

“Need a Ride?”

Improving Transportation to Dialysis Treatment (Part 1)

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This article describes a planning and evaluation process that identified existing challenges related to dialysis transportation in one Northwestern state. The strategies, best practices, and community resource ideas that came from participants in this process were numerous and can be grouped into four categories: education, advocacy, recruitment, and outreach. The planning process resulted in a transportation pilot project. Social workers developed and implemented these solutions. This process required making time, taking a step outside of one's normal caseload, and working with others to help implement change. The results offer promising practices that can be replicated elsewhere.

INTRODUCTION

Transportation problems are one of the most common barriers faced by low-income communities to accessing timely and necessary medical care (Rust, Ye, Baltrus, Daniels, Adesunloye, & Fryer, 2008). For hemodialysis patients in particular, good health depends on reliable transportation (Iacono, 2004). This article contributes to a growing body of literature showing that transportation is associated with greater quality of life, and supports improved patient outcomes, rather than merely moving people from “point A” to “point B” (Audino & Goodwill, 2014; Bambra, Gibson, Sowden, Wright, Whitehead, & Petticrew, 2010; Burkhardt, 2006; Hewlett, Atchley, Otto, & Hager, 2004; Rosenbaum, Lopez, Morris, & Simon, 2009; Silver, Blustein, & Weitzman, 2012; Syed, Gerber, & Sharp, 2013; Tucker, 2010).

One study funded by the Transportation Research Board of the National Academies showed that providing non-emergency medical transportation to those who are “transportation disadvantaged” can significantly reduce emergency room and hospital expenditures, thereby leading to better health outcomes and a higher quality of life for patients, as well as reduced medical costs (Wallace, Hughes-Cromwick, & Mull, 2006). This same study included a cost-benefit analysis of medical transportation services for patients with 12 specific conditions, and concluded that in the case of disadvantaged dialysis patients, providing transportation would prove highly cost-effective with improvement of resultant patient quality of life.

The growth in end-stage renal disease (ESRD) incidence and the decreased mortality rate in this population (USRDS, 2013) create increased burden on a transportation system that was not designed to accommodate life-sustaining treatment trips. It is often difficult for dialysis clinic staff to navi-

gate the transportation options available and support patient access to reliable transportation.

Transportation to and from treatment involves a tension between access and cost. According to the USRDS (2013), the majority of hemodialysis patients require the support of others to get to and from dialysis treatment, with 66.8% of patients being driven, including by ambulance. Nearly 8% of hemodialysis patients use public transportation, such as bus, subway, train, or taxi, while only 25.3% drove themselves or walked. Transportation coordination for patients who receive dialysis relates to medical coverage of dialysis care, because it affects the patient's out-of-pocket expenses.

Currently, there are three primary sources of medical insurance that provide coverage for kidney patients: Medicare, Medicaid, and private insurance plans. According to the USRDS (2013), nearly 84% of people receiving dialysis have Medicare coverage (through Medicare fee-for-service, Medicare-Medicaid dual coverage, a Medicare HMO, or Medicare Secondary Payer coverage). Medicare does not have a non-emergency medical transportation benefit. Medicare only covers ambulance services for medical emergencies, or if alternate forms of transportation could endanger the patient's health. Individuals who are eligible for both Medicare and Medicaid (or “dual-eligibles”), and Medicaid beneficiaries are eligible to use Medicaid's transportation in their local area.

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RIDE CONNECTION

Transporting patients to and from dialysis appointments presents both a challenge and an opportunity. More practical approaches are needed to support dialysis patients' transportation needs while also reducing costs. Ride Connection, a non-profit transportation provider in the Portland metropolitan region of Oregon, convened multiple partners and engaged in a participatory planning and evaluation effort to create a dialysis transportation pilot project with input from hemodialysis patients, social workers, drivers, and others involved in the care of patients. Ride Connection's mission is to link accessible, responsive transportation with community needs. For more than 25 years, in collaboration with 30 community partners, Ride Connection has provided customer-focused, safe, reliable transportation options for individuals in Clackamas, Multnomah, and Washington counties in Oregon. This includes rides to hemodialysis and other non-emergency medical transportation (NEMT) trips. In recent years, it was evident that in Ride Connection's capacity as a coordinator and provider of transportation, there was a need to address the difficulties associated with transportation for patients receiving dialysis treatment. Rider feedback over the years indicated that current transportation options were not adequately serving the needs of patients receiving dialysis treatment. In addition, transportation partners reported that the specific needs of patients receiving dialysis made transportation more challenging than for most passengers. Finally, there was evidence that there was a growing number of trip requests for dialysis transportation, which resulted in a shift in capacity to accommodate the requests.

In Oregon, over one quarter of new patients who receive dialysis are covered by Medicare only, and therefore their transportation costs are out-of-pocket. Further, as the National Kidney Foundation has noted, "in order to qualify for Medicare ESRD benefits, one must contribute to the Social Security system for 40 quarters. Thus, many individuals with kidney failure may not be eligible for Medicare" (Becker, 2010). Consequently, 7% of patients are not covered by any insurance, and therefore must also pay out-of-pocket for their transportation. In addition, 80% of new dialysis patients are not eligible for Medicaid and are not covered for transportation to and from dialysis, the National Kidney Foundation noted.

Unfortunately, the Affordable Care Act has not made any positive impact on coverage for medical transportation. The Americans with Disabilities Act (ADA) service is available in many communities with a public transit system. These rides, which are curbside-to-curbside, have to be scheduled in advance, and last minute changes cause delays in pickups. The system is a shared-ride option, and the trip's purpose cannot be taken into consideration when rides are scheduled (i.e., a trip to the mall is considered the same priority as a trip to dialysis). In addition, there is a cost to the customer for this service, and often these rides are not available before or after business hours (limiting the dialysis shift riders can use with this service).

CASE EXAMPLE

Social workers help patients who have challenges with access to treatment. Patients' experiences vary in difficulty, and social workers try to provide patient-centered approaches to resolve psychosocial barriers to care. Mr. C's experience is just one story, but represents challenges that social workers try to work through on a regular basis. Even when transportation options are available, they may not work for a patient's individual needs:

At the early time of 4:15 a.m., Mr. C prepares his dialysis bag for the day's treatment. He is not able to drive himself to treatment. His home is just four miles from his destination. Dialysis treatment does not begin until 6:00 a.m., but the shared-ride stops all over town, which means Mr. C will need to leave home more than an hour before his treatment begins. The route to the clinic seems bumpy in the over-sized short bus, and stirs discomfort from a previous lower back injury. This is Mr. C's only mode of transport to dialysis. He no longer drives and the walk to the bus stop is impossible. His significant heart disease brings on shortness of breath as soon as he begins walking. There are no other affordable means of door-to-door transportation; even this ADA shared-ride option is costly on his fixed income at \$65.00 per month for the service. Imagine adding this to transit fees for grocery shopping, pharmacy, doctor visits, and social visits. It can quickly become a question of, "Can I afford to get to dialysis today?"

The case of Mr. C just begins to touch on the transportation barriers dialysis patients face. Consider the patient who does not have the capacity to remember to call and schedule weekly rides; or the patient living in a rural area who cannot get a 15-mile ride into town because they are outside of ADA boundaries; or the patient who lives down too long of a driveway for the bus to make a safe connection. The transportation barriers are almost as diverse as the people who cope with end-stage renal disease.

PROJECT APPROACH

In the summer of 2013, Ride Connection launched a six-month participatory planning process (**Phase I**) that identified existing challenges related to transportation for patients needing dialysis treatment, and how these challenges impacted patient health. This process involved the creation of an advisory committee; conducting focus groups; administering a patient survey and a caregiver/healthcare provider survey; one-on-one patient interviews; and holding public workshops. Each of these steps helped to identify transportation challenges and informed specific changes that would not only improve the quality of transportation services, but also would ultimately improve the health outcomes of patients receiving dialysis treatment. Prior to beginning this process, Ride Connection obtained approval for this project

from the Human Subjects Research Review Committee of Portland State University to ensure the ethical integrity of its practices. Part of this process was to provide informed consent forms to all who participated in the process. Ride Connection staff reviewed literature related to end-stage renal disease, dialysis, and non-emergency transportation prior to engaging with patients, caregivers, and healthcare providers to ensure that we had an adequate understanding of the issues. This planning process led to the development of promising practices (Phase II) and a pilot project currently underway (Phase III).

PROJECT PARTICIPANTS

Ride Connection staff reached out to the dialysis community throughout this process to ensure input from many different perspectives, from those who work in the field, to those affected by the disease. An advisory committee met monthly, and was composed of five dialysis patients, a transportation provider, a caregiver, and five healthcare providers, including a social worker. The committee provided input on the project team's methodology of data collection, identified priority issues, developed survey and focus group questions, and helped develop solutions with next steps. The group also received technical assistance in designing the project, in focus group facilitation, and evaluation guidance from a public health non-profit, Upstream Public Health, who are active in the region dealing with health issues such as transportation access. During the entire project, the project team shared decision making, interpretation of findings, and development of recommendations with the dialysis community.

DATA SAMPLE

Eighty-three patients and 26 caregivers, transportation providers, and healthcare providers completed surveys. Two focus groups were held and were attended by eight patients and two caregivers, who provided details related to their challenges and experiences with transportation to and from dialysis treatment. These sessions were led by two facilitators trained in working with vulnerable populations. Finally, 19 stakeholders participated in a public workshop to help develop workable solutions to these challenges. Stakeholders included patients from both focus groups, caregivers, healthcare providers, advisory committee members, transportation providers, drivers, a non-emergency medical transportation administrator, and a coordinated care representative.

PHASE I – PARTICIPATORY PLANNING PROCESS

Here we describe the main themes and suggested strategies that came out of the first phase of the project. Involving participants in the planning and decision-making process ensured relevant outcomes. It also resulted in new relationships and a shared understanding among participants.

The advisory committee, patient survey, and focus groups helped us to identify numerous broad issues and areas of concern related to the impact of transportation on health

outcomes for dialysis patients. The main themes were dependability of rides, the need for flexibility in ride scheduling, rider frustration with wait times and indirect routes, cost being a barrier, the need for driver training, and a mismatch between clinic and home locations (Table 1).

Strategies, best practices, and community resource ideas were developed in the same way that we identified the issues that needed to be resolved. The advisory committee, workgroup, patients, social workers, and others from the dialysis community were asked to weigh in on solutions to these issues, and determine which would be best for patients, and feasible. The participants had numerous suggestions that can be grouped into two categories:

1. Develop education, advocacy, recruitment, and outreach activities such as: a regional transportation fact sheet specific to dialysis, a dialysis education campaign, enhanced driver training beyond the Ride Connection network, a recruitment program for volunteer drivers who would be on call for flexible return trips, and a system to support patients who are newly diagnosed. (All Ride Connection drivers are vetted, trained, and evaluated at the same level, whether they are volunteers or paid drivers. Ride Connection covers volunteers under both auto and general liability insurance.)
2. Develop a collaborative pilot program to affect change: Work with a dialysis clinic and all transportation providers to create a more reliable, affordable, friendly, and flexible dialysis transportation system.

Input from the advisory committee, workshop participants, and discussions among staff and stakeholders helped to identify a set of operational protocols for Ride Connection to use internally. These new protocols, strategies, and community resources from Phase I activities addressed issues to immediately improve the quality of our services. Ride Connection took the following actions as a result of the planning process:

1. Developed a transportation matrix that clearly stated all parameters of each available transportation option in our region. The matrix was provided to all 21 dialysis clinics in our area. A patient representative contacted each clinic and followed up with either a paper or electronic version of the matrix to social workers and clerical staff.
2. Implemented a revised no-show/late-cancellation policy that was clear to patients. No-shows or late cancellations that occurred because of a medical condition were not counted.
3. Provided a guaranteed return trip: ensured all Ride Connection customers understood that they will not be stranded at a clinic without a ride home.

Ride Connection combined these efforts into a pilot project in partnership with a dialysis clinic, described in the next section.

PHASE II – PROMISING PRACTICES

In Phase II, the planning project focused on developing the concepts from Phase I of this project and implementing the solutions that the dialysis community had generated in the process.

Education

Dependability and flexibility of rides does not just depend on the transportation system alone, but also on the driver, call taker, and scheduler of those rides. Our research indicated that those involved with providing the trip needed to more fully understand the experience of people undergoing dialysis treatment. Drivers also told us that they needed more training and had many questions about how to best provide transportation to this population. Our project team, therefore, embarked on designing a course with the advisory committee, patients, social workers, and additional partners that would develop not only an environment for learning best practices to assist the dialysis population, but would also to create an understanding of the dialysis patient experience. Patients, care providers, drivers, and caregivers were included in developing the curriculum and subsequent educational video. The objectives of the course, "What Every Driver Needs to Know About Dialysis Transportation (but was afraid to ask!)," were developed to ensure participants would be able to:

- Explain kidney functions
- Identify common reasons people experience chronic kidney disease
- List the stages of kidney failure
- Describe kidney dialysis
- Identify transportation concerns of people undergoing dialysis
- Assist riders to and from treatment
- Take appropriate action when there are concerns

The overall goal of the video component of the training is to show the reality of a patient's life, from leaving home, getting to the clinic, dialysis treatment, and then getting home again. Four patients agreed to participate, and each had a unique story to share. A skilled trainer, who also receives dialysis treatment, provided training. The evaluations from all who have attended this training were very positive. The tone of the video was emotional and impactful. The day's frustrations and successes are shown in documentary/cinéma vérité style. The viewer obtains a sense of how long the process takes, and how dialysis treatment has an impact on all parts of the person's life. Ultimately, the viewer should come away not with pity or admiration for the person in the video, but with sensitivity and empathy for what a person goes through when they are undergoing dialysis treatments.

Social workers were instrumental in promoting the concept of the educational video, and ensuring that diverse patients

were included in the video. They assisted the project team with getting permission from the clinics to film on site and kept clinic staff informed of the process. The video can be watched as a stand-alone educational tool and can be beneficial to anyone that watches, no matter what their location. This video is available free of charge and can be requested from the lead author.

Trainings were scheduled through Ride Connection.

Recruitment and Outreach to the Dialysis Community

Ride Connection worked with patients, care providers, and drivers from our advisory committee to:

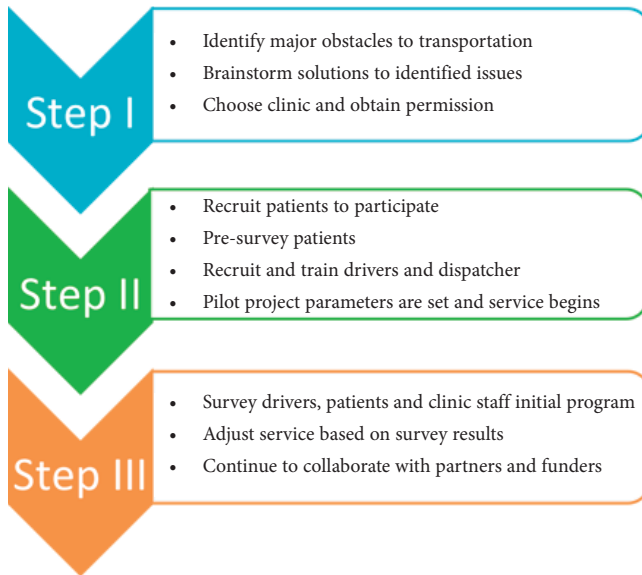
- Design outreach materials related to best practices in dialysis transportation that can be shared with other transportation providers in our region to encourage broader system-wide protocol changes;
- Assist in developing a volunteer driver program specific to creating flexible transportation options;
- Assist in outreach and advocacy related to the implementation of the transportation pilot project; and
- Engage additional stakeholders to support the cause.

This outreach and recruitment project resulted in a broader understanding of both the project and the challenges associated with dialysis transportation across all regions. Tools developed in this process can be replicated and used in areas outside our local region.

Volunteer driver recruitment was a large area of focus of this project. Based on what we had learned in the research phase, we knew that having direct routes home, especially after treatment, and limited sharing of rides with those being transported to places other than dialysis clinics, were best for patients.

The team used a recruitment model that focused on efforts to engage potential volunteers because of their interest in supporting individuals receiving dialysis. Our recruitment efforts included reaching out to transplant and diabetes support groups, as well as attending community events. Materials were created in a respectful way that "put a face" with the person who needed transportation and shared who they are, not just that they needed a ride. We also shortened the training video into impactful sound bites that could be sent as links, shown on social media, or used as part of a presentation. A name and logo were designed to capture people's attention and motivate them. The name of the program is Dahlia. The logo is a dahlia flower which shows growth, beauty, and vitality (Figure 1). Slightly used hybrid sedans were purchased and wrapped with the beautiful logo. This provided a moving billboard for volunteer recruitment. Hybrids were specifically chosen in the hopes that new volunteers, interested in environmental sustainability, might be encouraged to join our cause.

PHASE III: PILOT PROJECT



Working in partnership with our advisory committee, the dialysis community, drivers, a dialysis social worker, and our network of transportation partners, we developed a pilot project at a selected clinic so that we could test our theories, and use it as a model for best practices for flexible, reliable, and affordable patient transportation services. The committee used purposive sampling to choose the clinic for the pilot project to ensure that the quality of the pilot could be evaluated. The committee used the following criteria to select the pilot project site: an involved social worker who was supportive of the project, a manageable sample of patients with different transportation options, patients with varying mobility needs, patients with varying insurance eligibility, and a clinic in a region that had transportation providers available.

The selected clinic's social worker was involved in ensuring all protocols were followed. The social worker obtained permission to implement the pilot transportation project at the Fresenius Medical Care Hollywood Dialysis Clinic. The social worker informed patients of the risks and benefits of participating in the project before they signed an informed consent form. All patients understood the expectation of completing a pre-survey and quarterly surveys for one year to provide feedback on their transportation experience. The social worker offered patients translation services or assistance with reading the survey when needed. Participants agreed to release their treatment times and dialysis attendance as data for the outcomes assessment. Finally, participants understood their right to discontinue involvement in the project at any time without fear of reprisal.

The pilot model was informed by the focus groups and discussions we had with the advisory committee during Phase I. Our goal was for the transportation providers, drivers, social workers, clinics, and patients to collaborate in identifying strengths and weaknesses of all local transportation systems,

and make adjustments to service delivery modes by sharing customers, capacity, and resources. Throughout the pilot, we evaluated which of these practices worked best for patients, had positive effects on their health, and the costs needed to sustain the level of service, which we will describe in a follow-up article. The components of the pilot project included:

- Assessing individual customers' level of regularly needed service — Constant communication with customers provided more real-time information to assist with transportation.
- Dedicating a dispatcher — One dispatcher was dedicated to coordinating dialysis trips only. We had one number which was answered primarily by the same person.
- Collaborating with multiple partners and funders — Using a centralized scheduling system, we created a mechanism for multiple partners, with both volunteer and paid drivers participating and receiving reimbursement. Ride Connection became a provider of the Medicaid Medical Transportation Program in order to get reimbursed for rides if the patient was Medicaid eligible. A state grant was received to supplement the cost of the rides for the pilot.
- Not charging customers for the rides.
- Waiving the standard five minute wait time — The expectation of partners in the pilot was that customers would not be left behind if they were not ready within five minutes of the driver's arrival. The clinic staff was encouraged to contact the dedicated dispatcher if pick-up time changed. Rides were then dispatched.
- Allowing ride sharing in one vehicle, based on medical condition or trip purpose.
- Utilizing volunteers as primary drivers, paid drivers secondarily, and taxi cabs as backup.
- Purchasing hybrid vehicles to encourage new volunteers who may be interested in environmental sustainability.
- Offering mileage reimbursement to volunteer drivers for using their own vehicles.
- All drivers, paid and volunteer, taking the education course developed in Phase II of this project.
- Implementing a scheduling system that allowed constant communication between, patient, driver and clinic.
- Surveying patients regularly to ensure and adjusting service delivery methods based on responses.

The pilot project started February 1, 2015. Twenty eight patients at the clinic opted to participate in the project. All patients were asked to complete a pre-survey so that we would have a base-line account of transportation issues and health outcomes. Patients were asked to commit to taking a survey quarterly. To date, we have completed and analyzed

one round of surveys. The following results indicate that the transportation practices developed may have a benefit to both patients and clinic staff.

PATIENT SURVEY RESULTS

As of this writing, we are seeing changes in participant self-reported factors that contribute to health outcomes (Table 3). For example, a handful of patients reported "rarely," "occasionally," or "frequently" missing a dialysis appointment in the last three months because they could not find a ride. In the first quarter, this program appears to have improved those numbers so that *none* of the participants reported missing a dialysis appointment based on transportation. Staying on hemodialysis for the prescribed time is better for overall patient health. Exactly three quarters of respondents (71%) told us that, before this project they had rarely or occasionally experienced shortened dialysis treatment time. That has shifted to nearly all participants never or rarely experiencing this problem in the first quarter. Table 3 also shows improvement in three measures that contribute to patient stress. These include: being left waiting at a clinic; having to contact more than one transportation provider; and simply thinking about transportation to and from dialysis.

CLINIC SURVEY RESULTS IN RELATION TO PATIENT CARE

One of the authors distributed the clinic survey at the pilot clinic at each data collection period during the project. Initially, 12 individuals responded to the pre-survey. Currently, five individuals filled out the first quarterly survey, and will continue in further quarters based on their involvement with transportation at the clinic. From the survey results and conversations with clinic staff, the pilot project appears to be reducing the frequency with which clinic employees do extra work or manage transportation-related challenges. A few of the survey items relate to supporting dialysis patients' health. For example, in Table 4, 75% of clinic staff reported frequently needing to rush to get patients out the door before drivers leave. We learned in our advisory committee and focus groups that this rushing experience can feel stressful, can reduce the chances that a patient's dialysis access has fully stopped bleeding, and can take the clinic staff away from other tasks. Other survey items connect to the total time clinic workers may be handling transportation-related complications that are beyond normal procedures (Table 5). For example, clinic staff repeatedly needed to make calls to multiple transportation providers which take time that could be used to ensure the patient is stable enough to go home safely. This is important, as clinics must use time efficiently to stay on tight schedules for hemodialysis and aftercare.

After initiation of the pilot program, more clinic staff reported that the number of calls they are making, and time spent on the phone, are decreasing. Some clinic staff reported that the single call line has streamlined the transportation process, while others gave a neutral response (Table 5). In the

three months since the project began it is difficult to determine how streamlined things have become. In Part 2 of this article we will explore what worked and what did not, based on conversations we have with clinic staff.

TRANSPORTATION PROVIDER SURVEY RESULTS

The responses from the transportation providers participating in the pilot either confirm, or are neutral, in relation to results from patients and clinic staff. We are learning that the pilot is reducing some of the transportation factors that can poorly affect patient health. For example, in Table 6 the percentage of providers who could not provide a trip for a dialysis patient shifted from many reporting "frequently" to most reporting, "never," "rarely," or "occasionally." We have also learned that some of the drivers participating in this project have not encountered problems patients stated in the focus groups, such as a patient bleeding in a vehicle after dialysis, or driver lack of confidence about providing transportation for dialysis patients.

SOCIAL WORK IMPLICATIONS

"I never hear anything positive about transportation (and neither does the secretary). This made my day and I wanted to pass it on to you all. Thank you for all of the hard work you are doing to implement this project!!" —Renal social worker

"It is amazing that all of you are affecting positive change regarding this problem that has been plaguing this community for at least the last 40 years. Thank you for making a difference. Together we can change the world." — State of Oregon Client Surveyor

Social workers played a critical role in this project. While it is expected that social workers facilitate access to and coordination of care for their clients, this project involved an expansion of their role that was unexpected. Education went beyond helping dialysis patients understanding the transportation available; social workers also helped ensure that patients, clinics, and drivers were all equally educated about the connection between hemodialysis and transportation.

The social work code of ethics, asks the social worker to identify social problems, implement change to help the vulnerable and oppressed, to serve those in need, and to ensure access to services. In this project, social workers recognized the transportation problem within the dialysis population, helped document the problem by assisting in the organization of focus groups in their clinics, and passed out patient surveys. Social workers collaborated with a committee of patients and providers to troubleshoot problems and create solutions, helped to create an educational video, and implemented the pilot project overall. This required making the time, taking a step outside of one's normal caseload, and working with others to help implement change. Programs such as this can help social workers minimize the time they devote to tasks such as transportation, and help increase the amount of time they have for clinical interventions to improve patient outcomes.

PHASE IV – FUTURE PLANS

This project expands on the existing literature by highlighting numerous additional ways in which the health outcomes of patients are directly and indirectly impacted by barriers or inadequacies in their medical transportation. It suggests that improved transportation options would not only improve patient health outcomes, but could also potentially reduce future healthcare costs by reducing medical complications. This process was unlike any inclusive planning project we had undertaken before. The level of commitment, the importance of this issue, the devotion and expertise of all involved, and level of engagement encouraged and motivated us to go beyond our thinking about internal processes. The team brought up this project in regular staff meetings, encouraged staff to attend the patient-delivered training on dialysis, and embedded these efforts into the organization even before the project reached completion. We remain more committed than ever to involve our riders and the broader community of stakeholders in all of our organization's new initiatives.

Many challenges and successes have been encountered with this project. There are aspects to working in Oregon that helped with our success. We work in a metropolitan area that has positive transportation factors, such as multiple transportation options, that allowed us to understand what worked and did not work. Further, Ride Connection as a convening organization, had the following benefits: a) understanding the medical and transportation landscapes and their limitations before starting this work; b) Ride Connection is a trusted partner with clinics, transportation providers, and policy makers; and c) Ride Connection has its own organizational culture that prioritizes customers' needs. If another organization were to start a similar project, then the authors recommend ensuring a group of partners who can bring similar knowledge and relationships to the table at the beginning.

Without the leadership of patients, caregivers, and care providers, the project team would not have been able to identify issues or progress as succinctly. Directly involving people affected by this issue is paramount to achieving the goal of improving transportation to treatment. From the doctor to the patient to the transportation providers to family members, all were considered equally, worked hard, and gave thoughtful input. Constant contact and encouragement of all parties was a routine feature of the project, as was hiring multiple patients as consultants and specialists to develop the program, create the educational material, and provide continuity to the project.

Asking for cooperation from large corporations that own dialysis companies was challenging. Corporate structures are complex and there can be an impression that they will prioritize profits or will be inflexible, based on a "top-down" structure. That's an impression because of all the things we hear in media, and based on how patients feel big companies *treat* them on day-to-day basis. But what we experienced is

that the *people* in the big companies may not feel this way. Ride Connection is a mid- to large-sized non-profit that understands red tape components and was willing to be open minded in changing its own processes and practices as a role model. We were able to create a structure that could still address the interests of the partners while learning to better meet the needs of patients. We also have the non-profit's power of being able to *advocate* for change, based on what is heard. We have the flexibility that a large corporation usually doesn't. We used the power of story, of real-life experiences, and brought forward compelling real situations. That is effective in getting attention. We also had concerned, committed partners in each of these organizations who were willing to talk to the clinic's leadership about the project. Finding social workers who were respected and committed to the cause helped us to better understand the corporate structure and philosophy. Knowing this was critical to getting into a clinic to film the video and having the clinic agree to be a part of the pilot project.

The results we have seen to date suggest that this process directly addresses ways of improving transportation for dialysis patients. One of the findings of this work has been the benefit of thinking about transportation as more than just a means of moving people.

Transportation is directly related to many other social outcomes, including public health and quality of life. Committee members in our participatory process identified many ways that the quality of transportation services patients receive directly impacts the quality of their health and medical treatment. We tested how much other drivers (dialysis patients who drive themselves to treatment) and non-drivers (dialysis patients who do not drive themselves to treatment) agreed with these conclusions in a survey (Table 2). These include missing a ride, shortening a dialysis treatment, or being left behind without a ride home.

Our process identified that this area needs further research to document the impact of these conditions, such as missing a ride, can have on health outcomes, such as recovery time from dialysis and maintenance of dialysis hours on machine. The solutions we implemented can not only improve transportation, but also improve outcomes, potentially reduce healthcare costs, and positively involve those who are affected by this in the decision-making process. This approach to thinking about transportation has broad implications and increases opportunities for sustainability by looking beyond our normal transportation partners. We hope to build on relationships we have been fostering for continuing engagement, support, and voluntary commitment of resources. Our evaluation process, featured in Part 2, will demonstrate the relationship between access to treatment and health outcomes.

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Table 1. Transportation themes and representative quotations from the dialysis community

Theme	Description	Patient Quotation	Caregiver Quotation	Quotation
Dependability	When a ride is late or does not show up, a patient may have to cut their dialysis treatment short, which could have deleterious impact on their health. Patients can also be stranded at the clinic if they miss their ride home. For example, in the patient survey 45% of non-drivers respond negatively when asked if they have a reliable transportation backup.	X		“When I’m late my lunch isn’t at noon it’s at 2:00 p.m., then dinner supposed to be at 5, then have to move it back... being a diabetic then shots and other things at the wrong times... it’s too low.”
		X		“Go for dialysis late... it’s not good for my body. Come off too soon. If you are three times late in a week that adds up. Because transportation is late.”
			X	“[Transportation] service should be based on the individual care needs of each patient, and not the scheduling needs and/or financial gain for the transportation company. Each entity should have designated individuals who work collaboratively on an ongoing basis to design ride schedules, which have to be flexible and include allowances for movement of times, based on patient needs.”
Flexibility	Participants identified a greater need for flexibility in scheduling so that when patients need more time to complete their treatment or to stabilize after dialysis, they can easily reschedule their rides home. For example, in the patient survey, 19% of non-drivers disagree when asked if their transportation provider is patient and flexible.	X		“Dialysis is stressful. Whole outlook is changed; have to change entire lives for dialysis; figuring out how to get to and from rides should be the least of our concerns, but it’s become one of our biggest. A lot of us have to go through trials and tribulations. The last thing we want to worry about is rides.”
			X	“Reliability and flexibility is a big issue — if just a few minutes late, a lot of transporters refuse to wait.”
Waiting and Indirect Routes	Participants identified frustrations with the service they use related to patients having to ride across town and sometimes right past their home or clinic to pick up another person before they are dropped off. For example, in the patient survey, 27% of non-drivers were stuck at the clinic without a ride home at least once in the past three-month period.	X		“I feel frustrated or angry because can’t do anything to change it. Dialysis is very stressful anyway. Hard time dealing on a daily basis. If ride not there or shows up late, not fair to us. We may have to wait even longer, at time when extremely weak.”
			X	“Transportation does a pretty good job getting people to dialysis, but, patients are tired after dialysis, so less able to tolerate a long ride, which is a built-in feature of the system.”
Cost and Affordability	Results of the data collection showed that the majority of patients surveyed are low income, therefore the cost of transportation to and from treatment provides a huge barrier. For example, in the patient survey, two-thirds of respondents earn less than \$20,000 annually.	X		“..., they don’t provide us with transportation. We don’t have a choice; we have to go to treatment to live. People don’t realize, no pity party, just need a little help. All I want is to live long enough to see my children have children. I could just pluf [sic] the next day, that’s all I want.”
		X		“Takes the big bus [fixed bus route] or a taxi home. You have to pay for a taxi yourself. I get disability. I have to pay rent. I can’t tell my landlord I can’t pay you \$15 today because I had to pay for a ride home.”
		X		“...just costing us an arm and a leg. Costs and stress.”



Table 1(continued). Transportation themes and representative quotations from the dialysis community

Theme	Description	Patient Quotation	Caregiver Quotation	Quotation
Driver Training	Participants noted a need for driver education and training so that they can better understand the needs and rights of patients.	X		"...for my neighbors, operators have good or bad personalities. Sometimes their personalities come off that patients need them. 'You depend on us' not 'we depend on you.' Condescending. 'We'll get to you when we can when it's convenient for us as drivers.' 'Come on let's go, I got things to do.'"
		X		"Why can't they just do their job? They [all the other patients] talk to me about their transportation. I can sympathize with them."
		X		"... I have a mouth and I speak...They [drivers] are supposed to do things in a certain way. In my place, where you have to park to pick me up, [there is a] hill no sidewalk [on] Halsey [a street]. As soon as you turn, you park right there. If someone doesn't see the butt end of your vehicle, they will ram right into you. This makes it difficult for them to pick you up. They can't figure out where to pick me up at. They don't want to pick me up at the place that they should pick me up at."
Geography	Participants noted that some patients are often assigned to clinics that are far away from their home even when closer options are available.	X		"... [if miss a ride] I freak out. Can't afford to call a cab. They're very expensive. My dialysis is Milwaukie. I'm in K...and they assigned me. That's a frightening thought for me. I don't have a family here. I live in near the Lloyd center. [It's] very convenient here, but if go outside of that, I'm very fearful."

Table 2. Percentage of respondents who have experienced the following scenarios ≥ 1 time in the last 3 months (non-drivers compared to drivers)

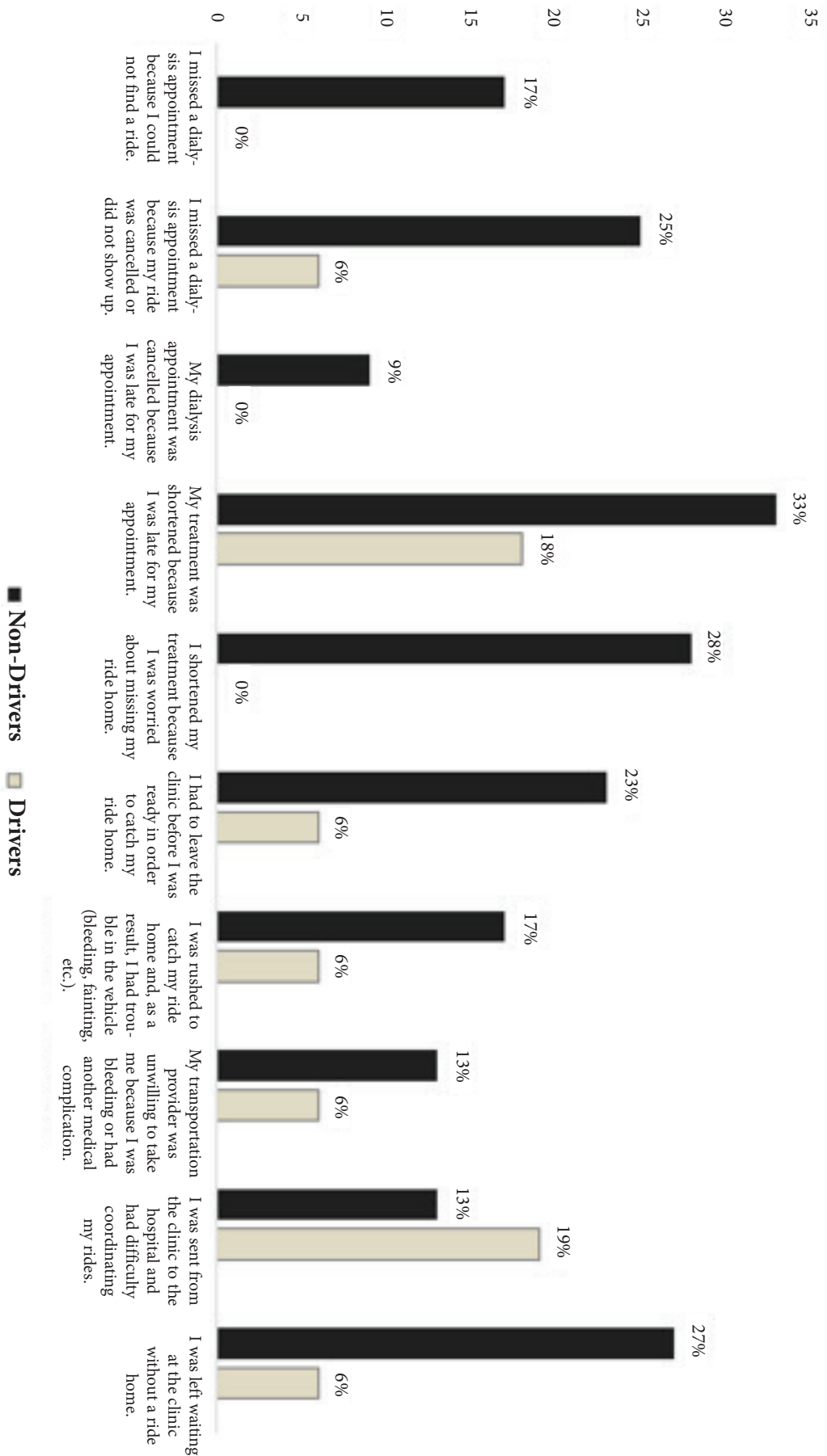


Table 3. Patient survey results relevant to health outcomes (N = 28)

Survey Item	Pre-survey	1st Quarter
I missed a dialysis appointment because I could not find a ride.		
Never	67%	100%
Rarely (1–2 times)	17%	0%
Occasionally (3–4 times)	12%	0%
Frequently (5 or more times)	4%	0%
My treatment was shortened because I was late for an appointment.		
Never	29%	91.67%
Rarely (1–2 times)	46%	8.33%
Occasionally (3–4 times)	25%	0%
Frequently (5 or more times)	0%	0%
I had to leave the clinic before I was ready in order to catch my ride home.		
Never	67%	75%
Rarely (1–2 times)	29%	20.83%
Occasionally (3–4 times)	4%	4.17%
Frequently (5 or more times)	0%	0%
I was left waiting at the clinic without a ride home.		
Never	67%	100%
Rarely (1–2 times)	33%	0%
Occasionally (3–4 times)	0%	0%
Frequently (5 or more times)	0%	0%
I felt stressed when thinking about transportation to or from dialysis.		
Never	29%	95.83%
Rarely (1–2 times)	8%	0%
Occasionally (3–4 times)	46%	4.17%
Frequently (5 or more times)	17%	0%
I had to contact more than one transportation provider to coordinate all my trips.		
Never	63%	95.83%
Rarely (1–2 times)	29%	0%
Occasionally (3–4 times)	4%	4.17%
Frequently (5 or more times)	4%	0%

Table 4. Clinic survey results related to patient health outcomes

Survey Item	Pre-survey N = 12	First Quarter Survey N = 5
A clinic employee was required to wait at the clinic after it closed for a patient's ride home from the clinic to arrive.		
Never	0%	0%
Rarely (1–2 times)	33%	80%
Occasionally (3–4 times)	42%	20%
Frequently (5 or more times)	25%	0%
I had a problem getting a hold of the Ride Connection dispatcher.		
Never	0%	40%
Rarely (1–2 times)	11%	40%
Occasionally (3–4 times)	78%	20%
Frequently (5 or more times)	11%	0%
I have rushed to get patients out of the door before drivers leave.		
Never	0%	0%
Rarely (1–2 times)	0%	40%
Occasionally (3–4 times)	25%	20%
Frequently (5 or more times)	75%	40%
I was concerned that if I gave accurate information about a patient's readiness for pickup, the driver would leave without the patient.		
Never	0%	20%
Rarely (1–2 times)	33%	0%
Occasionally (3–4 times)	17%	60%
Frequently (5 or more times)	50%	20%
In order to buy time for a patient who was not ready for pickup, a driver was told that the patient would be ready in "five minutes" or "soon," even if the ready time was unknown or longer.		
Never	17%	0%
Rarely (1–2 times)	8%	20%
Occasionally (3–4 times)	42%	60%
Frequently (5 or more times)	33%	20%
I had to contact more than one transportation provider to exchange information about a client's transportation.		
Never	8%	50%
Rarely (1–2 times)	0%	50%
Occasionally (3–4 times)	58%	0%
Frequently (5 or more times)	33%	0%

Table 5. Clinic experience with patient-related transportation calls

Survey Item	Pre-survey N = 12	First Quarter Survey N = 5
The number of calls I made to transportation providers decreased.		
Agree	17%	40%
Neutral	33%	60%
Disagree	50%	0%
The time I spent on calls to transportation providers decreased.		
Agree	0%	60%
Neutral	33%	20%
Disagree	67%	20%
The single call line has streamlined the transportation setup process.		
Agree	N/A	40%
Neutral	N/A	60%
Disagree	N/A	0%

Figure 1. Project logo and vehicle



Table 6. Transportation provider survey results

Survey Item	Pre-survey N = 3	First Quarter Survey N = 3
I was not able to provide trips for a dialysis patient because it was outside service hours.		
Never	0%	33%
Rarely (1–2 times)	0%	33%
Occasionally (3–4 times)	33%	33%
Frequently (5 or more times)	67%	0%
I had a problem getting a hold of the Ride Connection dispatcher.		
Never	33%	33%
Rarely (1–2 times)	33%	33%
Occasionally (3–4 times)	33%	33%
Frequently (5 or more times)	0%	0%
I had to pull a vehicle out of service as a result of bleeding in the vehicle by a dialysis patient that I transport.		
Never	100%	100%
Rarely (1–2 times)	0%	0%
Occasionally (3–4 times)	0%	0%
Frequently (5 or more times)	0%	0%
I felt that I carried out an important role in the care of a dialysis patient that I transport.		
Agree	67%	100%
Neutral	33%	0%
Disagree	0%	0%
I felt confident when thinking about providing transportation to or from dialysis treatment.		
Agree	67%	100%
Neutral	33%	0%
Disagree	0%	0%