Identifying access barriers to outpatient rehabilitative care after stroke

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Introduction

- Those who survive a stroke are often left with physical, cognitive, and/or communicative disabilities, requiring varying degrees of rehabilitative therapy and assistance with activities of daily living
- Stroke-related disabilities can negatively impact both survivor and caregiver quality of life and mental health, and many stroke survivors report having unmet needs
- Using focus groups, we aimed to identify access barriers to outpatient rehabilitative care among stroke survivors and moderating factors associated with encountering these barriers

Methods

- Five (5) one-hour focus groups (n=36)
  - Four (4) with stroke survivors with communication disorders (n=22) and/or caregivers (n=7)
  - One (1) with hospital administrators and rehab providers (n=7)
- Recruited from 1) a non-profit organization providing group therapy services for persons with aphasia (Triangle Aphasia Project Unlimited) and 2) a rehab services patient and family advisory board at an academic medical center (UNC Hospitals)
- Stroke survivor and caregiver groups
  - Stroke characteristics (e.g., type of stroke, impairment – immediately following stroke and long-term)
  - Rehab service utilization (e.g., types of inpatient therapy received, time to entry into outpatient rehab after discharge)
  - Barriers (e.g., financial and non-financial barriers experienced, how they changed setting and utilization of care, how to address to improve access)
- Hospital administrator and rehab provider group
  - Barriers (e.g., financial and non-financial barriers observed, how they change utilization of care, administrative challenges, potential solutions to improve access)
- This study was approved by the UNC Non-Biomedical IRB (#16-2295)

Participants

- Stroke survivors (n=22)
  - Average age: 58.1 years
  - Average time since stroke: 36.3 months
  - 14 male, 8 female
  - 13 White, 6 African American, 2 Asian, 1 Other

Quotes

Therapy caps (caregiver)

> "I think there was a lot of times that the speech therapist would have really liked to have worked with him more frequently but the speech therapy was lumped in with occupational and PT, and so if we'd have met more with speech it would have cut into his occupational and PT."

High costs (administrator)

> "So you need therapy three times a week…you're talking hundreds of dollars a week that people then decide not to get care because…it's too expensive."

Transportation (provider)

> "Then all of those transportation barriers can play into that but in particular I think Medicaid it has to be 48 hours…three days ahead of time and so even if I evaluated someone today and I had an opening two days from now, I can't see them...because they're not going to be able to get transportation..."

Table 1. Frequency of codes within each theme

Theme	Example codes	Frequency
Clinician/client relationship	dissatisfaction in therapy progress, provider/client miscommunication	92
Psychological factors	support for patients and/or caregivers	68
Family	caregivers balance multiple responsibilities	56
Administrative and organization	bureaucracy, discontinuity of care	49
Financial	copays/deductibles, therapy caps	30
Community resources	need for additional resources outside of therapy	20
Physical access	distance to services	10
Loss of identity	loss of identity	9
Other	interacting barriers	8

Results

Financial barriers

- Therapy caps and high costs were the most frequently mentioned barriers to accessing timely and appropriate outpatient rehabilitative care
- Therapy caps specifically appeared to be a source of a frustration given the seemingly arbitrary nature with which they are set (e.g., 30 visits per calendar year for physical, occupational, and speech therapy combined)
- These often changed the way people opted to get care
  - For example, a participant and his caregiver sought additional help from friends who were speech pathologists
- In addition to cost, loss of income—either by the stroke survivor, the caregiver or both—can have a major impact on a person's ability to access outpatient care

Non-financial barriers

- Non-financial barriers consisted largely of issues within the client-therapist relationship, issues with transportation and scheduling, and patient and/or caregiver characteristics
- Many stroke survivors and their caregivers did not feel as though the therapist had adequately included the patient in the goal setting process, which resulted in participants stated that they often went to therapy and completed activities without understanding why they were doing certain tasks
- Stroke survivors with physical and/or cognitive impairment often depend on a caregiver to attend therapy appointments
- When caregivers are not able to take time away from work or other responsibilities, stroke survivors miss therapy appointments and that creates scheduling issues for the facility
- Stroke survivors and caregivers sometimes struggled with the new reality of post-stroke life and spoke of loss of identity, which was often not addressed by families and/or providers

Conclusions

- Financial and bureaucratic barriers were common as were issues with the client-therapist relationship
- Consideration of alternative benefit designs for outpatient rehabilitative care may be warranted, focusing on continued progression in functional status rather than arbitrary caps
- Such an approach could allow for greater independence and lower social burden of stroke survivors in the long-term

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