Social networks after stroke in rural Appalachia: a qualitative study

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Disclosures

- The authors have no financial or non-financial relationships relevant to the content of the presentation to disclose.
Impact of stroke

- Leading cause of disability
- High prevalence in rural Appalachia
- Results in reported isolation and fewer contacts with individuals within the social network
- Social isolation reported even after twelve months after stroke
- Both fewer social contacts and dysphasia are predictive of depression after a stroke
Factors related to social support

- Strong/large social support can:
  - reduce institutionalization
  - improve physical function
  - result in more improvement
  - result in faster improvement
- Development of the social support system
- Relevance to health care providers
To understand the experiences of individuals living with stroke in this area relative to social network

Quantitatively investigate
• Stroke impact in various domains of function

Qualitatively investigate
• Changes in the social network
• Assets and needs of the social network
• Including interview with both individual with stroke and caregiver
Study Details

- Design: Interpretive Phenomenological Analysis
- Analysis completed as part of a larger study
- Multidisciplinary research team
  - 3 PTs, 2 SLPs, 1 OT, 1 RN
- Integration of 3 institutions
  - University of Kentucky
  - Cardinal Hill Rehabilitation Hospital
  - Appalachian Regional Healthcare
- Subset group of Kentucky Appalachian Rural Rehabilitation Network
- Work was supported by grant #1RC4MD005760-01, funded by NIH: National Center for Minority Health and Health Disparities
**Participants**

- N = 13 individuals with stroke, 11 caregivers

<table>
<thead>
<tr>
<th></th>
<th>Individuals with Stroke (n=13)</th>
<th>Caregivers (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>9 (69%)</td>
<td>7 (64%)</td>
</tr>
<tr>
<td>Male</td>
<td>4 (31%)</td>
<td>4 (36%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>13 (100%)</td>
<td>11 (100%)</td>
</tr>
<tr>
<td><strong>Age in years: Mean (Range)</strong></td>
<td>63.3 (42–89)</td>
<td>Missing data</td>
</tr>
<tr>
<td><strong>Years post-stroke: Mean (Range)</strong></td>
<td>3.3 (1–14)</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Participants

• **Inclusion criteria**
  - Primary diagnosis of stroke
  - At least 18 years of age
  - Cognitively capable of participating in a 60–90 minute interview
  - English as a native language
  - Reside in an Appalachian rural Kentucky county

• **Exclusion criteria**
  - Too medically fragile to participate in interview
    - Determined by caregiver
**Data Collection**

- **Quantitative**
  - Stroke Impact Scale 3.0 (SIS 3.0)
  - Self–perceived ratings relative to individual domains as well as percentage of overall recovery

- **Qualitative**
  - Semi–structured interviews
  - Occurred in participants home, current living facility or regional hospital center
  - 3 members of research team: interviewer completed field notes during and reflective notes immediately after interview
Sample Interview Questions

1. Describe your experience of having the stroke.
2. Tell me about any rehabilitation you had.
3. Tell me about coming home from the hospital.
4. How do you spend a typical day now?
5. What is the best thing and what is the hardest thing about living in your community in terms of having your stroke?
6. Describe any complications you have had since your stroke.
7. How and where do you get medical or other care when you need it?
8. How do you make decisions about your care and health?
Data Analysis

- **Quantitative**
  - SIS scores for each domain entered into SPSS
  - Pearsons $r$ correlations completed to look for any relationships across domains

- **Qualitative**
  - Interviews transcribed verbatim
    - As well as reflective notes from interviewer
  - Initial analysis of interviews with team
    - Needs assessment of people living with stroke
  - Further analysis to investigate social networks
All team members individually analyzed the first three interviews followed by a team meeting to discuss initial findings

Coding scheme developed and refined through iterative process

3 team member dyads: analyzed 2 interviews per pairing

Coding scheme refined by the team and discussion and reflection of existing theories that may inform analysis

Data coded and within-case thematic analysis completed by the 3 team member interviewers for the interviews she conducted

Single interviewer synthesized findings across all cases

Meetings with entire team to assess final analyses

Initial Data Analysis Flow

Triangulation: field notes, interview data, reflective memos

Reflection and analysis of Stroke Impact Scale 3.0 and descriptive data form findings within- and across-cases
Two methods:

- Mapping of social network from interview
  - Blackstone and Hunt-Berg (2003) model of social network
  - Layers of social network:
    1. Family
    2. Close friends
    3. Acquaintances
    4. Paid workers
    5. Unfamiliar

- Analysis of social network changes and needs via interview data
  - Needs/assets analyzed by original research team
  - Across case analysis triangulated with within case analysis
# Changes in the Social Network

<table>
<thead>
<tr>
<th>Factors Impacting Changes</th>
<th>Weakened Social Network</th>
<th>Increased: 4</th>
<th>Decreased: 4</th>
<th>Remained the same: 6</th>
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<tbody>
<tr>
<td></td>
<td>Inability to return to work/volunteer</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Inability to attend church</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Transportation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Communication skills</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Strengthened Social Network</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Small Community</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>More Frequent Visits from Family</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Expansion of Healthcare Provider Network</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Family**
  - Increased: 4
  - Decreased: 4
  - Remained the same: 6

- **Close Friends**
  - Increased: 4
  - Decreased: 6
  - Remained the same: 4

- **Acquaintances**
  - Increased: 3
  - Decreased: 6
  - Remained the same: 5

- **Paid Workers**
  - Increased: 6
  - Decreased: 1
  - Remained the same: 7

- **Unfamiliar**
  - Not commented on
General trends in social networks

- In MOST cases, family remained constant
- In general, the social network was comprised of caregivers, healthcare professionals, and immediate family members
- Family/caregivers were extremely important to the quality of life of the person with stroke
- Limited opportunities for interactions with others living with stroke
- Individuals living with stroke often had difficulty taking initiative to maintain outer layers of social network
Needs for social network or to expand social network

- Education of individuals within the social network about stroke and impairments
  - General education and specific to individual
  - Stroke prevention
  - Management of co-morbidities
- Assistance with navigation through the healthcare system
- Stroke support group, caregiver support group
- Transportation support for individuals with stroke— to improve social participation within community
- Respite services for family/caregivers
- Opportunities for volunteer work for individuals that cannot return to work
<table>
<thead>
<tr>
<th></th>
<th>Strength</th>
<th>Memory/Thinking</th>
<th>Emotion control</th>
<th>Communication</th>
<th>Daily Activity</th>
<th>Mobility</th>
<th>Hand Function</th>
<th>Social Participation</th>
<th>Overall Rating of Recovery</th>
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<td>89.29</td>
<td>86.11</td>
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<td>97.22</td>
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<td>56.25</td>
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</table>

***Significant correlation between social participation score and overall recovery ($r=0.605$, $p=0.028$)
Discussion

- Importance of the social network in the recovery trajectory after stroke
- Addressing factors that weaken the social network
- Large scale implementation of programs within rural communities to help with expansion of social network
- Clinical implications
  - Assessing the social network needs and assets as part of rehabilitative assessment


Questions