

Transportation Issues and Their Impact Upon In-Center Hemodialysis

Steven A. Iacono, LMSW, FMCNA Midtown Dialysis Center, Columbia, South Carolina

Reliable and consistent transportation is vital to patients receiving in-center hemodialysis. This is not only a matter of quantity, but also of quality. Two questionnaires, one for patients and one for dialysis social workers, were developed in order to assess the presence and types of transportation problems. Data was collected from 123 randomly selected patients and 16 social workers. Two-thirds of the patients reported having been picked up late by their transport provider and the average waiting time was one hour and two minutes. Only 5% of patients stated that their provider had ever informed them of how to file a complaint about their service, and only 45% reported that the matter was corrected when they did complain. The primary identified problems included difficulty scheduling trips, conflicts with drivers, late service and failure to be picked up. Social workers noted that 4.5 treatments are missed on average each month at their clinics due to transportation. Missed treatments represent a risk to the health of patients, cause complications with clinic scheduling and are a loss of income for dialysis corporations.

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The provision of in-center hemodialysis depends upon adequate, reliable transportation. Whether treatment is in a large urban city or a rural town, patients must have a consistent method of getting to and from the treatment location. Compliance with the prescribed hemodialysis regimen is a common concern of medical staff, medical corporations and numerous regulatory agencies. Though patients often report personal reasons for missing or shortening their dialysis, external factors are also frequently noted. A study by Gordon, Sehgal and Leon (2003) found that transportation issues were reported by 22% of their research subjects as a reason for missing treatments. A lack of late-day transport is also a factor in early sign-offs from treatment (Rocco & Burkart, 1993).

The United States Department of Transportation [DOT] estimates that 3.5 million people in the United States never leave their home and that 54% of them are persons with disabilities (DOT, 2003). The DOT survey found that the lack of availability and cost of public transportation were the primary reasons that the disabled population never left home (DOT, 2003). This can be an even larger problem in rural areas. The Community Transportation Association of America [CTAA] found that 38% of rural residents in the United States were without public transportation and that a further 28% lived in areas where its availability is negligible (CTAA, 1995). Along with availability, the issue of quality is also important. Maintenance of vehicles, driver education, and use of harnessing devices for wheelchairs along with other factors play important roles in the consistency of service.

An issue that goes along with the quality of transportation is the legal compliance of public transportation providers. There is a large amount of regulation that affects access to public transportation. The Americans With Disabilities Act of 1990, Title Nineteen of the Social Security Act, and Section 504 of the Rehabilitation Act of 1973 are often cited as core legislation with regard to transport accessibility for people with medical needs. These laws forbid discrimination, designate Medicaid requirements, and denote expected practices. The National Easter Seal Society's Accessible Community Transportation in our Nation Project [ACTION] published a large survey regarding the views of drivers and consumers of public transportation. A lack of understanding and preconceived notions among drivers were identified. For instance, 9% of drivers believed that people with disabilities are angry because of their disabilities (National Easter Seal Society, 1995). The Americans with Disabilities Act requires that drivers announce stops along a route in order to notify passengers who are visually impaired, however 9% of drivers in the survey did not believe that this was necessary (National Easter Seal Society, 1995). When asked if they believed that equipment was poorly maintained, 5% of drivers strongly agreed as compared to 19% of consumers. A report by the United States Department of Health and Human Services [DHHS] noted issues with regard to the provision of non-emergency medical transport for people on dialysis. They found that long waiting times for pick-up were the most common problem mentioned by dialysis social workers regarding transport for their patients (DHHS, 1994). Cost of transportation was second and lack of provider assistance was third. For instance, the majority of surveyed providers did not assist riders with going up stairs. Thus, the day-to-day accessibility of transporta-

tion appears to be not only a matter of availability but also of quality, compliance to federal laws, and general aid.

Method

Design and Procedure

In order to evaluate the availability and quality of dialysis transportation two questionnaires were created. The first one was directed toward in-center hemodialysis patients in one southeastern state. The two-page questionnaire form notified the reader of its purpose and noted that participation was voluntary and that responses would be anonymous. Ten copies of the form were then sent to 20 randomly selected dialysis social workers for distribution to 10 randomly selected patients. Social workers were instructed on the procedures for random selection of patients. A total of 123 forms were returned. A second, shorter questionnaire was provided to twenty dialysis clinic social workers, which assessed their experiences with transportation. Sixteen forms were returned. The data from both questionnaires was descriptive in nature. This study was designed to be a pilot project for stimulating further review and research on the impact of transportation on in-center hemodialysis.

Results

Nearly 62% of the patient respondents reported using a Medicaid funded transportation source to get to dialysis. When asked if they had ever missed a treatment due to a mistake made by their transportation provider, 39% responded yes. However, many reported that if their provider had failed to pick them up, they used a friend, neighbor or taxi to get to the clinic and thus did not miss treatment. Therefore, the 'yes' response is believed to be higher. Two-thirds of respondents reported late service with an average waiting time of one hour and two minutes before being picked up.

Patients were asked questions about their efforts to correct poor service quality. Half of them stated that they had filed a complaint with their transportation provider. Of those who had filed a complaint, only 45% stated that the problem was corrected and 85% stated that it reoccurred. Only 45% reported that they believed the provider was interested in correcting the problem. When asked about their knowledge of grievance processes, 5% of the patients reported that their transportation provider had never informed them how to file a complaint and 98% of them reported that their provider had never asked their opinion about the quali-

ty of their service. Fifty-two percent reported that they feared retaliation if they were to file a complaint. A review of the specific problems faced by patients who ride on Medicaid funded transport was completed. This found that difficulty scheduling trips, conflicts with drivers, and late service were the top three most common problems.

Table 1

Problems Reported By Hemodialysis Patients Using Medicaid Funded Transportation

	% Reporting
Difficulty scheduling trips	35%
Conflicts/arguments with drivers	21%
Late service	19%
Failure to provide requested trip	14%
Mechanical problems with vehicles	6%
Concerns about vehicle safety	5%

The social work questionnaire inquired about transport availability and missed treatments. Social workers reported an average of 4.5 missed treatments each month at their clinics that were caused by transportation providers. Only 25% of them stated that they believed there were adequate transportation resources for their patients. When asked if their local Medicaid provider had ever surveyed them about the quality of their service, only 17% stated yes. Seventy-five percent of the social workers reported that they were familiar with the transportation provisions of the Americans with Disabilities Act.

Implications for Social Work Practice

The methods by which patients travel can be simple or part of a complex web of public service providers, regulations, costs, and time constraints. Social workers can be key personnel in assisting patients with navigating this process. However, research by Merighi and Ehlebracht (2002) found that only 34.3% of dialysis social workers believed that giving transportation assistance was an appropriate use of their time. Scheduling trips might be tedious, but helping patients when they run into transport problems can be of great benefit to the patient and the dialysis clinic. As advocates, social workers can bring about systems change. The research by Gordon, Sehgal and Leon (2003) noted that African Americans more frequently expressed transportation

problems as a reason for missing or shortening treatments. Therefore, social workers can be instrumental in identifying potential social inequalities and inadequacies that might be present in transportation systems. They can also educate patients and providers about the laws, regulations, and rights of those using these systems. Social workers should help staff to realize that these problems are a reality and not merely an excuse. Several suggestions on how to make improvements were rank-ordered by the social workers who participated in this research.

These included the following:

- 1) Request that transportation providers conduct annual anonymous service quality surveys of their riders.
- 2) Assist in the creation of local rider advocacy and advisory groups.
- 3) Conduct routine meetings between transportation providers, dialysis personnel, and riders to assist in assessing needs and issues.
- 4) Improve driver education regarding medical conditions, special needs, and conflict resolution.
- 5) Educate patients about their rights with regard to accessing transportation, regulations that providers must adhere to, and how to file a complaint.

Conclusion

Problems with transportation appear to influence the provision of in-center hemodialysis. This has the potential to cause a ripple effect not only to the specific patient, but also to the dialysis provider. Missed or shortened treatments can affect physical well-being and induce psycho-emotional stress. When treatments are missed companies lose income through being unable to administer the treatment, staffing time, and materials. Transportation problems can also impact upon other patients, in that missed treatments may cause gaps in scheduling, leading to unexpected changes to the shift system that many clinics use.

Transportation needs to be viewed not only within the context of availability but also on the basis of quality. Customer feedback and informing riders of their right to

file a complaint appear to be lacking in some areas. Issues with driver education and their understanding of people with disabilities need further investigation since these appear to affect how drivers perform their duties.

There are many variables within the context of this problem. Bureaucratic systems, legislation, social inequalities, economic status, driver attitudes, insurance, and locality are but a few of the many facets that determine whether or not patients are able to get to the clinic and complete their full treatment. Social workers have the ability to influence these facets on both an individual and macro level. Educating patients and advocating for them has the potential to bring about real change and better service. Further research is recommended due to the enormity of this issue and the impact that it has upon the provision of in-center hemodialysis treatment nationwide.

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Notes

The author would like to thank all of the patients and social workers who participated in this research. For further information about public transportation and accessibility contact:

Community Transportation Association of America:
www.ctaa.org

Easter Seals Project ACTION: **www.projectaction.org**

United States Department of Transportation:
www.dot.gov