Innovations in Hemodialysis Care: An Evaluation of Quality and the Patient Experience

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Lori Harwood, RN(EC) PhD¹, Darrin Pye, RN, MN¹, Elizabeth Clinton¹, Kyle Goettl, RN, BScN, Med, IIWCC², April Mullen, RN, BSc, MHM¹, and Janice Qubty, RN, BScN²

Abstract

Hemodialysis (HD) performed in a tertiary care facility is the most prevalent and costly treatment for end-stage renal disease in Canada. This life-sustaining treatment is usually performed thrice weekly in an in-center facility. When people on HD also require a rehabilitation/complex care inpatient program, the burden of transportation for dialysis is immense to both the patient and health-care system. To improve the patient experience, create efficiency, and reduce travel costs, the renal team and a team from a rehabilitation/complex care center collaborated to provide HD services in the rehab/complex care setting. A patient/family representative was involved in all aspects of the design through to evaluation of this project. This study used realistic evaluation to examine the efficacy of this program from the perspective of the patient experience, HD staff, rehab/complex care staff and costs. The decreased travel with having dialysis on-site and adequate resources in the HD unit were the mechanisms for success in improved patient experience, quality of life and rehabilitation patient outcomes, decreased costs as well as increased communication and satisfaction.

Keywords

access to care, patient engagement, patient satisfaction, transitions of care, hemodialysis, rehabilitation

Introduction

People with end-stage kidney disease require the lifesustaining therapy of dialysis or a renal transplant. The most prevalent form of dialysis in the United States and Canada is in-center hemodialysis (HD) requiring the person to travel to the dialysis center 3 times a week (1). People on HD have decreased levels of physical functioning which is predictive of poor patient outcomes (2). In a worldwide sample of 7226 HD patients, 81% reported the ability to independently perform some basic activities of daily living (ADL; eating, dressing, bathing toileting, and transfers); however, only 36% of patients were able to perform all the tasks of ADL (3). The most common problematic areas were housework, handyman work, getting to places beyond walking distance, and doing laundry. This functional dependence did not discriminate by age and was strongly associated with mortality.

The reasons for functional dependence are multifactorial. Fatigue is one of the most common and bothersome symptoms people on HD experience affecting their physical (4–6) and emotional functioning. People on dialysis are often more frail (7–9) and have lower exercise tolerance, functional

capacity, endurance, strength, and more muscle wasting as compared to peers without kidney disease and those with chronic kidney disease not yet on dialysis (10). People on HD may also have preexisting cardiac problems and diabetes which further contribute to their symptom burden. Unfortunately, very few people on HD are able to maintain good physical condition and deterioration is common (11). In addition, once in a rehabilitation (rehab) program, the time requirements for HD thrice weekly can further impede an individual's progress. Yet, people on dialysis can benefit greatly from rehabilitation programs specifically designed to meet their needs (12).

Corresponding Author:

Lori Harwood, London Health Sciences Centre, Victoria Hospital, Rm A2-335, 800 commissioners Road East, P.O. box 5010, London, Ontario, Canada N6A 5W9.

Email: lori.harwood@lhsc.on.ca



¹ London Health Sciences Centre, Victoria Hospital, London, Ontario, Canada

² Parkwood Institute, Main Building, London, Ontario, Canada

Various types of programs exist to address this problem. Some HD units include exercise programs in their dialysis units with the exercise taking place while the person is having their dialysis (13). In a survey conducted with 58 dialysis centers, 14% of these centers indicated that they had this type of exercise program (13). Alternatively, some specialized programs exist where HD is offered in complex chronic care and/or rehabilitation settings. However, to our knowledge, these programs do not exist beyond some of the largest urban areas in Canada. As a result, in most other areas, people who receive inpatient rehabilitation/chronic care are required to travel to the dialysis center. This is costly and most likely increases fatigue, delays rehabilitation, contributes to 2 fragmented medical teams, negatively impacts on caregivers and decreases HD patients' quality of life.

There is little published data evaluating existing dialysis rehabilitation/complex care programs. Where data are available, the results have been positive. A 5-year review of 148 patients who received HD at the same facility as their rehabilitation or chronic care reported that 34% (n = 50) were discharged home, 35% (n = 52) died, and 13% (n = 19) were still residents in chronic care (14). The most common problems were related to HD vascular access which necessitated temporary transfer to the acute care center. A cost analysis of this program showed a savings of CAD37 022 per patient year (15). A more recent program evaluation of HD in a geriatric rehabilitation setting found improved functional gains for this population with a total of 70% of patients discharged to community and 12% of patients with substantial gains in function but unable to return to their home for social/medical reasons (12). A long-term follow-up of those discharged revealed that 85% were still in their homes or died while residing in their own homes. These existing evaluations tend to focus on elements of the program (quantitative outputs) rather qualitative process outcomes from the patient/family and health-care providers prospective.

Program Design/Setting

The impetus for the development of our program was the "patient voice." A family member representative on our renal program patient/family advisory council voiced the need to decrease transportation for HD when a patient is admitted for rehab. The family representative was integrated in the development of this program with partnerships in fundraising by telling their story, planning and implementation in the design, use of space and layout, selection of equipment and furnishings of the dialysis unit, service scheduling decisions, research, evaluation, and presentations about the program.

We developed a program for people on HD who require a variety of rehabilitation services based on patient needs such as geriatric rehabilitation, stroke, and amputation rehabilitation as well as those living in the facility for complex continuing care and long-term care for veterans. To achieve high-level health care (16), that is, improving the patient

experience, creating efficiency, and reducing costs, the renal team from London Health Sciences Center (a patient representative and the rehab team from Parkwood Institute Main Building (Parkwood) at St. Joseph's Health Care London, Ontario, collaborated to provide HD services for patients admitted in the rehab/complex care setting. Prior to the opening of this dialysis unit, rehab inpatients who required HD were transported 3 times a week to the acute care setting for their dialysis. This added up to a significant number of trips per year (1400-2600) using costly medical transportation services. The goals of providing on-site HD were to improve the patient experience and enable patients to meet their rehabilitation and recovery goals by decreasing the detrimental effects of transportation on patient fatigue levels as well as to create efficiency by reducing transport costs. A patient-centered approach was used in the design, delivery, and evaluation of this high-level program which includes health outcomes meaningful to patients relative to the cost of delivering this care (16). The purpose of the evaluation of this health service was to understand the patient/caregiver experience, and complexities and nuances associated with the program which is lacking in the current literature.

Research Objective/Aim

Our objective was to conduct a theory-driven, patient-oriented research study to evaluate the patient experience, financial impact, and operational evaluation of this proof of concept project (created with existing funding) of providing HD in the rehab/complex care facility. The specific objectives were (a) to qualitatively evaluate on-site HD in the rehab/complex continuing care setting from the perspectives of the patient/family and health-care professionals; (b) to survey the opinions and perspectives of the rehab/complex continuing care staff on this service and the impact on the individuals' goals of care; and (c) to compare the costs of this initiative with the previous model of care which included transportation from the rehab/complex care center to the acute care HD center.

Method

Realistic evaluation (RE) is an established method of program and policy evaluation (17) and was used for this study as it is well suited to meet the objectives. Realistic evaluation is a process oriented inquiry which aims to discover complexities; not "if" the program works but "what works, in which setting, for whom, under what circumstance(s) and why" (18). The result of RE is a midrange theory that takes into account how context influences interventional mechanisms which produce both intended or unintended outcomes (19). The method starts with a theory which is refined by examining the mechanisms which represent peoples' actions, choices, behaviors, and/or reactions (18). The results are often reported in a context–mechanism–outcome (CMO) diagram. In our evaluation, the starting theories or

hypotheses were that dialysis on-site decreases travel and should improve the patient experience. How does it improve the patient experience/if not why? How does providing dialysis services in the rehab setting impact on the work life of the health-care staff? Does/how does the program have the associated predicted cost savings?

Verification strategies (20) were used to ensure rigor of the qualitative component of the study. The primary investigator of this study was involved in the design of the unit as a steering committee member but not directly involved in the patient care delivered. This provided a perspective of the context of the program. The research team included a family representative and investigators from both the dialysis program and the rehab center which we believed enhanced the design of the study and credibility of the interpretations of the findings. The family member on the research team also had knowledge of navigating rehab and the need to travel for HD. Other verification strategies used in this study were methodological coherence with RE, appropriate sampling, ongoing review of concurrent data collection and analysis for all 3 data sources which allows for researcher responsiveness. The preliminary data analysis was also shared with all members of the research team for discussion and consensus of results.

Patient/Family Interviews

Purposeful sampling was used. Once ethical approval from the local research ethics board was obtained, patients who received or were receiving HD in the new unit and their family/caregivers were approached to participate in an interview about their experience with this service. Participants were asked about their perceptions of how the new service impacted their rehab/complex care and quality of life. Data saturation guided the sample size when we determined that further interviews would not reveal more new information. This was reached at 12 interviews. The interviews were conducted face-to-face, employed a realist interviewing style (18), were audio-recorded, and transcribed literally. The premise of realist interviewing is that the researchers' theory drives the exchange of ideas and the information gathered helps to validate, refine, or refute the theory (18). Directed content analysis was used to find common themes and categories which provided an understanding of the phenomenon in regard to the CMO (21).

Hemodialysis Staff

The dialysis staff providing the HD services were purposefully asked to participate in a focus group to gain insight into their experiences, challenges, and perceptions of the program, impact on their work life, and their perceived impact on the patient. Two focus groups were held and 2 individual interviews were required as these staff were unable to attend one of the focus groups. The focus groups were audiorecorded and transcribed literally. Content analysis was used to analyze the transcripts for common themes and categories

which contributed to the understanding of the phenomenon in regard to the CMO.

Rehabilitation/Complex Care Staff

The rehabilitative and complex care staff were asked to complete an online survey regarding their impressions of the impact of providing HD at the patient and systems levels as well as conditions of their own work life. An e-mail was sent to staff after each patient was discharged from rehab/complex care requesting they complete the questions as they applied to that particular patient's admission. Content validity and readability of the survey were examined by one of the investigators who is an expert clinician in the area of rehabilitation. An online survey was determined to be the best method to capture data as there were a large number of staff on many different units who may/may not have been involved in the care of the patient. The staff could then self-select if they felt they had enough exposure to the patient and situation to respond. The survey contained dichotomous questions (yes/no) and open-ended questions. The dichotomous questions were analyzed by calculating those agreeing/not agreeing to the statement. The data from the open-ended comments were analyzed as qualitative data. Data collection was determined to be complete when further requests to complete surveys did not yield further completed surveys.

The data from the interviews, focus groups, and surveys were analyzed separately and concurrently. The data were then analyzed as a whole to examine common themes and categories, in addition to the context and mechanisms which contribute to the program outcomes (see Appendix A)

Evaluation of Costs

To evaluate the costs and utilization of the service, there was ongoing recording of the number of patients and dialysis treatments performed each month with the associated costs. These costs were examined on a monthly basis and reviewed regularly for accuracy. Comparisons of travel costs incurred by the rehab hospital were compared to preprogram costs.

Results

In total, 12 (1 patient/family dyad (n = 2), 1 family, and 9 patients) people were interviewed. A total of 43 surveys were completed by the rehabilitation/complex care team members staff from 12 different roles including: registered practical nurses (21%), registered nurses (19%), registered dietitians (12%), therapeutic recreation therapists (12%), physical therapists (10%), nurse practitioners (5%), occupational therapists (5%), social workers (5%), medical doctors (5%), occupational therapy assistants (2%), personal care providers (2%), and pharmacists (2%). Seven HD nurses participated in the focus group.

The CMO analysis was grouped into 3 overall common themes that patients and staff described as outcomes of the program (see Appendix A). These were as follows: (a) improved patient and family experience and quality of life, (b) improved patient health outcomes, and (c) HD staff quality of work life. Support for the common themes and mechanisms are described below using the words of the patient, family, rehab/complex care staff and dialysis staff with further supporting exemplars listed in Appendix B.

Context

The context for this study was derived from the investigators' knowledge of the program, setting, processes and data sources as well as reflections as part of the steering committee member, and discussions with the research team. A philosophy and culture of patient-centered care was present in both organizations as demonstrated by the responsiveness to the need for the program brought forward by the patients/ family. This is also demonstrated in the implementation of this program with the goal to improve the patient experience by providing HD on-site in the rehab setting. This research is an example of patient-centered outcome research with a family member being present throughout all stages of the research as well as being part of the planning for the design of the program including site visits and input into the design and equipment in the unit. This program was designed as a proof of concept project, recognizing the need for an evaluation while also acknowledging the uncertainty regarding the permanency of the program. There are many instances of patients and staff commenting on the overall pleasing design, equipment, and ergonomics of the unit.

Improved Patient Experience and Quality of Life

Having HD on-site relieved the stress of traveling for dialysis which had a positive impact on patients' entire experience. Some of the first patients interviewed had the experience of traveling for dialysis before the new unit opened. Postamputation, 1 patient commented about the pain associated with the travel as "Bumpy. It's a rough ride between those things [transport vehicles] and not having very good shocks and the roads being so beat-up. Pretty rough ride" (Patient 4). Another patient commented on waiting for the medical transport and late evenings which contributed to the fatigue:

We were designated to be patients in the evening which was around 5:30 [p.m] and we wouldn't get finished at 10:30 [p.m] sometimes... And sometimes it was a problem getting back on time. Sometimes they didn't get the message and there were nights that we were [incenter unit] until 12:30 [a.m]" (Participant 5).

The travel also had negative consequences for nutrition:

... And then I'd get back and it would be like an hour past supper time. My tray would be sitting on my table. The soup was cold. The meal was cold. It's really hard; you lose your appetite after so many times... It was great once it changed to staying at Parkwood and having my dialysis. The transferring back and forth was very costly to the hospital, and it was at night in the winter when it was cold and snowing and freezing. You know, who really wanted to go out then (Participant 5).

When surveyed, 100% (n = 41) of the rehab/complex care staff reported the on-site HD service positively contributed to the patient's quality of life. They frequently reported benefits of the program on patient's quality of life such as "Less time in transit, more time for rehab. Pt less fatigued" (HCP 39) and "The convenience for the patient to just have to go up one floor to receive dialysis allows the patient to meet their dialysis needs in the same building as their rehab needs" (HCP 20).

Improved Patient Outcomes

In addition to a positive patient experience and improved quality of life, other positive outcomes were realized from not traveling such as more opportunities for improved nutrition due to fresher food, more timely medication administration, less stress, and less fatigue with more time available for rehabilitation and rest. All of which are important factors for rehabilitation. The rehab staff also noted less disruption by not having to use the external medical transportation. Many patients and staff commented on the calm pleasant environment in the dialysis unit "It was very nice, very bright and airy. Quieter because there were only five beds...and the two girls [nurses] that were sort of in charge on a daily basis were from here [in-center] and I knew them both" (Patient 5). The rehab/complex care staff (95%) reported that having HD on-site positively contributed to the patient meeting his or her goals of care. A rehab staff person respondent described the overall positive effects as:

Less stress on the client. Able to get proper rest after treatment without becoming further exhausted waiting for inter-hospital transport and was then better able to participate in therapy. Less stress on staff, not having to book transport, able to provide meds in a timely fashion related to no delays in transport times to and from dialysis. Incredible improvement in communication with the staff providing dialysis treatment... patient concerns were addressed more quickly (HCP 43).

Communication is an important element in patient care particularly with this program when 2 different organizations are involved. The rehabilitation staff were also asked their opinion if having HD services on-site improved communication between the dialysis team and rehab staff (n = 38) for patient care issues. Improvement was noted by 66% of respondents, versus 5% who responded with no improvement, and 29% reported communication remained the same. The staff reported that having the dialysis on-site facilitated the communication between centers. The rehab/complex care staff could go to the unit and talk to the staff face-to-

face which also increased staff understanding of each settings expertise. For example,

It's easy to go to the unit and discuss concerns with the staff there. Somehow it feels like it's part of our rehab process and I am more likely to pick up the phone and make a call to ask questions or express concerns (HCP 21).

Hemodialysis Staff Quality of Work Life

Compared to the nurses who work solely at the in-center unit, the HD nurses are required to travel to the rehab/complex care setting thrice weekly to perform the dialysis. Also, the nursing duties in this unit are more autonomous and different such as the responsibility for opening and closing the unit, ordering the supplies and medications, and following correct start up, disinfection, shutoff, and daily maintenance of the dialysis machines and water systems. Despite all of these differences, the staff felt prepared, had the appropriate resources, enjoyed providing this service to patients in this setting, and reported providing continuity of care such as "You also have the consistency with the smaller staff knowing the patients better" (Nurse 1).

The environment was pleasant to work in such as, "No, there's nothing to improve. It's a nice quiet place to come, it's not like the big spot [in-center unit] like across the street. No, I wouldn't change anything" (Nurse 8). The HD staff expressed satisfaction with the infrastructure, furniture, human resources, and equipment available. Staff reported adequate orientation, staffing levels, teamwork, safety, and autonomy as factors that affected their job satisfaction at the unit.

Associated Costs

The utilization and associated costs of operating this service were recorded and reviewed on a monthly basis. The rehab/ complex care facility reported monthly cost savings. The area that predicted the most cost savings was in regard to the reduction in medical transportation between the 2 organizations. The unit did not always operate at full capacity during the study period due to low patient volumes. Low patient volumes were due to many factors such as the patients not meeting the eligibility criteria relating to medical stability. These patients were required to travel for their dialysis whereby cost savings were not achieved. Subsequently, the eligibility criteria were reexamined. On occasion, the number of patients admitted to rehab requiring dialysis dropped below the previously determined number in the service agreement that the unit would operate requiring some transportation back to the acute care center for dialysis. The dialysis service was also unavailable for a few treatments due to a lack of HD staff available and the patients were required to travel to the incenter unit; however, this was a very rare occurrence. Costs were neutral for the renal program based on the Clinical Service Agreement and existing government dialysis funding models.

Discussion

This study framed in RE was conducted with the objective of evaluating HD on-site in the rehabilitation/complex care setting from the perspectives of the patient/family and health-care professionals. Common themes representing the program outcomes were reported as well as the context and mechanisms (ie, actions, choices, behaviors) that contributed to the success of this program. The initial theory that the program would decrease patient travel and fatigue and improve their experience and quality of life was realized. The program also positively contributed to patient outcomes and the likelihood of meeting their rehab goals. Our aim with this program was that the staff would not be negatively impacted upon. This was also realized on the rehab/complex care units due to less disruption caused by patient movement between the 2 organizations and an improvement in the dialysis staff quality of work life. The aim was that this high-level service would also have associated cost savings. Modest cost savings were achieved. The program was also noted to improve communication between the 2 organizations for patient care, and this has important implications for patient safety and teamwork.

The results of this study indicate that having HD on-site reduces fatigue; an essential factor of rehabilitation and quality of life. The importance of this finding cannot be understated as fatigue is one of the most prevalent and debilitating symptoms with kidney disease and can have an impact on a patient's energy level. Furthermore, mental fatigue makes it difficult to focus and remember conversations (22). These factors are important in the rehabilitation process in being able to participate in strengthening programs, regain the ability to perform ADL, and focus one's attention to learn/relearn new tasks. Having dialysis on-site in a calm environment also contributed to more efficient use of the patients' time and decreased travel time allowing for more time for rehabilitation and/or rest.

The context of this study is an example of patient-centered care and patient-centered outcome research. A patient/family representative was involved throughout the design, planning, opening, and evaluation of this service. This study provides support for patient-centered care in designing and evaluating patient programs. The results of this program evaluation were very positive and having a patient representative involved throughout the process may have greatly contributed to the success of this program in meeting patient and family needs. The successful partnership between the 2 health-care organizations established the context in which the collaborative dialysis unit could be implemented.

Hemodialysis care is costly to deliver and this analysis showed cost savings. More specifically, cost savings were realized by the rehab/complex care center with respect to travel to and from HD. This is a very desirable high-level service which increased patient experience, quality of life, and outcomes while decreasing costs that others in this situation could emulate. We continue to examine ways to

increase utilization of this service. Health-care providers believed that on-site HD positively contributed to positive patient outcomes and meeting their goals of care. Quantifying if or by how much HD on-site decreased the rehabilitation length of stay or increased the patients' rehabilitation was beyond the design and scope of this study.

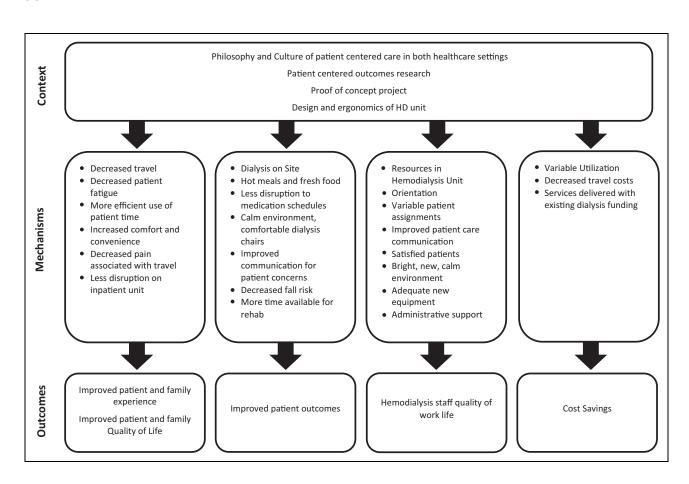
A limitation of this study is the nonrandom sampling strategy used. As a result, there is a potential for selection bias. The sample of patients, families, and staff were also self-selecting in that they volunteered for the study. They were aware of the purpose of the study and may have wanted the program to succeed and this may have influence their willingness to participate in the study and their comments. It is important to note that no additional staff were hired specifically for this program and therefore a negative "proof of concept" evaluation would not have resulted in any job loss. Some benefits associated with the "newness of the unit" such as up to date equipment and new technology may have contributed to some of the positive outcomes and

this may change over time. However, the calm environment and brightness of the unit due to the large windows should not change over time. Another limitation is the single setting of the study. The study was conducted in 1 geographic area across 2 collaborating facilities. The characteristics of this partnership may not be generalizable to other organizations or feasible to implement in other facilities or geographical areas.

Conclusion

Providing HD services in a rehabilitation and complex care facility improved the patient experience, quality of life, and health outcomes while decreasing health-care costs. This high-level service was delivered with minimal impact to health-care providers. An improvement in communication between the 2 clinical teams and the job satisfaction of the HD staff were realized. Opportunities exist to increase the utilization of this service in the future.

Appendix A. Results, context-mechanisms-outcomes.



Appendix B. CMO Analysis Supporting Quotes.

Outcomes	Exemplar Quotes
Improved Patient Experience and Quality of Life	"The convenience of being here in Parkwood and then coming right here, was superb." (Patient 3) "I think having it here is ideal. He's [father] really happy with it which makes us extremely happy with it. And I think because it is so centrally located and he doesn't have to, you know, put his coat on, get out, you know, all those things. It's the ideal situation for anyone who has to have dialysis to have it here". (Caregiver 8)
	"Oh, it was great, because I only had to go up one floor and I went up and dialyzed and when I got down back to my room my supper was ready. So, it was fantastic, I didn't have to go outside, like it was cold in the wintertime doing this As I say, I felt more relaxed over there [rehab setting], it was more calming and over here [in-center unit] it's just everybody's so busy it's just, it was just so different over there." (Patient I)
	Patients are more able to participate in their daily therapies. I found they had more time available to them whereas before they often would be wasting time waiting for rides, etc. I have also found our patients are not as tired as well (HCP 10).
Improved Patient Outcomes	"The patient does not have to waste his time waiting for transportation to and from hemodialysis. Patient can have a more restful sleep, does not have to be woken up early for meds and to get ready to go to hemodialysis." (HCP 5)
	"From a pharmacist's viewpoint, patients returned to their unit promptly after dialysis which facilitated medication administration in a timely fashion. Better for overall pharmacotherapy and patient care." (HCP 19)
	"We easily communicated with the team here, and our patient felt that in-house dialysis felt more a part of her program here. My student was able to visit our patient during her time on the dialysis unit which improved the patient experience and contributed to the student's placement experience." (HCP 3)
Hemodialysis Staff Quality of Work Life	"I like the environment of the Parkwood unit as it is quiet and has a beautiful open view and provides a lot more natural light from the large windows." (Nurse 6)
	"There it's such a nice environment for the patients and the consistency with their
	Staff and us, and their staff come back, help, like if we need help, like a couple
	are, well the one's a ceiling lift, Hoyer lift, and so they'll come and help with that,
	or if the other nurse is free the two of us can do it together." (Nurse 1)

Abbreviation: HCP, health-care provider.

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ORCID iD

Lori Harwood https://orcid.org/0000-0001-9612-1605

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Author Biographies

Lori Harwood is a nurse practitioner in the Adam Linton Hemodialysis Unit, at Victoria Hospital, in the South West Regional Renal Program at London Health Sciences Centre, London, Ontario, Canada.

Darrin Pye was the research assistant for this study, at London Health Sciences Centre, London, Ontario, Canada.

Elizabeth Clinton is the co-chair of the Renal Patient and Family Advisory Committee in the South West Regional Renal Program at London Health Sciences Centre, London, Ontario, Canada.

Kyle Goettl is a nurse clinician in the Amputee and Spinal Cord Rehabilitation Program at Parkwood Institute, Main Building, London, Ontario, Canada.

April Mullen is the director of the South West Regional Renal Program at London Health Sciences Centre, London, Ontario Canada and regional director of the South West Regional Renal Program of the Ontario Renal Network.

Janice Qubty is the coordinator of the Specialized Geriatric Services, Regional Geriatric Program, Parkwood Institute, Main Building, London, Ontario, Canada.