

# A Qualitative Study of Transportation Challenges Among Intracerebral Hemorrhage Survivors and Their Caregivers

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## Abstract

*Post-discharge barriers of hemorrhagic stroke survivors in Hawai'i have not been extensively studied. The purpose of this qualitative study was to identify common driving and transportation barriers among patients with intracerebral hemorrhage (ICH) and their caregivers in the Honolulu community. Semi-structured interviews were conducted with ICH patients (n = 10) and caregivers (n = 11) regarding their driving and transportation barriers. Inductive content analysis was used to analyze the interviews. Participants reported that they needed transportation to attend to their recovery and remain safe. Informal transportation was desired, yet not always available to patients. A local paratransit service for people with disabilities was the most common form of alternative transportation used by patients; however, they reported difficulty obtaining this method of transportation. Participants with no other option used costly, private transportation. Most ICH survivors expressed great challenges with the available transportation services that are essential to their reintegration into the community after hospitalization. Greater effort to provide transportation options and eligibility information to the ICH patients and their caregivers may be needed to improve their post-discharge care.*

## Introduction

Transportation is an essential part of post-hospitalization care for stroke survivors in order to attend to their ongoing outpatient medical and rehabilitation care. Furthermore transportation is essential for stroke survivors to physically attend stroke support groups and work, which would help them reintegrate into the community. Because the majority of stroke survivors are initially medically unfit to drive, they typically depend on their families, friends, or public means for transportation during the first year after their stroke.<sup>1-3</sup> Prior studies have shown that stroke survivors often experience difficulty finding transport and encounter unpredictability and unreliability of readily available transportation services.<sup>4-5</sup> Therefore, lack of adequate transportation often becomes a barrier to receiving recovery services for people who have had strokes.<sup>6-9</sup> While some public transit agencies have provided more transportation options for people with disabilities that go above and beyond those required by the Americans with Disabilities Act of 1990 (ADA), others have not.<sup>10</sup> This study aimed to assess common transportation barriers for patients who survived acute intracerebral hemorrhage (ICH), and their caregivers, in the Honolulu community.

Stroke survivors with disabilities that limit their ability to drive may access transportation services, which were developed as a result of ADA.<sup>10</sup> The ADA, as amended in 2008, prohibits discrimination and ensures equal opportunity for people with disabilities in receiving public services and transportation. People with disabilities include those who have a physical or mental impairment that substantially limits one or more major

life activities, such as walking, caring for oneself, concentrating, or communicating. Public transportation, including buses and rail systems, is included as a public entity that must be accessible to and usable by individuals with disabilities, including those using wheelchairs. Additionally, paratransit services must be provided for: (1) individuals who are unable to board, ride, or disembark public transportation vehicles due to their impairment, (2) individuals whose impairment prevents them from traveling to a boarding location or from a disembarking location, and (3) another individual accompanying a person with a disability.<sup>10</sup> Paratransit or other special transportation services for people with disabilities should be “comparable to the level of designated public transportation provided to individuals without disabilities using such systems” and “in the case of response time, which is comparable, to the extent practicable, to the level of designated public transportation services.”<sup>10</sup>

One study found that 46% of people with disabilities use public transportation rather than private transportation or obtaining a ride from a friend or family member for general transportation purposes.<sup>11</sup> Approximately 40% of people with disabilities use public transportation to go to and return from work, which demonstrates the significance of public transportation to their community integration.<sup>11</sup> Most people with disabilities who are evaluated for paratransit services are eligible. A study of evaluations of 500 potential paratransit customers found that 92% were eligible, and 11% of those evaluations were for stroke survivors.<sup>12</sup>

Evaluations for paratransit are conducted by a physical or occupational therapist who administers cognitive and physical ability tests.<sup>12</sup> The cognitive test assesses temporal orientation as well as the ability to identify bus routes and landmarks, handle bus fare, and communicate travel destination information. A modified version of the Mini-Mental State Examination is included in the evaluation. The physical abilities test assesses ambulation skills, use of mobility devices, and the applicant's ability to ascend and descend curbs, slopes, and bus steps.<sup>12</sup>

While paratransit services are widely used by people with disabilities, the service costs are much higher than fixed route transit, such as buses and rail systems. In expert panel focus groups of transit providers, a transit agency reported that 40% of expenses went to paratransit services, while less than 40% of their customer base included paratransit riders.<sup>13</sup> Because of the cost of this service, transit agencies have developed several methods to encourage paratransit eligible customers to

use fixed route transit or taxis.<sup>14</sup> Some agencies provide travel training for newly certified paratransit customers, which teaches them how to use fixed route transportation. This has decreased paratransit use by 12% thus decreasing public transit costs and increasing inclusion of people with disabilities in public transit services for people with and without disabilities.<sup>13</sup> The second method offers paratransit eligible customers the use of a taxi to get to their destination instead of paratransit. It is offered as a supplement to paratransit. A study of 40 city transit agencies found that taxis provide services that are “above and beyond” ADA standards.<sup>14</sup> Taxis can be scheduled on the same day of the service. This offers more flexibility than paratransit, which must be scheduled 24 hours prior to an appointment. The passenger pays the standard ADA paratransit fare; the transit agency pays the cost above the typical one-way ADA fare up to a set limit, and the passenger pays anything above the set limit. For example, if an agency sets a limit of \$15.00 per one-way trip, and the customer takes a trip costing \$20, then the ADA customer would pay a standard ADA fee of \$2.00 and the transit agency would pay \$13.00. The customer would also have to pay the remaining \$5.00 of the fare. The savings to the transit agency is the difference between the amount of the fare they subsidize (ie, \$13.00) and the typical one-way cost of an ADA paratransit service (ie, \$20.00). In this case, the transit service would save 30%.<sup>14</sup>

The City and County of Honolulu Department of Transportation Services provides both a public fixed route transit service and a paratransit service for people with disabilities.<sup>10</sup> The fare in 2014 is \$2.00 per one-way paratransit trip. Paratransit trips must be reserved at least 24 hours prior to an appointment as specified by ADA. Curbside service is provided; therefore, a customer must be able to ascend and descend curbs themselves or with a caretaker’s assistance, who must ride with them. Eligibility is determined by an in-person evaluation (as previously described).<sup>10</sup> Neither supplementary taxi service nor travel training for new paratransit customers are provided. While taxis are available in Honolulu, people with disabilities pay the same fares as other customers. Since Honolulu has not provided these supplementary services, which can offer people with disabilities with more transportation options, this study aimed to assess how ICH patients and their caregivers in the Honolulu community perceived their transportation strengths and challenges.

## Methods

### Participants

Participants were recruited from an ongoing cohort study of ICH patients at The Queen’s Medical Center in Honolulu, HI. Patients were included if they; were hospitalized with ICH, over 18-years-old, a Hawai’i resident for more than 3 months, and available by telephone for recruitment and an in-person interview. These criteria were developed for the original purpose of the cohort study. Participants were excluded if their ICH was directly related to trauma or subarachnoid hemorrhage from ruptured cerebral aneurysm, which was related to the original

	Caregiver (n = 11)	Patient (n = 10)	Combined (N = 21)
Male	6	3	9
Female	5	7	12
Age, mean (s.d., range)	60.8 (9.1, 49-76)	61.1 (13.2, 42-82)	60.9 (11.0, 42-82)
<b>Education</b>			
<High school	1	2	3
High school	2	1	3
Some college	1	2	3
College	7	4	12
<b>Race/Ethnicity</b>			
White	2	2	4
Taiwanese	1	1	2
Asian Indian	1	1	2
Filipino	1	2	3
Japanese	1	1	2
Chinese	2	1	2
Native Hawaiian	2	3	5
Other Pacific Islander	1	0	1
<b>Caregiver Relationship to Patient</b>			
Parent	1	N/A	1
Spouse	6	N/A	6
Son/Daughter	1	N/A	2
Friend	1	N/A	1
Niece/Nephew	1	N/A	1

purpose of the cohort study. Ten interviews are recommended for inductive content analyses to meet saturation, which is met when no new themes are found with each subsequent interview.<sup>15</sup> In order to assess this, the interview transcripts are analyzed following each interview, and the themes from the new interview are compared to themes found in previous interviews conducted.<sup>15</sup> Thirty patients and 30 of their primary caregivers as identified during recruitment for the original cohort study were screened and approached by telephone to participate in the study at least three months post-hospital discharge. Ten ICH patients and eleven caregivers participated in semi-structured interviews. Participant self-identified demographic information is displayed in Table 1. Participants identified their primary race or ethnicity only.

### Design

The Queen’s Medical Center institutional review board (IRB) approved this study. Semi-structured audio-recorded interviews were conducted with participants at the hospital after they signed IRB approved consent forms. Two authors conducted interviews utilizing an interview script, which included open-ended questions on topics related to ICH stroke, such as stroke information, emotions, and transportation. The script was developed based on

a literature review, which included identification of important aspects of recovery to people who have experienced strokes in previous research.<sup>6-9</sup> Twelve interviews with the participants lasted an average of 47 minutes (*MIN* - *MAX* 36 – 86 minutes). Nine interviews were conducted with the patient and his or her respective caregiver. One was conducted with two caregivers, and another with one patient. Participants received a \$25 gift card for participation in the interview. Only one gift card was given per interview. For example, if a patient and caregiver participated together, only one gift card was given to them to share as an incentive.

### Analysis

Interview recordings were transcribed; pseudonyms were used to refer to participants. Inductive content analysis was used for this study, which is the analysis of text to obtain replicable and valid inferences of the data. This qualitative form of analysis often sacrifices breadth, or large sample sizes, for depth.<sup>15</sup> For the purposes of this study, authors aimed to understand the in-depth phenomenological experience of participants; thus, interviews provided participants with the space to share their lived experiences, and inductive content analysis provided the authors with an opportunity to develop a theory regarding their transportation needs from the data. The authors worked together to develop a codebook, which described each identified theme, by reading the transcriptions and identifying codes in the transcripts. Codes, or themes, were given weight based on participants' repetition, use of stories or examples, or emotion to refer to the themes. All data was read to identify initial codes that were used to identify prominent themes across participants. This study included the development of a codebook with multiple coders with different expertise to prevent bias. The methodology used is referred to as triangulation, which is a common approach used to improve the rigor of qualitative research.<sup>15</sup> The coders discussed the three themes related to transportation they found with one another after each interview until all three coders agreed upon the final codebook. Every segment of text could be double-coded. Two authors independently coded all text with the final codebook. Adequate interrater reliability ( $\kappa = .72$ ) was reached on a total of 154 codes. This means that the themes were discussed a total of 154 times throughout the text. A  $\kappa$  of .70 or above is considered to have good reliability.<sup>16</sup>

### Results

Three major themes were found pertaining to the transportation needs of participants with ICH and their caregivers: (1) participant reliance on assisted transportation, (2) barriers to informal transportation and (3) barriers to formal transportation.

#### Reliance on Assisted Transportation

Transportation options were essential to participants for safety, to attend medical appointments, and increase independence. Participants expressed that they could no longer drive themselves safely. One participant, Maile, described her difficulty with driving, "I'm afraid [to drive], only because my right side still comes numb sometimes, and my judgment. Sometimes...

I'll get up and I'll get dizzy or...I miss my step in the house." Participants reported using both formal and informal transportation options. Informal transportation included such options as obtaining a ride from a caregiver. The most common form of formal transportation discussed by participants were paratransit services and mass transit using buses; however, participants discussed issues accessing paratransit services. Other forms of formal transportation discussed by participants included taxis or hired cars.

#### Barriers to Informal Transportation

While informal transportation was preferred by participants, this option was not always available to the participants in our study. Participants noted several challenges to informal transportation. For example, Sondra, a caregiver, explained that she drives her husband wherever he needs to go, because it is the safest option. However, she explained that he "[has] to squeeze into my little Kia Accent." This suggests that having a car that is suitable for a person with a disability (ie, a minivan or larger vehicle) is essential if a patient is using transportation provided by caregivers, and the absence of a well-suited vehicle can pose an important challenge. In addition, Sondra said, "... if he had to go somewhere, I would have to take off from work." Sondra works full time and helps her husband eat, manage medications, do physical therapy, and shower. This illustrates that informal transportation potentially places an additional burden on caregivers to make themselves available to patients at times that may not be mutually convenient.

#### Barriers to Formal Transportation

Barriers to formal transportation could be categorized into two primary themes, issues with scheduling paratransit services, and challenges to becoming eligible for paratransit services. Each of these issues is addressed below. In addition, other challenges to formal transportation are discussed in a separate section.

#### Scheduling Paratransit Services

The most common form of alternative transportation used by participants was the paratransit system. However, every participant who spoke of the paratransit except one reported issues scheduling rides. The one participant who did not report issues simply reported that she used paratransit when she needed. Other participants who reported issues did not appear to be aware of the policies associated with scheduling rides. For example, Ron thought that he had to schedule rides within two hours of the desired pickup time. Ron expressed that in order to get to his interview for this study, he "tried to get the [local paratransit services]." Ron explained:

"I call up at 8 o'clock and I get put on hold...I talk to them, finally, and 'Oh, I doubt we'll be able to get you an appointment today, you should have tried to call a couple of days ago,' and I'm going, 'well, you're supposed to be able to get a ride in 2 hours'... That's why I had to drive instead of taking the [local paratransit service]. Yeah—not that I particularly care to do that, or am supposed to do that you know? After a stroke you're not supposed to drive for a year."

After revealing that he drove to the appointment, Ron was asked how the stroke had impacted his driving. He said, "I think that the hardest thing for me was getting my right foot coordinated from the gas to the brake, because I don't have feeling." Another participant demonstrated her confusion with paratransit scheduling policies, since the policy states that patients must call 24 hours prior to the time they need a ride: "You have to call at least a day before or up to seven days and you have to tell them the time they are going to pick you up and drop off and where, and sometimes you have to wait so long." In addition, if participants were able to schedule a paratransit ride, they reported that the paratransit often picked them up late. Six participants stated that the paratransit had been at least two hours late on at least one occasion. Many participants said they were using transportation to attend scheduled medical appointments, suggesting that paratransit delays substantially impacted their access to health care.

### **Eligibility for Paratransit Services**

Paratransit was not reported as a viable transportation option by everyone. Two participants reported that their disability prohibited them from using the paratransit services. Kealii, a caregiver, described how his wife's physical abilities prevented her from using paratransit:

"[The local paratransit service] only does curbside service. So if she cannot do the curb or get to the curb or get off the curb and into the house by herself, then I pretty much have to bring her. I mean we got a ramp and stuff like that, but with the [local paratransit service]—I mean you could be stuck at the hospital 2-3 hours if the [local paratransit service] gets delayed. She cannot sit in the chair for 2-3 hours waiting on the curb for this [local paratransit service]."

### **Other Formal Transportation Challenges**

While riding the bus was possible for some participants, many expressed that it was very difficult, because it did not directly take them to where they needed to go. Many of the participants described experiencing confusion and physical challenges that prevented them from taking the local public bus service. Patients who had no other options were subject to expensive private transportation. Kealli reported, "Tried the private service once, and that cost me \$185 a run, and I'm going, 'you're crazy!'" Another reported spending \$70 to \$140 for a one time private transportation trip to a medical appointment.

### **Discussion**

This study showed that hemorrhagic stroke participants in our study had new dependence on public and private transportation services after their stroke. These transportation services were felt to be limited in availability and inadequate in meeting their needs. These findings are consistent with prior studies in other population.<sup>4-5</sup> Those who were unable to use the public transportation services were making unsafe decisions, such as driving themselves prior to medical clearance. The strength of this study is that transportation issues after stroke hospitalization specific to Honolulu County have not been previously published and

highlight the possible need for further local system improvement. While this study has the limitation of generalizability due to its qualitative methods, small sample size and selective eligibility criteria, it provides a first glance into the barriers of ICH survivors and their caregivers in Honolulu. Although saturation was reached with our study size, the small number of participants in this study weakens the generalizability of the results. Furthermore, there may have been selection bias toward those with transportation issues, since ICH patients and caregivers who lacked post-discharge barriers may not have shown interest in participating in this study.

Specific needs reported by participants could be addressed by the medical professionals and local transit department. Overall, it would be helpful to provide education about paratransit services and offer more options that would increase timeliness of services, which are both methods used by 40 other public transit agencies in the United States.<sup>14</sup> Medical professionals could improve the patient discharge process by (1) consistently offering the Disability Parking Permit, which would assist the caregiver with informal transportation; (2) accurately describing the protocol for arranging local paratransit services; and (3) providing a list of known local, privately owned transport agencies to patients and caregivers. Additionally, paratransit services may consider expanding services to include drop off of participants at the door, rather than curbside, of their destination.

The local transportation services could also improve their information delivery. For example, further education about the need to call the paratransit services 24 hours prior to their requested services can be more explicitly stated to the public. Unfortunately, the City and County of Honolulu Department of Transportation Services website specifies that advanced reservations of paratransit services are required, but does not specify the 24- hours advanced notice, which may lead the users to make more last minute reservation attempts.<sup>10</sup> Since people with disabilities in Honolulu are already using taxis as a transportation option, the local transit agency might consider providing taxis as a supplement to paratransit services, since they can provide more reliable and timely transportation and have demonstrated cost savings in other transit agencies.<sup>13</sup> However, further information pertaining to the average cost of taxi rides among people with disabilities is needed prior to pursuing supplementary taxi services.

### **Conclusion**

A multidisciplinary approach is needed to address transportation challenges among people with disabilities, especially those with ICH. Both medical professionals and transportation agencies need to adequately address the transportation challenges of people with disabilities. Prior to discharge, medical professionals have an opportunity to ease patients' transition into the community by providing them with a Disability Parking Permit and instructions on paratransit services and other local transportation agencies. Future research should evaluate whether medical professionals are able to successfully implement these



services at local hospitals. Local transportation agencies can provide additional information on their website about their scheduling policies and options for people with disabilities to use taxis for transportation. Future research should assess the feasibility of providing a taxi option for paratransit eligible people with disabilities.

### Conflict of Interest

None of the authors identify a conflict of interest.

### Acknowledgment

We gratefully acknowledge The Queen's Medical Center's Native Hawaiian Health Program for supporting this study. Dr. Nakagawa and this study were supported in part by the National Institute on Minority Health and Health Disparities of the National Institutes of Health under Award Number P20MD000173. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Health or The Queen's Medical Center.

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