Symptom Clusters of Stroke Patients by Rehabilitation Stages

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Stroke Statistics

• About 16 billion people were diagnosed with stroke every year and up to 6 billion deaths from stroke over the world (Strong et al, 2007).

• About 105,000 Korean people experience a new or recurrent stroke every year; prevalence = 795,000 in people aged older than 30 years

• The second leading cause of death in Korea; mortality rate = 53.2 per 1000,000 individuals

Hong et al, 2013; Strong et al, 2007;
Impact of Stroke

- Stroke survivors with persisting deficits showed impaired health-related quality of life (Adamit et al, 2015). The most frequent problems were related to mobility and pain/discomfort (Min & Min, 2015).

- Disability after stroke is an important burden to patients, their family, and society. Disability-adjusted life year lost due to stroke. Direct and indirect cost for stroke care = $3.3 billion in 2005 (Hong et al, 2013).

Adamit et al, 2015; Hong et al. 2013; Jokinen et al, 2015; Min & Min, 2015
Post-stroke Symptoms

- **Movement**
  - Chorea, dystonia, myoclonus, asterixis, Holme’s tremor, palatal tremor, tics, and vascular parkinsonism
  - Trouble with regulation

- **Mood**
  - Mania, depression, anxiety
  - Posttraumatic stress disorder
  - Personality changes

- **Sensory function**
  - Numbness
  - Trouble seeing/hearing
  - Headache
  - Dizziness

- **Language**
  - Difficulties in reading & writing
  - Phonological disorders, lexical semantic impairments, and syntactic impairments

- **Cognitive function**
  - Domain-specific (attention, mental speed, memory)
  - Global deficits in multiple domains
Movement

- Occurs uncommonly after stroke and tend to resolve over time, depending on the lesions, type, and size of stroke
- The frequency of movement disorders is unclear; however, this was reported with a range of 1% to 3.7% of stroke patients and survivors
- Includes chorea, dystonia, myoclonus, asterixis, Holme’s tremor, palatal tremor, tics, and vascular parkinsonism after stroke or in delayed setting or in progressive conditions
- The time course for the development of movement problems varies depending on a type of problems

Bansil et al, 2012; Siniscalchi et al, 2012
Sensory Function

• Making sense of sensory impairment
  – Insight and understanding
  – Articulating lived experience

• Interplay of sensory impairment in performing basic tasks
  – Describing sensory impairment in terms of functional impairment
  – Associating physiotherapy with motor recovery and lower limb
  – Perseverance versus learned non-use
  – Pragmatic approach to adaptations

Connell et al, 2014
Cognitive Function

• Neuropsychological problems versus cognitive complaints
  – No explicit definition for patient-reported impairment
  – Various prevalence of objective and subjective cognitive dysfunction
    • Deficits can manifest in the areas of attention, memory, working memory, spatial abilities, verbal abilities, and executive function.
    • 28.6% - 92.0% with subjective impairment about memory, mental speed, and concentration from 1 month to 54 months after stroke.

• Typically mild and “hidden” which increases the difficulty of identifying them unless specifically examine.
• Linked with language function and mood changes (i.e., worry, depression, and irritation)

Adamit et al, 2015; Rijsbergen et al, 2014
Language

- Perceived difficulties in reading, writing, and speaking
- Includes phonological disorders, lexical semantic impairments, and syntactic impairments --- show substantial recovery in the first few months following a stroke

- How to recover ...
  - Truly due to reorganization of language abilities to other functionally capable regions
  - Due to utilization of abnormal cognitive strategies

Kiran, 2012
Mood

- Approximately 20 -30% of patients were experienced
- Emotional impairment after stroke includes poststroke mania, poststroke depression, poststoke anxiety disorders, posttraumatic stress disorder, personality changes with focus on apathy and disturbances of emotional expression control
- Some patients recover spontaneously but symptoms may persist in subset of patients related to lesions in the anterior parts of the left hemisphere

Ferro et al, 2009; Fure, 2007; Kiran, 2012, Murray & Martensson, 2004
Unanswered questions

• What are patients’ perspectives on post-stroke symptom trajectory in terms of frequency, severity, and impact on their everyday activities over time?

• How can we select valid instruments that would be consistent with patients’ symptom experiences?
Study Purpose

To explore specific post-stroke symptoms of stroke survivors to deeply understand them according to their rehabilitation stages of acute, sub-acute, and chronic conditions
Data Collection

• Semi-structured interviews which was developed with the guideline of accurately assessing symptom burden
• The question was flexible, opened-ended
• The interviews which were carried out by the principle investigator and research assistants and took about one hour and were audio-taped using recording equipment
Open-ended Questions

• During the past month, what kind of symptoms do you experience?
• How much have your symptoms affected your daily activities?
## Sample Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>0 – 3 months (n = 7)</th>
<th>4 – 6 months (n = 4)</th>
<th>7 – 12 months (n = 7)</th>
<th>13 – 24 months (n = 5)</th>
<th>After 24 months (n = 4)</th>
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Data Analysis

• Qualitative content analysis was used to analyze the data from each interviewee.
• All interviews were audio-recoded and transcribed.
• Each transcript was independently coded by two researchers and codes were compared.
• Themes that emerged from the data were organized to develop a conceptual model of post-stroke symptom burden; The first transcript was read a number of times making a note of significant pieces of text; The transcript was then re-read transforming these initial notes into emergent themes.
### Frequency of symptom categories

<table>
<thead>
<tr>
<th>Symptom category</th>
<th>0 – 3 months (n = 7)</th>
<th>4 – 6 months (n = 4)</th>
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<th>After 24 months (n = 4)</th>
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</thead>
<tbody>
<tr>
<td>Movement</td>
<td>7 (100)</td>
<td>4 (100)</td>
<td>7 (100)</td>
<td>4 (80)</td>
<td>3 (75)</td>
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<tr>
<td>Sensory function</td>
<td>7 (100)</td>
<td>4 (100)</td>
<td>7 (100)</td>
<td>4 (80)</td>
<td>4 (100)</td>
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<td>Mood</td>
<td>6 (86)</td>
<td>3 (75)</td>
<td>7 (100)</td>
<td>3 (60)</td>
<td>3 (75)</td>
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<tr>
<td>Cognitive function</td>
<td>4 (57)</td>
<td>4 (100)</td>
<td>5 (71)</td>
<td>5 (100)</td>
<td>1 (25)</td>
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<tr>
<td>Language</td>
<td>3 (43)</td>
<td>2 (50)</td>
<td>3 (43)</td>
<td>2 (40)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

- Impairment in movement, sensation, and mood still persisted over time while cognitive and language-associated dysfunction were alleviated two years after their diagnosis.
Description of symptom categories

• Movement
  – Difficulties in walking, lifting arms, chewing food, bending and stretching out fingers
  – Mobility problems due to
    • Time dependent stiffness
    • Extra burden related to a leg with paralysis, such as a sense of heaviness, perceived feebleness
Patient responses:

“I feel stiffness in the morning when I get up... However, I continue my routine exercise...so I think no injection to treat pain is needed...”

“I feel like... carrying a heavy sack of rice on my left leg all the time [Her left leg was paralyzed]... Even when I sit still in the chair or am in bed, I feel heaviness. It was the most agonizing symptom.”
Description of symptom categories

- Sensory function
  - Changes in sensation:
    - absence of sensation, dull sense
    - Itching or burning sensation, a sense of tearing at flesh
    - Hyperstimulation on the paralyzed site of the body i.e., severe pain when touching something cold
  - Articulating sensory impairment in performing tasks which require sensory information, in terms of losses of visual, thermal, and taste senses
Patient responses:

“My pain is almost uncontrollable... I feel a burning sensation in my left leg... feel like a sense of tearing at flesh... A stinging pain moves around my leg and face.”

“After stroke, my sensation changed... I cannot feel temperature change... however, I become very sensitive to touch especially something cold, leading to feeling a nip in the cold air”

“When something even gazes my skin, I have unbearable pain... like pricking the skin with a awl... even when taking a shower”

“I lose my palate... so I had trouble in serving meals to my family”
Differences in perceiving symptoms

- **Cognitive Function**
  - Difficulties in understanding what I’ve seen or heard
  - Uncontrolled mind wandering
  - Domain-specific cognitive complaints: attention, speed in cognitive processing, face recognition, calculation, comprehension, time recognition
Patient responses:

“I have short-term memory problems... such as when to take medication, names of others that I knew before... However, I think it’s getting better.”

“Although I watch TV drama, I cannot understand from time to time and remember what I’ve seen...”

“My forgetfulness is out of my control.”

“I cannot control day dreaming”
Differences in perceiving symptoms

• **Language**
  - Frequently reported in survivors with a left-side stroke
  - Closely linked with cognitive function and muscle movement

• **Mood**
  - hot-temper, anger, lowered stress threshold
  - Depression, hopelessness, sense of shame, endless despair, suicidal thinking
  - Being unable to control their emotions
  - Perceived shortage of abilities to cope
Patient responses:

“My tongue wasn’t often in accordance with my thought... because I cannot speak as I think”

“Severe depression might occur recently... It is not rare to me... When I was hospitalized to treat stroke, I suffered from illness of mind. As time passed, the fact that I could not walk by myself drove me nuts... like panic disorder. It was extremely serious and made me want to die”

“I think I was fully in control of my emotion before stroke. Now I cannot stand for something that I let go before... very stressed out... depressed... mood changed after stroke”
Connectedness among symptoms

**Movement**
- Greater mood changes associated with walking problems
- Lack of coordination between movement and intention to move
- Walking disturbance with poor sense of balance

**Mood**
- Articulation problems & difficulties in speaking loudly due to muscle weakness/paralysis
- Association between mood change and pain

**Language**
- Difficulties in choosing proper words & comprehending conversations

**Sensory function**
- Difficulties in learning something new
- Anger associated with loss of self-control
- Pain is getting worse when being in unfamiliar settings

**Cognitive function**
- Difficulties in choosing proper words & comprehending conversations
- Association between mood change and pain
- Difficulties in learning something new
- Anger associated with loss of self-control

CNU, 2015
Consequences of symptom distress

- **Movement**
  - Social isolation

- **Sensory function**
  - Reduce ADL (e.g., eating, washing, clothing)

- **Cognitive function**
  - Barriers to self-care (e.g., medication adherence)

- **Mood**
  - Social isolation
  - Discord in family relationships
Summary

• Except for language dysfunction associated with the effect of stroke in the left hemisphere, patterns of symptom experiences was not related with gender, age, having a job before stroke diagnosis, and region of injury (not shown).

• Impairment in movement, sensation, and mood still persisted over time while cognitive and language-associated dysfunction were alleviated two years after their diagnosis.

• We found interesting connection among symptoms. Movement disorder was closely linked to sensory, cognitive, and emotional problems. However, language problems were connected with cognitive and mobility problems.
Summary

• Each symptom categories showed distinctive impacts on daily lives although there seemed to be slightly shared consequences among symptom categories.

• Our increased knowledge of poststroke symptom may contribute to a better understanding of patient’s perspective on symptom distress, improve communication between healthcare professionals, patients, and caregivers, and establish multidisciplinary collaboration for therapeutic management that meets the needs of the patients.