

# Investigation of Stroke Needs (INVISION) Study: Stroke Awareness and Education

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## Abstract

*The objective of this study was to assess the overall understanding and effectiveness of current inpatient stroke education practice by using the data from the Investigation of Stroke Needs (INVISION) Study, a qualitative study assessing various challenges and barriers of the hemorrhagic stroke survivors and their caregivers. Semi-structured interviews were conducted on patients who were recently hospitalized with intracerebral hemorrhage (ICH) and their caregivers during the follow-up visits. The electronic medical record for each patient was reviewed to assess whether they received standard stroke education material during their hospitalization. A phenomenological approach was utilized to identify gaps of education and knowledge in the targeted sample. A total of 21 participants were interviewed. Despite receiving formal stroke education material during their hospitalization, there were three major gaps in stroke knowledge that participants noted, including (1) lack of stroke knowledge/awareness, (2) need for stroke education, and (3) fear of recurrent stroke and comorbid diseases. The majority of ICH survivors had no memory of their hospitalization. This study suggests a need for increased continuity and communication with health-care providers to address the evolving educational and practical needs of stroke patients and their caregivers after hospital discharge.*

## Keywords

*Intracerebral hemorrhage; Patient education; Patient discharge*

## Introduction

Stroke is the 4th leading cause of death in the United States and a leading cause of disability among adults.<sup>1</sup> Although most healthcare providers acknowledge the importance of understanding the signs and risk factors of stroke,<sup>2</sup> the general public continues to have a significant deficiency in stroke awareness and knowledge.<sup>3</sup> Hawai'i-specific data from year 2009 indicates that only 41.9% of adults were aware of all 5 symptoms of stroke and the importance of calling 911 when a stroke is suspected.<sup>4</sup> Studies focused on stroke patients and their caregivers indicate dissatisfaction with the stroke information they receive, especially during post-stroke care.<sup>5,6</sup> Although stroke education is perceived as important by stroke patients and their caregivers,<sup>7</sup> access to medical knowledge remains a consistent challenge.<sup>8</sup>

Overall, deciphering medical terminology is problematic for many patients and caregivers. Difficulty in understanding educational materials creates a communication barrier between the patients, caregivers, and their healthcare providers.<sup>5</sup> A qualitative study by Eams, et al, revealed that stroke patients and caregivers often felt uncomfortable or intimidated to ask their healthcare professionals questions during acute care, and right before discharge.<sup>5,6</sup> As a result, many failed to obtain significant information regarding their disease and care plan.<sup>5,6,9</sup> This is

especially important among stroke patients since many of them recently acquired new physical and/or cognitive disabilities, resulting in more need for external assistance. Post-discharge barriers among stroke patients and caregivers include a lack of continuity of care and not knowing where to go to find answers to medical questions.<sup>5</sup> To address these concerns, we assessed the stroke awareness and education component from an exploratory qualitative study entitled Investigation of Stroke Needs (INVISION) Study to: (1) identify gaps in knowledge among stroke patients and their caregivers, and (2) assess the adequacy of stroke education provided to patient and caregivers prior to hospital discharge.

## Methods

### Participants

INVISION participants were recruited from an ongoing cohort study of patients with intracerebral hemorrhage (ICH) at The Queen's Medical Center (QMC).<sup>10</sup> QMC is a 505-bed medical center located on O'ahu, the largest hospital in Hawai'i and the tertiary referral center for the Pacific Basin (Hawai'i, American Samoa, the Commonwealth of the Northern Mariana Islands, Micronesia, and the US territories of Guam). QMC has the only Joint Commission-certified Primary Stroke Center and the only Neuroscience Intensive Care Unit for the state of Hawai'i. All stroke patients hospitalized at QMC and their caregivers are highly recommended to receive the stroke education packet that includes information about the etiology of stroke, treatment and prevention strategy for stroke, and aftercare guidance. The stroke education material was created using the content provided by the National Stroke Association. These materials are organized into a folder and are handed to the patients and/or caregivers by the nurses prior to discharge. Although the nurses are encouraged to provide more in-depth verbal education to review the content of the material, this practice is often not being done.

This study was approved by the Queen's Medical Center Institutional Review Board. Patients enrolled in an existing longitudinal cohort were eligible for participation in the current study. The inclusion criteria for the longitudinal ICH cohort study are age 18 years or older, a diagnosis of ICH by brain computed tomography (CT), and residence in the state of Hawai'i for greater than 3 months in a household with a telephone. Exclusion criteria for the original cohort study included ICH related to trauma or subarachnoid hemorrhage from ruptured cerebral aneurysm. This exploratory qualitative study was conducted during outpatient follow-up period. Family caregivers of the ICH patient were recruited if they provided structured care,

free-of-cost, to the stroke patient. Hired-care was excluded from eligibility.

Thirty caregivers and stroke patients were screened and approached by telephone to participate in the study. A total of 21 participants including 11 caregivers and 10 patients were enrolled in the study. Nine interviews were conducted with the patient and his or her respective caregiver. One was conducted with two caregivers, and another with one patient. Each interview was conducted with both caregiver and patient in the same room, with the exception of one interview with two caregivers and another interview with one patient only. The interviews were reviewed after they were conducted. Saturation, or redundancy of information, was met after interviews with these participants, thus recruitment of new participants ended at that time. Table 1 includes information about participants' age, education, and caregivers' relationship to patient.

The institutional practice highly recommends that the patient or caregiver be given the stroke education packet prior to hospital discharge. The nurses are encouraged to provide oral education to review the packet, but this is not required and may not be practiced consistently. The nurse indicates that they have completed the stroke education by checking off a series of boxes in the education portion of the electronic medical record and then writes into their notes that the stroke packet has been given. An electronic medical review was conducted to check the documentation of stroke education for only those who participated in the interviews.

### Design and Procedure

Following verbal consent over the phone, caregivers and ICH patients were asked to return to QMC to sign the consent forms and participate in face-to-face, semi-structured interviews. Caregivers and ICH patients were given the option of being interviewed together or separately. Thereafter, two trained research staff members conducted face-to-face, semi-structured interviews with caregivers and/or patients utilizing a script developed by the research team. Research staff members opened each interview with an explanation of the study, and then asked participants to speak freely throughout the interview. The script included open-ended questions and focused on nine major topics, one of them being information about stroke. Participants were probed with non-leading questions and neutral statements to elicit further narrative. Some of the specific questions regarding stroke awareness and education used during the interviews were: "How did you feel about your receipt of information about stroke while you were here?" "Did you feel that the doctors told you everything you needed to know to take care of your health?" "Do you think they provided you folks with enough information for you to take care of yourself?" "Do you think you received enough information about the condition?" "As far as education goes about stroke, what kind of resources do you have?" "How do you feel about you and your family's receipt of information about the situation when in the hospital—like the education you received? Now did you receive a stroke packet education book?" "Do you feel that you got enough information

Table 1. Demographics			
	Caregiver (n = 11)	Patient (n = 10)	Combined (N = 21)
Male	6	3	9
Female	5	7	12
Age, mean (s.d., range)	61 (9, 49-76)	61 (13, 42-82)	61 (11, 42-82)
Education			
Less than High school	1	2	3
High school	2	1	3
Some college	1	2	3
College	7	4	12
Relationship to Patient			
Parent	1	N/A	N/A
Spouse	6	N/A	N/A
Son/Daughter	2	N/A	N/A
Friend	1	N/A	N/A
Niece/Nephew	1	N/A	N/A

about the condition?" The audio portion of the interviews were digitally recorded for later transcription and analysis.

After completion of the interviews, the electronic medical records of the 10 participating stroke patients were reviewed for documentation of stroke education during hospitalization. After review of the electronic medical records, the stroke education packets currently utilized for patient education were examined for content. Lastly, any cognitive deficits that may have impaired the patients' capacity to retain information were collected for rule-out purposes.

### Data Analysis

The audio-recorded data was transcribed and all identifying information mentioned during the interview, such as the patient or family caregiver's name, was de-identified to protect patient confidentiality. Inductive content analysis was used whereby initial codes were grouped into recurrent and prominent themes across participants. The research team revised the codebook several times until agreement was reached and broad themes were apparent, based on the frequency, emotion, and extensiveness of the narrative. Two authors then discussed and created the final codebook. A kappa coefficient of 0.72 was reached.

### Results

On average, interviews lasted 47.57 minutes, ranging from 36 to 86 minutes. Analysis of the interviews revealed three areas of concern: (1) lack of stroke knowledge/awareness, (2) need for stroke education, and (3) fear of stroke recurrence.

### Lack of Stroke Knowledge and Awareness

Interviews revealed that ICH patients and caregivers delayed calling 911 and did not identify their symptoms as stroke during acute onset. Patient 1 mistook her initial symptom of stroke,

which was a sudden onset of severe headache, as a symptom of influenza and decided to wait to seek medical attention. It was not until Patient 1 return home when her symptoms significantly worsened that she decided to go to the Emergency Department.

Caregivers who responded immediately to stroke symptoms did so only when the patient exhibited clear signs of impairment or if he/she had experience with a previous health emergency. Caregiver 1 recalled the day she came home from work and found her daughter, Patient 2 in the bathtub minimally responsive. Caregiver 1 "...tried to wake her and call her," and responded to the situation immediately by calling 911. Patient 3 compared her symptoms of stroke to the time she had a myocardial infarction. Although she did not realize at the time she was having a stroke, she sought urgent medical attention because of her inability to walk.

### Need for Effective Stroke Education

Table 2 shows the different domain of difficulty that both the patients and their caregivers faced with obtaining stroke education. When participants were asked about receiving education prior to discharge from inpatient care, interviews revealed that it was generally the caregiver who took on the chief responsibility for receiving education, especially if the patient lacked decision-making capacity at the time. In fact, a majority of the ICH patients had no memory of the hospitalization all together. Caregivers who were not present and therefore unable to receive direct education from hospital staff were dissatisfied with the provided educational methods. Caregiver 2 said,

"I read the packet. I couldn't make sense out of the packet...If I knew what kinds of questions to ask after I read it...that would be great. I could understand some of it. But even your packet tells you like the two or three different types of strokes you can have, but I didn't even know what she had."

As demonstrated in this narrative, people affected by stroke may not be utilizing the information that was given during the hospitalization due to difficulty comprehending the educational materials. For example, Caregiver 2 said, "I mean because, I tried to read about it, but I mean—it's not in layman's terms. When you read it, it looks like that's the worst thing in the world."

In some cases, caregivers did not recall receiving information during hospitalization, or misplaced their educational packet. When prompted about the packet, Caregiver 3 stated, "I don't think they gave me any information, or they may have given me some written information, but I never read it." Caregiver 4 said, "Yeah I think we did. We have it at home in a file some place., I think," further demonstrating that caregivers and patients may not be utilizing the provided packets. Participants valued face-to-face education during inpatient care and appreciated when information was provided in plainspoken language. Suitable language created a welcoming environment where patients felt comfortable to ask questions.

The majority of the interview participants reported relying mainly on their primary care physician and post-stroke services as a significant source of education after discharge from acute hospitalization. Caregiver 4, who was an active information seeker, stated, "Well, the first thing I would contact is [doctor] and you guys first." Caregiver 4 further displayed his belief of going to the "doctor's" office not only to receive direct health care, but also to acquire advice for managing the disease. In Caregiver 1, remembering what to ask was a challenge:

"That's why I should write down on paper what kinds of questions I need to ask...But I never do...When I go there (the doctor's office), I forget, and then when I go home I remember, "oh I forgot to say this, I forgot to ask this."

When patients and caregivers forgot to ask their questions during outpatient visits and required additional inquiry, they resorted to searching for answers on the Internet. However, despite the presence of Internet resources in the education packet, many felt that the Internet was inadequate in providing trustworthy information.

### Factors That Motivate Stroke Prevention Measures

Some patients who had previous substance-abuse challenges felt empowered after learning that cessation of drug abuse could lower their stroke risk. Caregiver 2 reflected, "When I talked to [doctor] the first time, he said, 'got to stop the dope.'" Experiencing the stroke served as a turning point when the

Patient (n = 10)	
No memory of the hospitalization	7/10 (70%)
Stroke education material was not helpful or did not read the material	3/3* (100%)
Caregiver (n = 11)	
Had inadequate knowledge of stroke prior to hospitalization	5/8 (63%)
Felt inadequately educated about stroke prior to discharge	4/6 (67%)
Felt that stroke education material was difficult to understand	5/5 (100%)
Felt that stroke education material not helpful or did not read the education material even though it was provided during hospitalization	7/7 (100%)

\*Only the patients who remembered the hospitalization (n = 3) were used for the denominator.

Denominator may not equal the total number since some respondents did not specifically address or describe each domain during the interview.

patient adopted healthier behaviors. Patient 7 spoke about her past with methamphetamine use:

“...I didn’t know what was going on until my husband and friends told me that I had bled in my brain and I didn’t understand why... it was an experience that I don’t want to go through again. But it was a life changing learning experience for me that it made me stop doing drugs.”

In Patient 2’s case:

“... I used to drink like crazy. Every day. I don’t drink anymore. I don’t know why—but after the stroke, nothing... Either the stroke was going to kill me, or the drinking...”

However, some patients demonstrated apathetic attitude towards managing their health even after their stroke-related hospitalization. One interview revealed that even after having a stroke, the patients’ perspective on secondary prevention remained unaltered for the reason that she did not believe that stroke was preventable. Patient 2 stated, “Well, if you’re going to get it, you’re going to get it. You can’t stop it.”

Another area of motivation that emerged from the narrative was fear of experiencing recurrent stroke, and knowing how to prevent stroke. Interviews revealed that both caregivers and patients acknowledged the occurrence of stroke and accepted that preventing the recurrence of stroke would require a lifestyle adjustment. Patient 6 said, “That’s what I kind of worry about. They say you can have another one and another one and... He (ref. to doctor) told me the next one will be my last one. I won’t survive it.” Experience with having a stroke became a chief cause of anxiety that at times prevented patients from returning to independence: “...I don’t know which doctor said, she’s high risk for another stroke. That’s been laying heavily on my mind so I try not to let her do too much—although maybe I should let her do stuff around the house,” admitted Caregiver 1.

### Provision of Stroke Education

Results from review of the electronic medical records showed that 8 of 10 patients received a formal stroke education prior to discharge from the QMC. Stroke education includes a packet with information about: signs and symptoms of stroke, when it is important to activate EMS by calling 9-1-1, personal modifiable risk factors for stroke, information about prescribed medications, and importance of follow-up after discharge. Although none of the patients in this study initially had a significant cognitive or language deficit that impaired the patient’s ability to comprehend the provided educational material, only 3 out of the 10 patients actually retained the memory of their hospitalization. This highlights the importance of not relying on the acute hospitalization period as the sole venue for stroke education.

### Discussion

The results from this study reveal what 10 stroke patients and their caregivers knew before having a stroke, and the knowledge attained after having a stroke. Similar to prior studies,<sup>11</sup> many individuals in our study who experienced a first-time stroke

did not believe that their symptoms were serious, and believed that their symptoms would resolve on their own. In addition, research demonstrates that people who are at high-risk for stroke or have experience with stroke are no more knowledgeable about stroke, than those without history or experience.<sup>2</sup> When surveying a sample of individuals who had a stroke, less than 35% could describe signs and symptoms of a stroke and would take action to call 911.<sup>9</sup> This lack of knowledge in stroke signs and symptoms is noteworthy, suggesting that future first-time stroke victims may delay seeking medical attention and that more public education is needed.

Our study suggests that despite providing the stroke education packet to the patients and caregivers, the stroke packets are not actually utilized by the patients. While presenting information just prior to discharge may be a practical time for stroke care providers to educate caregivers and patients, the results from this study demonstrate that patients need information pertaining to care after discharge. In past studies caregivers and patients were focused on information directly related to stroke disease during the acute phase, while, almost 6 months later, wanted information about how to manage their disease, and prevention of another stroke.<sup>9</sup> This lack of information causes unnecessary anxiety about preventing another stroke from occurring.<sup>6</sup> Similar to other areas of chronic illnesses, educational needs change over time during the illnesses, and the optimal timing and mechanism of effective delivery of stroke education needs to be further considered,<sup>7</sup> especially since the majority of the stroke patients that were interviewed could not remember the hospitalization at all. Since stroke is potentially a life-changing event for many people, the post-stroke period may serve as the optimal “teachable moment” when stroke survivors’ and their caregivers’ behavior and lifestyle could potentially be significantly changed. Our findings indicate pre-discharge education may not be effective; instead, the first outpatient visit after stroke occurrence may be the ideal opportunity to positively influence a patient who is motivated to change by offering stroke awareness and prevention education in a comprehensible manner.

### Limitations

First, the small number of caregiver and patient participants limits the generalization of these results; however, qualitative methods were used to capture the depth of stroke education and awareness experienced by patients, which often sacrifices breadth. Secondly, the unique archipelagic geography of Hawai‘i restricted our ability to conduct face-to-face interviews with prospective participants who resided on neighbor islands, therefore limiting our selection. Thirdly, caregivers and/or patients were required to speak English in order to participate in this study and it is possible that certain populations were overlooked due to language barriers, and therefore unintentionally excluded from this qualitative study. In the future, incorporation of a scale assessing functioning abilities of stroke patients may help us to understand how it affects the educational needs of both patient and caregiver. In addition, educational needs of outer-island stroke patients should also be explored.

## Conclusion

Our findings demonstrate that most stroke survivors do not recall their hospitalization experience and the stroke education given during the hospitalization are not effective. This suggests the need for health professionals to promote stroke awareness and provide education to caregivers at discharge and to both survivors and their caregivers after discharge. While patients may not be utilizing the educational material provided at discharge, interviews revealed that having a stroke can serve as an influential experience to motivate patients to change their behaviors. Health care providers should improve education materials and delivery methods to utilize this powerful moment to deliver comprehensive education on stroke-related topics.

## Conflict of Interest

None of the authors identify a conflict of interest.

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