Illness Representations of Stroke from Healthcare System-Based Perspectives: A Comparison between USA and China

Yalian Pei, PhD, CCC-SLP[1] & Amy M. Kemp, PhD, CCC-SLP[2]

[1]Department of Communication Sciences and Disorders, College of Arts and Sciences, Syracuse University

[2]Department of Speech and Hearing Sciences, College of Medicine, Washington State University

Background

- The Common Sense Model (CSM) is a framework for describing and understanding processes involved in responding to or managing illness threats (Leventhal et al., 1980).
  - By addressing underlying beliefs for evaluating injuries, the CSM can aid in predicting adherence and health outcomes, both influential in recovery.
- The CSM has five main perceptions of illness:
  - What the illness is (identity); how long it will last (timeline); the believed consequences (consequence); the cause; if the individual can control the illness; and if the illness is accurately represented (coherence)
- Illness perceptions inform rehabilitative practices to provide education on symptoms, effect on daily life, and the recovery process, ultimately generating better health communication.
- Healthcare systems and their approaches to rehabilitation services differ between the USA and China. The USA operates on a fee-for-service model with a well-established rehabilitation industry, including speech-language pathology (Nationwide Audit, 2021).
- In contrast, China provides nearly universal healthcare (Yu, 2015), but despite steady growth in rehabilitation resources over the last decade, the speech-language pathology profession is still developing. Moreover, regional disparities, particularly between eastern and western regions and urban and rural areas, greatly affect the availability of rehabilitation services in China (Jung et al., 2020).
- Differences in cultural beliefs as well as healthcare system between China and the US may shape people's perceptions and responses to stroke and aphasia differently.

Objectives

1. Participants will be able to identify each construct related to the Common Sense Model (CSM) illness representation in people with aphasia's (PWA) "My Stroke Story" discourse.
2. Participants will be able to discuss differences in CSM illness representations between Chinese and American PWA.
3. Participants will be able to interpret how different CSM illness representations in Chinese and American cultures may play a role in rehabilitation after a stroke.

Participants

Participant Demographics	Chinese PWA (n=11)	American PWA (n=11)
Gender		
Female	3 (27.27%)	2 (18.18%)
Male	8 (72.72%)	10 (90.09%)
Age M(SD)	44.36 (12.08)	55.27 (10.74)
Aphasia Type		
Anomia	8 (63.64%)	8 (63.64%)
Transcortical Motor	2 (18.18%)	2 (18.18%)
Conduction	1 (9.09%)	1 (9.09%)
WAB Score M (SD)	79.45 (10.29)	79.45 (10.29)

Note: No significant differences between groups.

Methods

Design
- Informed grounded theory (CSM) was used to qualitatively analyze "My Stroke Story" from Chinese and American PWA.

AphasiaBank
- Data were collected from AphasiaBank (MacWhinney et al., 2011) which provided pre-transcribed structured discourses for the questions:
  - "I'm going to be asking you to do some talking. How do you think your speech is these days?"
  - "Do you remember when you had your stroke?"
    - If yes, "Please tell me about it."
    - If no, "Well, how about your first memories after the stroke. What can you tell me about that?"
  - "Tell me about your recovery. What kinds of things have you done to try to get better since your stroke?"
- Both authors reviewed and coded transcripts in their first language (YP-Chinese; AK- English).

Data Analysis
- Each transcript was inductively coded to discover important categories and interrelationships. This first analysis stage compared key codes between the two languages.
- Themes were identified in an iterative, literature-informed investigation.
- The final codebook was then derived from the CSM cognitive constructs, and both authors coded deductively.
- Finally, authors looked for commonalities and differences between cases about each construct in the CSM.
- Data are represented based on Qualitative Consensus Coding (Hill et al., 1997) which described themes as represented by each group *consensus* (50%+), *occasional* (25-50%), and *variant* (<25%).
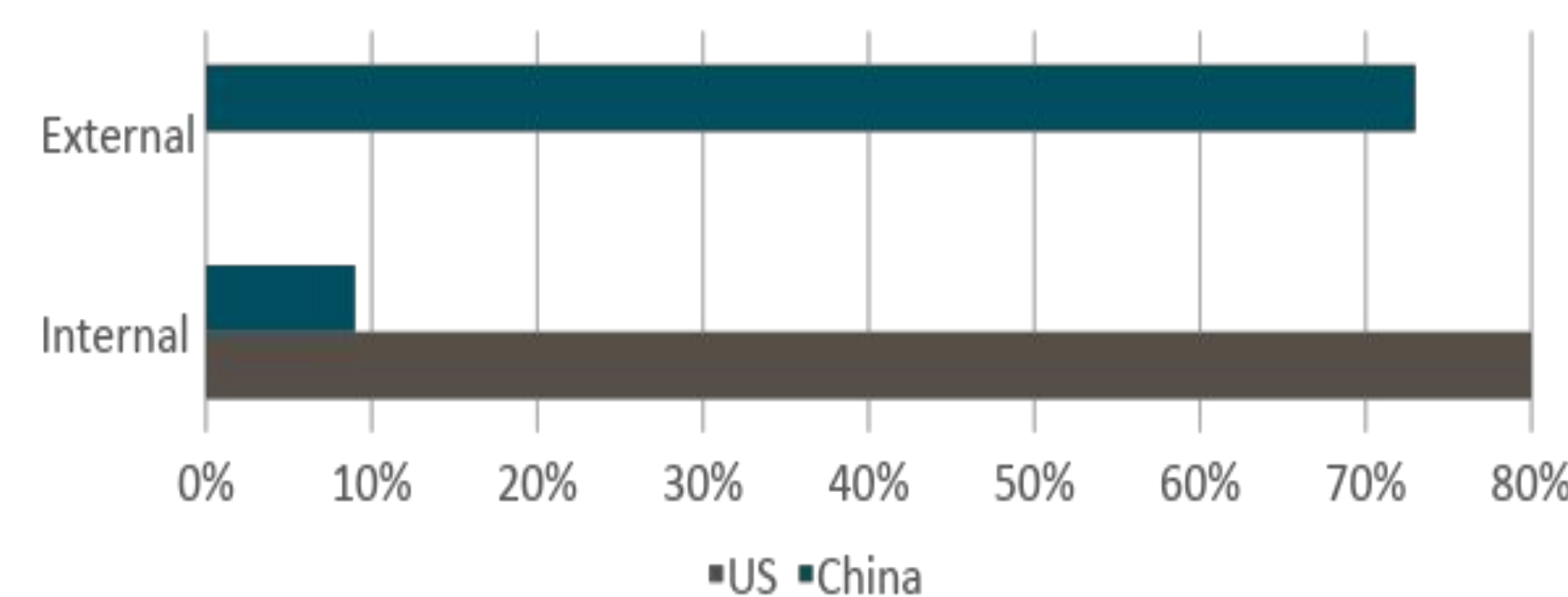
Results

Cause and Identity
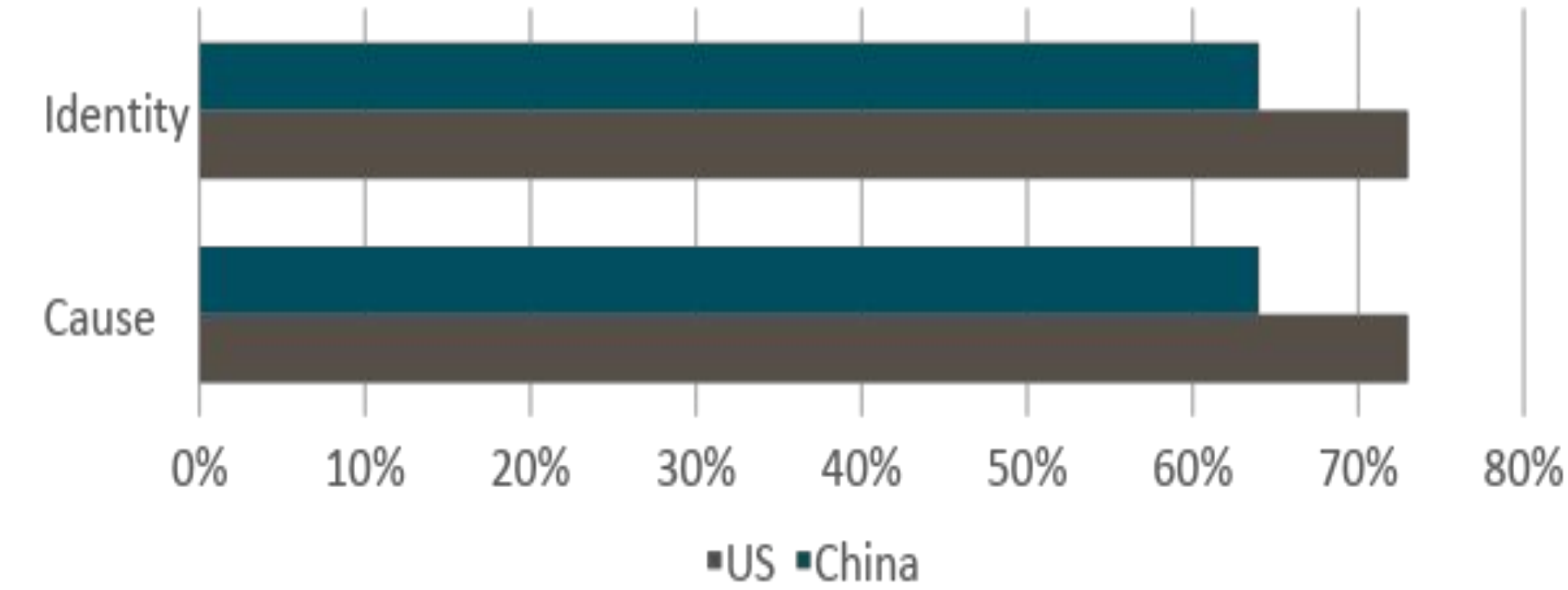
Typical consensus on *cause* and *identity* of a stroke.

"I remember waking up my husband and telling him I had a really bad migraine and I couldn't take it anymore from there and we went to the hospital and I don't remember anything."

"七月 [/] 七月 六号 [/] 六号 吧; 就是 <坐着 车 然后> [/] 坐 车 然后 头 [/] 头 疼, 抬_起_指_头, 然后 是 去 了 然后 我 就是 昏迷 的."
(July 6th, I was in a car, then headache, passed out.)

Controllability

Typical consensus of US internal *control* vs. typical consensus of China external *control.*
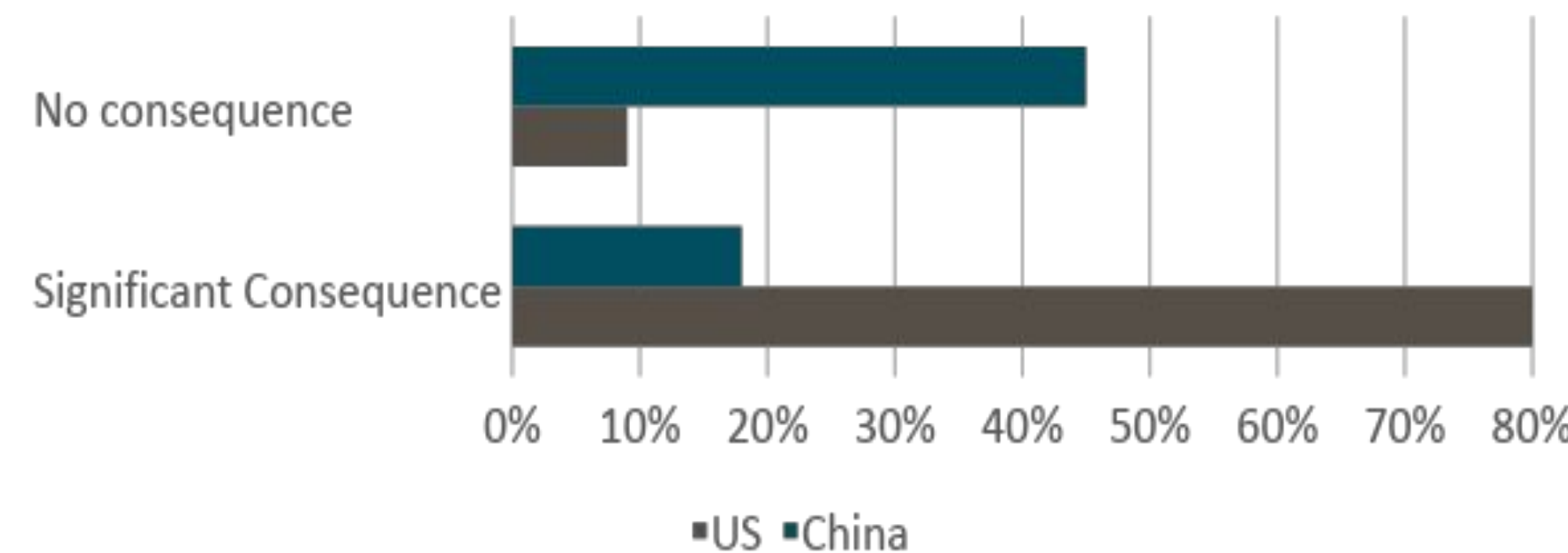
"I went to REHAB and you know they did physical therapy…speech therapy… Intensively and I worked really hard and I got better.

"我 很 积极, 配合 医生" (I actively cooperate with doctors.)
""哎, 我 能 做 什么 呢" (Sigh,What can I do..)
"嗯, <在 康平> [//] 在 [/] 在 建宁 康复 医院 (..) 做 了 高压氧; 嗯, 在 建宁 康复 医院 做 了 经颅磁" (I did Hyperbaric oxygen and t-DCs at Jianning hospital.)
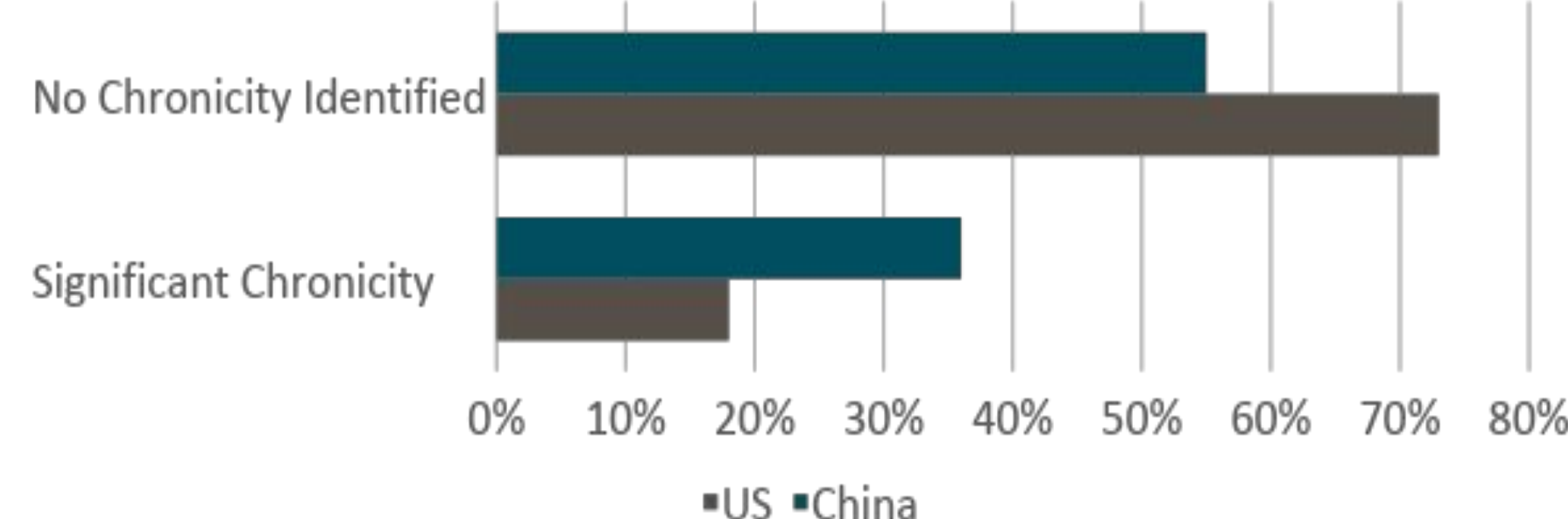
Consequence

Typical consensus of US significant *consequence* (Variant in each)
"it's definitely getting better but I still have a long way to go. My biggest obstacle is reading. I can't read like at all."

Occasional consensus in no *consequence*, especially on language functions for China

"就是 (.) 洗澡 不 会, (啊, (..) xxx 烧 饭 也 [/] 也 还 可以 吧 . . .好 [/] 好像 <就 是> [/] 就是 少 了 +... • " (Can't bathe, cook, less…)

Chronicity of Illness

Typical consensus of no chronicity discussed in both
"because I was an active guy. I was an iron worker…then I had a stroke and I said "whoa boy" and then I can't even read of nothing. I said what am I gonna do? sit here and tube you know television? and I didn't even like television."

Occasional consensus of chronicity in China (variant in US)
"现在就基本上是不能上班啦." (Basically can't work any more)

Discussion

- Overall, illness representations differed between PWA and the USA and China, primarily in controllability, consequence, and chronicity.
- Specifically, PWA from the USA represented their stroke with high controllability and high consequences in language, but low chronicity, which may offer support for the adoption of problem-based coping strategies but decrease appropriate emotional coping strategies.
- The US healthcare system uses a fee-for-service approach to rehabilitation which may account for the reliance on seeking rehabilitation services to support favorable outcomes.
- Consequently, the reliance on continued treatment may impact processing and coping of the consequences of stroke.
- Alternatively, PWA from China represented their strokes with low controllability, low language consequences, but high chronicity, which may lead to an emotion-focused coping response and a decrease in problem solving coping.
- Limited understanding about the differences between rehabilitation and medical treatment may cause many patients to passively receive the services and feel less control over the recovery process..
- The emphasis on productivity in Chinese culture may cause individuals to downplay their communication difficulties.
- To improve coping responses, clinicians should pay particular attention to components of illness representations likely to affect PWA treatment responses, namely controllability and chronicity.

Limitations

- These data represent a static timepoint in the representation of a stroke which may not account for time post onset, social/peer support, insurance factors, or healthcare opportunities.
- Further, as a standardized discourse, natural conversation with the interviewee may have decreased the opportunity to elaborate or explain certain aspects of the stroke story relevant to illness representation.
- Other demographic data was not available for analysis.

Acknowledgements
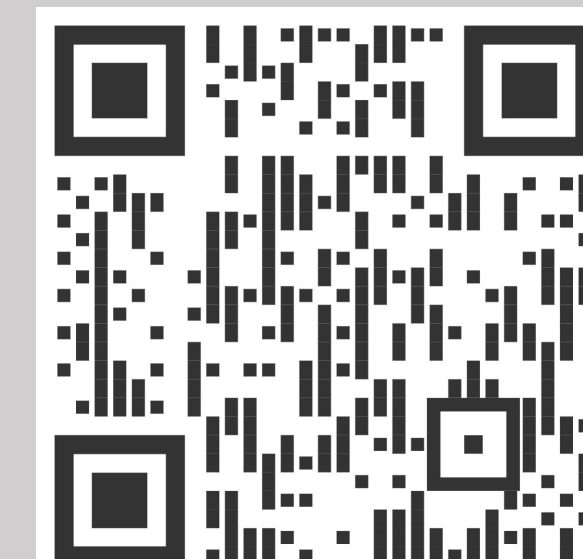
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