some help with your dialysis?” (3) “What part of your PD do you do at home?” (4) “What do you like about having the help in doing your dialysis at home?” and (5) “What involvement did you have with assisting your family member with PD prior to receiving help?”

Feedback was elicited from the PD staff and the external service provider teams through semi-structured, facilitated focus groups. Each focus group lasted approximately one hour and the PD staff and external service providers participated in separate focus groups. Sample questions asked during focus groups included: (1) “What are your experiences with the pilot project so far?” (2) “What would the ideal PDA program look like?” and (3) “What feedback, positive or negative, do you hear from the patients and families who have been receiving PDA?”

**Data Analysis**

Transcripts of the interviews and focus groups were independently coded and analyzed by 2 of the researchers to determine common themes related to the perceptions of the values, enablers and barriers of the program, as well as required assistance and suggestions for providing assistance to patients who may not otherwise be eligible for receiving home PD therapy.

The data were analyzed via a thematic process outlined by Miles & Huberman [37], in a 3-step approach: (1) data reduction, whereby participants’ responses were sorted into themes and clusters; (2) data display, whereby participants’ responses were organized and assembled; and (3) conclusion drawing/verification, whereby conclusions were deemed trustworthy, credible and reliable through repeated readings of participants’ responses, multiple group discussions and consensus development [38].

**Results**

**Participant Demographics**

Throughout the pilot, 64 patients utilized PDA service. From these, a convenience sample based on patient availability and willingness to participate identified 12 patients, 9 of whom participated in interviews regarding their experience with PDA. They ranged in age between 40 and 87 years old. The majority (67%) were male; one patient had been on PD for only 313 days, while the individual who had been on it the longest was 1890 days and the average number of days on PDA was 287 days. Table 1 summarizes patient demographic information.

In all, 9 patients and one family member/caregiver who received PDA support provided feedback. Ten PD clinic staff including representation from nursing and social work provided feedback to represent PD clinicians and to represent the external contracted service providers, 5 caregivers and 2 program administrators participated.

**Themes Identified from all Participants**

The interview and focus data were sorted into 5 main themes and related sub-categories and are summarized in Table 2. Values, enables, barriers, requested/required support and opportunities were the themes identified based on participant responses; sub-themes are summarized under each theme. Examples of narrative comments are provided to highlight salient points within each theme or sub-theme.
Table 1 Patient Demographic Data

<table>
<thead>
<tr>
<th>Patient</th>
<th>Age</th>
<th>Sex</th>
<th>Duration on PD prior to initiating PDA (days)</th>
<th>Duration of PDA service prior to interview (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>77</td>
<td>M</td>
<td>313</td>
<td>308</td>
</tr>
<tr>
<td>2</td>
<td>51</td>
<td>F</td>
<td>unknown</td>
<td>326</td>
</tr>
<tr>
<td>3</td>
<td>87</td>
<td>F</td>
<td>342</td>
<td>325</td>
</tr>
<tr>
<td>4</td>
<td>76</td>
<td>M</td>
<td>1228</td>
<td>329</td>
</tr>
<tr>
<td>5</td>
<td>83</td>
<td>M</td>
<td>307</td>
<td>286</td>
</tr>
<tr>
<td>6</td>
<td>78</td>
<td>F</td>
<td>1107</td>
<td>181</td>
</tr>
<tr>
<td>7</td>
<td>63</td>
<td>M</td>
<td>141</td>
<td>153</td>
</tr>
<tr>
<td>8</td>
<td>84</td>
<td>M</td>
<td>1890</td>
<td>338</td>
</tr>
<tr>
<td>9</td>
<td>40</td>
<td>M</td>
<td>unknown</td>
<td>336</td>
</tr>
</tbody>
</table>

Table 2 Overview of feedback themes, categories and narrative examples

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sample Patient, Family/Caregiver Comments</th>
<th>Sample PD Staff Member Comments</th>
<th>Sample APD Service Provider Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value</td>
<td>&quot;Well, it’s a big help to me. It’s a big relief to know that somebody is coming in. Not only do they set up the machine. They make sure you’ve done your weight and blood pressure and decide what type of bags you’re going to use because of your blood pressure. They are a big help. Other than just the manual part of setting it up, the knowledge that somebody is coming every day to help you is a big relief too.&quot;</td>
<td>&quot;PD Assist has helped the patients who have questions and anxiety at home to have someone to check with regarding their care. Having a caregiver in the home provides a sense of security and comfort. Many patients never get to the point where they feel confident performing PD on their own, so, having PD Assist has increased the patients’ confidence level.&quot;</td>
<td>&quot;They know that someone is coming in that knows a lot more than they do, you are giving them that sense of security that if something goes wrong or isn’t quite right that you are going to catch it.&quot;</td>
</tr>
<tr>
<td>Enablers</td>
<td>&quot;When you’re not able to get out and do much on your own, you know, you at least get somebody coming in that will talk to you for 45 minutes to an hour, you know ... She could become more than just help you know; she becomes just somebody that has a schedule with you. And you know, you have something to look forward to during the day ...&quot;</td>
<td>&quot;Communication between all partners was excellent. We always knew what was going on at the patient’s home, what was going on with the project.&quot;</td>
<td>&quot;NND extended themselves beyond the call of duty. Consistent follow up was always provided.&quot;</td>
</tr>
<tr>
<td>Enablers</td>
<td>&quot;We are minimally invasive. It is not just PD but we are also checking on the quality of life. We are the PD unit’s eyes and ears on the ground.&quot;</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Barriers
Access, communication, environment, logistics, operational support, patient factors, quality of service, scheduling, scope of service

"It's either the [external service provider] or me and the odd time, you know. [External service provider] has not been able to come for whatever reason and that generally they have a replacement. Sometimes the replacement time will conflict with another medical appointment I have."

"The limited geography that the project covers might be considered a negative"

"Getting the rhythm with a stable group of caregivers has taken time. Trying to deal with the logistics of scheduling, rotations, routes etc. was challenging at first but slowly became smoother over time as we put structure into place."

Required support
General assistance, psychosocial support, self-management support, support for disabilities, technical support

"If I didn’t have [external service provider], you know who I’d be calling (the hospital) and saying ... what about this, and what about that and ... so, it relieves the pressure on the medical facility because if a question arises, the [external service provider] can frequently answer the question and without having to call the hospital."

"I think PD Assist does provide a huge amount of social support for patients. Patients have someone coming into their home daily. The caregiver makes the PD world smaller by being a connection between all PD patients that they see every day."

"Just asking a patient “how are you feeling” is something that they are not asked on a regular basis. We can pick up things that are not normal even though to the patient, it is normal. We can see anything obvious in their changes in their health because we are there every day."

Suggestions
General assistance, logistics, process, program, scheduling, scope of service, service provision, staff training, system, quality of assistants, quality of service

"We [My family and I] hope the program continues and I hope that more people get to participate in it...And one comment I would make: I think it’s keeping people out of hospitals and allowing them to stay in their homes longer. Keeping them out of nursing homes and allowing them to stay in their homes longer."

"We know that the [quantitative] data may not support but we hope that there will be some way for the program to continue to be offered."

"The PD Assist program is so positive. The program needs to be expanded."

| Table 3 Identification of program delivery and improvement opportunities informed by the qualitative evaluation |
|-------------------------------------------------|-------------------------------------------------|
| Key Learnings from Qualitative Evaluation | Planned and/or future opportunities for PDA program improvement |
| It is feasible to gather high quality feedback from key stakeholders involved in PDA to inform program improvement. This feedback allows program planners to focus on outcomes that are important to patients/families and care providers | Ongoing assessments of patient and provider experience of PDA will be included as part of the future provincial program implementation plan |
| PDA provides valuable and acceptable support to PD patients that eases the physical and psychosocial burden of their disease. Patients who may not have otherwise been PD candidates reported feeling well-supported on by PDA. | Positive patient-reported and provider-reported experiences with PDA substantially enriched the overall evaluation and complemented quantitative outcomes to provide justification for ongoing provision of PDA to functionally-limited patients |
| Use of a third-party care provider to administer PDA was acceptable to patients/families and eased the logistic burden associated with care provision in a large and diverse geographic area | The planned provincial PDA program will continue to use a third-party care provider |
| Communication and consistency were key enablers of success for the PD staff and contracted care providers | Strong communication plans will be emphasized in the ongoing provincial PDA program. Given the value placed on consistency by patients, all efforts will be made to enable scheduling and staffing consistency |
| The current tasks supported by PDA are highly valued but some patients and providers identify a need for individualized support in other areas | In the first iteration of the provincial PDA program, the same level of support will be offered, but as the program matures, ways to individualize and enhance patient support based on direct feedback will be explored |

Values Associated with the PDA Program

In terms of quality of life, both patient and family caregiver respondents felt better supported and experienced relief from some of the burden previously associated with self-care PD. Patients valued the core PDA services and many requested more assistance from PDA providers with tasks such as blood pressure, blood glucose
and dietary assistance. A common value expressed by both patients and PD staff was the maintenance of independence enabled by PDA and the psychosocial support that the home visits provided. In many cases, feedback indicated that PDA service enabled patients to receive home-based PD where it might otherwise not have been feasible. At the program level, health authority participants acknowledged that PDA closed existing gaps in renal care, enabled surveillance of patients’ health with enhanced self-management support and aided with the transition of patients commencing PD.

**Enablers Associated with the PDA Program**

PD staff and external service providers were generally pleased with the partnership and implementation process, as well as with ongoing communication that facilitated program outcomes. Care providers perceived the service as responsive, timely and well-suited to individual needs and identified that utilizing an external care provider addressed logistical challenges around home-based care delivery that would have been difficult for existing PD unit staff to overcome without compromising their other clinical duties.

**Barriers Associated with the PDA Program**

Approximately half of the patient respondents commented on occasional scheduling conflicts and inconveniences due to unanticipated changes in visit times that affected their daily routines. When barriers were explored with the PD staff, they described both the inability of the external caregiver to provide troubleshooting support for patients with impaired cognitive function, as well as barriers with supporting patients residing in geographical locations not served by the PDA pilot. Other barriers included the clarity around the role and responsibilities of the caregivers and inconsistency in caregiver assignment.

**Required/Requested Support Associated with the PDA Program**

Aside from the core dialysis-related tasks of PDA, most respondents commented on the needs for general assistance, including assistance with lifting of heavy dialysis solution bags, clean up and keeping track of supply inventory. Two patients noted the importance of blood pressure monitoring offered with the service and 2 different patients described the value of expanding caregiver support to assist with PD treatment decisions, medication support and assist with PD catheter exit site care. Several of the patients and a family caregiver acknowledged the need for addressing health-related inquiries and providing increased psychosocial support at the time of the home visits. Consistent with patients’ feedback, one of the nurse participants highlighted a possible role for psychosocial support via facilitating peer connections between PDA patients.

**Incorporating feedback into PDA program evaluation and ongoing program planning**

When asked about the future of the PDA program, all stakeholder groups strongly advocated for continued provision of PDA services. This qualitative feedback provided an informative complement to the quantitative outcomes assessed in the pilot evaluation and the resultant multi-source evaluation was viewed positively by key stakeholders and decision-makers in the renal care community, all of whom supported continuation and expansion to a standardized provincial PDA program. In accordance with the evaluation framework (Figure 2), feedback was also employed by the PDA development team to inform PDA service improvement in ways that would be meaningful to both patients/families and healthcare providers. Specific insights gathered from the qualitative feedback along with the resultant improvements to PDA service provision inspired by stakeholder feedback are described in Table 3.

**Discussion**

This study elicited qualitative feedback from all key stakeholder groups involved in the PDA pilot project and reinforces the value of PDA as well as the feasibility of using external service providers to deliver PDA services to patients distributed throughout multiple health authorities. Combined with the quantitative PDA evaluation which demonstrated clinically effective support of functionally-limited PD patients at a cost that is lower than the alternatives [26], the two components of the mixed-methods PDA evaluation demonstrated that PDA is an effective and acceptable way to support patients who desire PD but would be unable to perform home PD without assistance.

From a chronic disease management framework, this study highlights the unique nature of PDA and the complex relationships between patients, family/caregivers, PD staff and external PDA providers. Despite the complex interactions between stakeholder groups, this study demonstrates that it is feasible to use a qualitative evaluation framework to elicit meaningful patient and provider feedback to inform program development. Participants clearly advocated for continuation of the program and provided insights into potential areas for further program development that are patient-centered and that bridge the gaps that might exist between patients, family/caregivers, PD staff and external PDA providers.

From the patient perspective, retention of independence and autonomy were key values to maintain in home care programs such as PDA. Another important value expressed by patients that was not previously apparent to PDA program staff was consistency in both staffing and scheduling; this will be incorporated into further PDA planning and aligns with previous studies wherein program consistency was associated with higher patient satisfaction and considered an integral component of patient-centered care provision [39-43].
From the staff perspective, communication was a key enabler to the success of this program where caregivers assist patients in delivery of a complex treatment modality such as dialysis in the home setting. This is consistent with existing literature which demonstrates that supporting strong communication in chronic disease home care management is challenging, but an integral component of providing patient-centered care in the home [43,44]. It is also worth noting that PD unit staff found that use of a contracted external service provider to deliver PDA rather than using dedicated PD unit staff was an enabler of program success as this arrangement allowed the program to serve a large and diverse geographic area without unduly adding to the already full workload of the PD unit staff.

Both patients and staff valued the presence of additional caregivers in the home. PDA patients valued the reduced feeling of isolation that is otherwise associated with performing independent therapy at home and staff valued having an ‘additional set of eyes’ to keep track of patients. PD staff also appreciated the reduced sense of patient isolation and felt that this may reduce burnout amongst patients and patients’ family/caregivers.

All participants felt that expanding or individualizing the criteria for support or the types of support provided would potentially enhance the value of this program. As the PDA program expands, it will be important to consider the individual needs of patients rather than adopting a ‘one size fits all’ approach to PDA. This evaluation confirms that structured patient and provider feedback is a useful way to gain insights into individualized needs that can be translated into actionable items for program improvement.

There are several limitations to this study. Participants’ availability for interviews, focus groups and for response validation limited the ability of some PDA patients to participate in the feedback process. Given the researchers’ previous or current experience with the PD programs and/or external service providers, there was a potential for reporting bias which may have altered the feedback provided. Interview and focus group questions were developed for program evaluation purposes, but were not validated for reliability. Due to time constraints, validating participant responses through subsequent processes was not undertaken and might have strengthened the validity of the study.

Finally, the sample size of this qualitative evaluation was not large, but it represented a cross section of patients and care providers associated with a PDA program within two health authorities. Additional studies that include larger sample sizes across multiple health authorities could enhance understanding of PDA and program outcomes. Future assessments of a mature program may also yield insights about the program that were not apparent in this short-term evaluation of a time-limited pilot program.

Conclusion

This study presents the use of a structured qualitative evaluation framework to explore the perspectives of patients and their PDA providers which offered insights into the unique experiences of each group with an assisted PD program. Participant responses provided valuable evidence to inform PDA program planning and development. Furthermore, participants agreed that PDA provided patients with a viable means to perform PD where it may not have otherwise been feasible and thus allowed them greater independence. Results from this evaluation study were combined with previously reported quantitative outcomes to guide ongoing quality improvement of PDA services and confirm that a well-designed PDA program can provide effective, acceptable and person-centered support to PD patients in the home setting.

Acknowledgements and Conflicts of Interest

We would like to thank all patients, families and the PDA care team who participated in this pilot and offered their invaluable feedback for the evaluation. We also gratefully acknowledge all members of the PDA Committee for their participation in this work and Brenda Lee of the BC Provincial Renal Agency for her assistance with conducting and transcribing the interviews. We declare no conflicts of interest.

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