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Lived Experiences of Chronic Cognitive and Mood Symptoms among Community-Dwelling Adults Following Stroke: A Mixed-Methods Analysis

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Abstract

Objectives: Few studies have explored the lived experiences of chronic cognitive and mood symptoms following stroke using a racially/ethnically diverse sample. Therefore, we aimed to explore the perceptions of chronic post-stroke cognition and mood symptoms and goals among a racially/ethnically diverse sample of community-dwelling adults aging with stroke.

Method: This qualitative study using mixed-methods analysis included semi-structured interviews regarding perceived post-stroke cognition and mood symptoms among community-dwelling stroke survivors at least one-year post stroke. Transcripts were subjected to thematic content analysis, and differences in theme usage patterns by age, gender, race/ethnicity, and post-acute rehabilitation setting were assessed using an inferential clustering technique.

Results: The majority of participants (93%) reported cognition-related themes, including language and communication, memory, thinking abilities, comprehension, visual-spatial

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processing, and cognitive assessments and training. Nearly half of participants mentioned mood-related themes, including depression, aggression and anger, mood fluctuations, anxiety, and psychological services and medication. Nearly half reported an unmet need for cognition or mood-related treatment. Inferential clustering analysis revealed that older participants reported a different pattern of cognition and mood symptoms than those aged younger than 65 (p=.02). Older adults were more likely to describe post-stroke language/communication changes, while younger adults described post-stroke mood changes.

Conclusion: Stroke survivors experienced cognitive and mood-related symptoms beyond one-year post stroke, which has implications for long-term assessment and management. Incorporation of continued symptom monitoring into existing community-based services is needed to address chronic cognition and mood symptoms affecting the quality of life of persons with stroke.

Keywords

Stroke; Cognition; Psychological and Behavioral Symptoms; Quality of Life/Wellbeing; Qualitative methods

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INTRODUCTION

Stroke incidence occurs in approximately 800,000 people annually in the United States (Winstein et al., 2016). Stroke-related disability affects persons with stroke (PwS), their families, and the entire health-care system, with estimated annual costs of $33 billion (Mozaffarian et al., 2015). Nearly one-third of PwS report post-stroke cognition and mood impairments (Hackett, Yapa, Parag, & Anderson, 2005; Serrano, Domingo, Rodriguez-Garcia, Castro, & del Ser, 2007). Cognition and mood changes may affect the PwS' recovery process (Babulal, Huskey, Roe, Goette, & Connor, 2015), physical functioning (Saxena, Ng, Koh, Yong, & Fong, 2007), social integration (Nys et al., 2006), and quality of life (White et al., 2008).

Post-stroke cognitive impairment may (Ayerbe, Ayis, Wolfe, & Rudd, 2013; Kauhanen et al., 1999; Nys et al., 2006) or may not be associated with depression (Aben et al., 2002). About 30% of PwS develop anxiety and depressive symptoms (Hackett et al., 2005), which frequently go undetected or untreated (Aben et al., 2002; Ayerbe, Ayis, Wolfe et al., 2013; Dafer, Rao, Shareef, & Sharma, 2008; El Husseini et al., 2012; Nys, et al., 2006; Vuletic, Sapina, Lozert, Lezaic, & Morovic, 2012). Research on emotional and cognitive functioning has focused primarily on the first year following stroke (Ayerbe, Ayis, Wolfe, et al., 2013; Campbell Burton et al., 2013); few studies address concerns beyond 5 years (Ayerbe, Ayis, Crichton, Wolfe, & Rudd, 2013; Ayerbe, Ayis, Crichton, Wolfe, & Rudd, 2014). Few studies have explored the lived experiences of chronic cognitive and mood symptoms following stroke (White et al., 2008). Racial/ethnic disparities in post-stroke outcomes have been well documented. Racial/ethnic minorities have greater risk for depression and poorer neurocognitive outcomes post-stroke than non-Hispanic Whites (Fei et al., 2016; Johnson et al., 2017).

Therefore, we conducted a thematic content analysis to explore the experiences of post-stroke cognition and mood among a racially/ethnically-diverse sample of community-dwelling PwS. Since older adults, ethnic minorities and women are disproportionally affected by stroke (Reeves et al., 2008; Wang, Rudd, & Wolfe, 2013), and post-acute facility variation in post-stroke outcomes exist (Alcusky, Ulbrict, & Lapane, 2017), we used a novel inferential clustering technique to detect theme usage patterns in the narratives by age, race/ethnicity, gender, and post-acute rehabilitation setting. The clustering technique compares observed patterns of theme usage between people to hypothesized clusters (e.g., age or ethnic groups) to determine if more homogeneity exists within groups rather than between groups. We studied racial/ethnic differences because racial/ethnic disparities in post-stroke outcomes have been well documented. Racial/ethnic minorities have greater risk for depression and poorer neurocognitive outcomes post stroke than non-Hispanic Whites (Fei et al., 2016; Johnson et al., 2017).This study is part of a larger mixed-methods project on patient-centered outcomes following stroke rehabilitation.

METHODS

Study Design

A convenience sample of 42 community-dwelling older adults at least one-year post stroke was recruited from hospital-based stroke support groups, a retirement community, and an assisted living facility in Houston and Galveston, Texas in the United States. Inclusion criteria were: self-referred or referred by family or support groups as having a stroke; English-speaking; and older than 18 years. Exclusion criteria included inability to respond and understand interview questions prohibiting informed consent and study participation.

Procedures

A multi-disciplinary team of three clinical researchers (SK, CH, TR) conducted in-person interviews using a semi-structured interview guide (Table 1). Interviewers probed participants for details on their experiences, including post-stroke cognition and mood symptoms. A modified interview, using a pictorial card sorting system, was used for two individuals with expressive aphasia (Helm-Estabrooks, Haley, & Womack, 2007). The 30- to 45-minute interviews were audio-recorded and transcribed. Participants received a US $25 gift certificate for their study participation.

Data collection was not stopped upon reaching theoretical saturation (i.e. no new information) (Francis et al., 2010), as we aimed to obtain rich data from different perspectives. Our sample size exceeded published suggestions for identifying recurring patterns in qualitative data (Fugard & Potts, 2015; Guest, Bunce, & Johnson, 2006; Hennink, Kaiser, & Marconi, 2017; Onwuegbuzie & Leech, 2007). Two individuals’ data were excluded due to a need for Spanish translation and an uninterpretable audio recording. Therefore, forty participants provided informed consent and their data were analyzed for this study. The Institutional Review Board of The University of Texas Medical Branch approved this study.

Qualitative and Statistical Analysis

Using a thematic content analysis approach (Bernard & Ryan, 2009), data were coded both inductively (i.e., line-by-line coding) and deductively (i.e., codes created from previous conceptualizations of cognition and mood subcategories) (Bradley, Curry, & Devers, 2007). Two clinical researchers (MRP, TR) independently coded transcripts making constant comparisons to identify reoccurring themes (Bernard & Ryan, 2009; Ryan and Bernard, 2003). Coding discrepancies were discussed until resolved. Final coding was entered into NVivo 10.0 by the lead author. To ensure data *trustworthiness* and credibility of emerging codes (Lincoln and Guba, 1986), three clinical investigators were used for member checking and checking coding quality (CH, BJ, AMS). Text searches of keywords and synonyms were employed to identify all cognition and mood statements (e.g. mood, depression, memory, think, sad).

Using SPSS 25, a dichotomous profile was created for each participant representing the cognition and mood themes mentioned. Themes mentioned or not were coded with “1” or “0,” respectively. Possible group differences were tested for age (<65 or ≥65 years), race/ethnicity (Non-Hispanic White (NHW) or Minority [Black/African American (NHB), Hispanic, and Asian]), gender (male or female), and rehabilitation setting [inpatient/skilled-nursing facility (IRF/SNF) or other (no in-facility post-acute rehabilitation)]. A similarity matrix based on calculated Pearson correlations depicted the level of agreement between the participants. Clustering in themes between subgroups was tested with a matrix permutation test, the quadratic assignment procedure (QAP) (Hubert and Schultz, 1976) using UCINET (Borgatti, Everett, & Freeman, 2002).

QAP is a nonparametric permutation procedure used in social network analysis that tests the null hypothesis that two structural matrices are similar. QAP compares the observed similarity matrix (i.e., correlation matrix) with a hypothesized matrix of the subgroups. By performing numerous permutations, random datasets are created and the likelihood of randomly matched matrices is determined. We then tested for possible clustering by age, race/ethnicity, gender and rehabilitation setting based on the theme profile and a significance level (P) of .05. With QAP, statistical significance ($p<.05$) indicates that significant clustering is present.

RESULTS

Sample Characteristics

The average age of the persons with stroke was 65.1 years (SD = 12.7), with the majority being at least 65 years or older (55%) and male (70%). The sample was racially/ethnically diverse, including 58% NHW (n = 23), and 43% Minority [NHB (n = 11), Hispanic (n = 5), and Asian (n = 1)]. Post-acute care received prior to participation included going to an IRF (n = 17), SNF (n = 6), outpatient rehabilitation or home health (n = 10), or no rehabilitation (n = 8). About 43% of the sample was 1–2 years post stroke, followed by 3–5 years (21%), six-to-ten years (24%) and greater than ten-years post stroke (12%). Out of the 40 participants, 93% reported cognition symptoms, 48% reported mood symptoms, and 7% reported no cognition or mood changes following stroke. The results are presented based on the emerging themes from the two major domains, cognition, and mood. Following, we present the QAP results of the subgroup analysis.

COGNITION

All but three participants reported post-stroke cognitive symptoms. Our cognition data were grouped into the six themes: *language and communication*, *memory*, *thinking abilities*, *comprehension*, *visual-spatial processing*, and *cognitive assessments and training*.

Language and Communication

More than half the participants reported language and communication difficulties post stroke. The most common difficulty reported was speech and language expression deficits. Perceived communication-related changes were dysphagia, reading, or writing difficulties, and social communication changes.

Memory

Nearly half the participants reported memory impairments, such as *'forgetting what to say'* and *'difficulty remembering things.'* They described feeling *'in limbo'*, or *'ignorant of what was going on.'* Memory troubles caused safety concerns, such as the potential for walking away while cooking. Memory deficits caused difficulties with attention and staying focused: '*I have a lot of things in my head….I have a busy mind*.'

Thinking abilities

Decreased thinking abilities were also reported by one-fifth of PwS. They described how their stroke negatively affected their *'mental abilities'* or described having *'cognitive issues'*, which affected their day-to-day activities or ability to drive. PwS desired to return to normalcy, such as the desire to '*think a little bit more logically*' or '*be like I used to be, normal [mentally and physically].'*

Comprehension

Some PwS had difficulty with understanding or being understood by others, which caused frustration, and affected how they interacted with others. One participant described his difficulty with understanding others: *'I understand 50%. I understand only me.'*

Visual-spatial processing

Visual-spatial processing difficulties were mentioned by one-fourth of the participants. Changes to peripheral vision or visual-spatial attention abilities caused significant frustration and negatively affected PwS' relationships with others. One participant described how his wife sits on his left side so that he does not ignore her, and feared potentially forgetting about her.

Cognitive Assessment and Training

Nearly one-fourth of participants mentioned receiving either cognitive assessments or therapy, and expressed frustration and difficulty during the assessments. Many were unsure about who provided their cognitive rehabilitation. Others mentioned playing games, using aids or apps, or receiving therapy from a speech language pathologist or occupational therapist. Cognitive impairments negatively affected the ability to return to work: 'I am also trying to improve my cognitive…I'd like to try to regain the capabilities that I had before' (P19, NHW male, <65 yrs old, outpatient).

MOOD

Nearly half of the participants perceived post-stroke mood changes. Our mood data were grouped into five themes: *depression*, *aggression and anger*, *mood fluctuations, anxiety*, and *psychiatric/psychological services and medications*. Mood changes caused feelings of frustration regarding their circumstances, as they made pre- versus post-stroke comparisons, including changes in employment, financial resources, and overall post-stroke abilities: *'Just feelings of frustration about this stroke and not recovering quick(ly) enough….It's almost been 2 years.'*

Depression

Participants described being depressed, and questioned why the stroke happened to them. They described wanting to just *'stay in bed'* and *'not want[ing] to be around people.'* Many of them spoke of how the stroke negatively affected their life. They found difficulty in not being able to do previous activities and feeling *'inadequate'*. Some participants began to isolate themselves from others, as they did not want to deal with others and noticed changes in their friends:

> Depression is terrible, at least mine is. I don't know about anyone else's but mines is bad. It actually feels like I'm in quick sand sinking down and you can't get back up. The more you try to get back up, the more you try to deal with people the more you try to get up…you just don't have any patience. I mean just tell them to go away, you know? Leave me alone and that's just how I feel. (P2, NHW male, <65 yrs old, IRF)

Others spoke of accepting the changes, despite not liking their current situation. They understood the importance of self-talk or changing their attitude to overcome depression.

Aggression and Anger

Some participants described being angry after the stroke or easily losing their temper. Other participants mentioned becoming angry and upset easily when others tried to tell them what they could or could not do. A participant described his anger as getting '*mad and then I run my blood pressure up real high*.'

Mood fluctuations

Fluctuating moods were common among a few of the participants. It would often vary each day, '*sometimes up, sometimes down.'*

Anxiety

Several participants described being anxious or worrying a lot. Some participants had anxiety along with depression. One individual stated: 'I still see a psychiatrist…anxiety and depression. Most of it's for not being able to do the things I use to do' (P7, NHB female, <65 yrs old, acute rehab).

Psychological Services and Medications

Of those reporting post-stroke mood changes, one-fifth of the sample reported being prescribed mood stabilizers and/or receiving psychological services. Despite being several years post stroke, many were still visiting a psychiatrist or therapist. One participant described the benefits of antidepressants, "*I started taking medicine. I feel like I can be around people without any problems."* In contrast, some participants did not receive treatment for depression.

COGNITION AND MOOD-RELATED GOALS

Nearly half desired to still work on areas of cognition and/or mood despite being greater than one-year post stroke. Some individuals described the prevailing need for additional speech/language services. Most of the participants were referred to stroke support groups, and described their perceived benefits of attending.

You are not alone!

Participants expressed gratitude for support groups and their benefits when dealing with the post-stroke changes, especially with funding cuts. A key factor was universality, where the participants finally felt that others understood them. It was important to '*share your experience and know that you are not alone.*' Support groups also served as an information source, which provided information on stroke and treatment options. PwS mentioned that support groups improved their social skills, provided new friends, and allowed them to '*actually open up and talk to people*.' They gained experiential knowledge or insight through the positive and negative experiences of others,

> They struggle from time to time to get a little bit more of themselves back. It's gratifying when you see what they do but it's sad when you see they're still struggling with some things that you take for granted (P6, NHW male, ≥65 yrs old, no rehab).

SUBGROUP ANALYSIS

The QAP inferential clustering test revealed that participants aged 65 years and older reported a different pattern of cognition and mood themes than those aged younger than 65 (r=0.09, p=0.02). Younger (<65 years) were more likely than older participants were to describe post-stroke mood changes (72% vs. 27%); whereas, older participants (≥65 years) were more likely than younger participants were to describe post-stroke language/communication deficits (86% vs. 56%). The QAP analysis did not identify differences in theme patterns by race/ethnicity (r=−0.01, p=0.50) or rehabilitation setting (r=0.02, p=0.23); and only weakly by gender (r=−0.08, p=0.09).

DISCUSSION

Most studies of recovery have focused on post-stroke physical changes, and cognitive and mood deficits receive less attention. In this study of community-dwelling adults aging with stroke, nearly all reported cognitive changes, and half of them reported post-stroke mood changes. We did not find significant differences in cognition and mood-related themes mentioned by gender, rehabilitation setting or race/ethnicity. Some studies revealed racial/ethnic or gender differences in reporting of mood changes or cognitive dysfunction following stroke (Fei, et al., 2016; Johnson, et al., 2017), whereas others have not (Boehme et al., 2014; Kutlubaev and Hackett, 2014). Therefore, further exploration of the role of racial/ethnic and gender differences in psychological adjustment and cognitive functioning among PwS is needed.

We did identify age-related patterns in their narratives, specifically a greater proportion of PwS <65 years described post-stroke mood changes, specifically depression, anxiety, and use of psychological services and/or medications. This is consistent with prior literature showing that age under 65 is a significant risk factor for anxiety up to 5 years, and potentially up to 10 years following stroke (Ayerbe et al., 2014). Furthermore, a greater proportion of older PwS (≥65 years) described difficulties in their language/communication including speech and expression. Older PwS are more likely to have aphasia than younger PwS (Ellis & Urban, 2016), which may explain these results.

Communication plays an integral role in activity participation, having meaningful relationships, and receiving support from others (Brown, Worrall, Davidson, & Howe, 2012). More than half of the PwS experienced significant communication difficulties and memory deficits, which negatively affected their quality of life. Memory impairment is common following stroke (McKevitt et al., 2011) and often long-lasting (Patel, Coshall, Rudd, & Wolfe, 2003). Few participants reported being assessed for cognition or receiving cognitive rehabilitation. PwS in a recent study perceived cognitive problems as *invisible* and not well understood (Patchick, Horne, Woodward-Nutt, Vail, & Bowen, 2015).

Our results indicate the need for referral for appropriate services and continued monitoring of PwS from acute care to the community. As one transitions from hospital to community, better coordination of community-based resources to PwS at-risk for developing cognitive impairment (Tang, Price, Stephan, Robinson, & Exley, 2017). Several memory strategies are suggested for use by individuals with memory deficits (Cicerone et al., 2011). However, evidence is lacking on the effectiveness of memory-focused cognitive rehabilitation following stroke (Nair & Lincoln, 2007), and future research is warranted.

About half the PwS in this study reported co-morbid depressive and anxiety symptoms but only one-fifth of PwS with mood changes indicated use of psychological services or prescribed medications, with many requiring a psychiatrist or therapist years following stroke. This supports the need for continued monitoring of depression, and provision of appropriate interventions to improve mood self-regulation in PwS. Evidence-based treatment of post-stroke depression is lacking, as some evidence exists on the benefits of pharmacotherapy but not psychotherapy (Hackett, Anderson, House, & Xia, 2008). Attending support groups was an alternative for dealing with their psychosocial needs. Peer support groups can provide numerous benefits to PwS, such as advice, providing stroke-related information, peer relationships and awareness of post-stroke deficits (Morris & Morris, 2012).

Furthermore, only adequately trained healthcare professionals should provide psychological assessments and support. Non-behavioral health specialists are often providing these services in the acute-care setting, resulting in inaccurate assessment or inappropriate use of therapeutic techniques. PwS and non-behavioral health professionals have expressed concern about healthcare professionals assuming a specialist role without psychological expertise (Harrison, Ryan, Gardiner, & Jones, 2017).

This study adds to previous investigations of psychosocial consequences of stroke by describing the experiences of chronic post-stroke cognition and mood symptoms among a diverse sample of PwS. This study's strength is the use of a novel inferential clustering technique, QAP, which allowed us to investigate theme patterns by socio-demographic characteristics and discover patterns in theme usage by age. Dyadic data are interdependent; therefore, Chi-square analyses of dyadic data would result in incorrect standard errors and inability to identify such patterns. In addition, the inclusion of PwS at various time points following stroke allowed us to understand their experiences with chronic cognitive and mood symptoms.

Impaired awareness might have influenced the perceptions of post-stroke changes. Greater emphasis is usually placed on physical limitations than cognitive and mood changes, which may not be as noticeable (Ellis, Focht, & Grubaugh, 2013; Patchick et al., 2015). However, qualitative assessment of perceived changes permitted the identification of several cognition and mood domains and allowed us to understand how these changes affected their recovery and personal life. Qualitative interviews provide richer data that are not captured by brief cognitive or mood batteries. Another consideration is the time since stroke, as this may influence the reporting of cognitive and mood symptoms.

In addition, most of our study participants were recruited from the community, primarily from support groups. The participants who were recruited from support groups might have been higher functioning and had greater insight into their post-stroke changes than those recruited from a retirement or assisted living community. Furthermore, differences in awareness of deficits may be influenced by several factors, such as lesion location, stroke type, or underlying cognitive deficits, such as impaired reasoning or memory. Unfortunately, data on stroke type and severity were not obtained, which may confound the results identifying age differences. However, using life course theory, age cohorts may have different perceptions of post-stroke changes. Since we did not use a matched pairs design, the extent of age-related differences needs to be further explored.

In conclusion, community-dwelling PwS reported a variety of chronic post-stroke changes in cognition and mood. Our results support the need for continued assessment of cognition and mood following stroke, even several years after initial stroke event. Older PwS aged 65 and older reported a different pattern of themes than younger PwS. Our results support the need to study prospectively cognitive and mood changes over time, and the development of person-centered community-based interventions to address cognitive and emotional deficits.

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Table 1.

Interview Questions for stakeholders

Topics	Questions
Stroke Event	Tell me more about your stroke.
	Tell me more about your stroke recovery? What was helpful? What wasn’t helpful?
Symptoms	Have you noticed any changes since after your stroke? Independence? Cognition? Mood?
Acute Care	Where did you receive your care?
Rehab Activities	Where did you receive rehabilitation? Did you receive any therapy once you came home?
	What type of treatments/therapy did you receive (e.g. physical therapy, occupational therapy)?
	How long did you receive therapy?
	What information was provided to you about your rehabilitation?
Rehab Goal	What do you wish they have worked on while you were in therapy?
	What was your goal(s) during rehabilitation?
Decision Making	How were decisions made about your care?
	Who helped you make the decision about your rehabilitation goals?
	How comfortable are you with the decision that was made and what would make you more comfortable?
	Was there any information that was not helpful for the decision making process?
	What are the top three to five things you thought about when you made a decision about your rehabilitation?
Overall Goals	Overall, what are your top three to five goals following the stroke?
Advice	What information would you share with others who have to decide where to receive stroke rehabilitation?
	What would you tell somebody else if they were to have a stroke? What advice would you give?
	Is there anything else we should know, or do you have any questions for me?