

**Development and Validation of
the Community Participation Activation Scale**

BY

DANBI LEE

B.O.T., Yonsei University, Wonju, South Korea, 2005

O.T.D., University of Illinois at Chicago, 2009

THESIS

Submitted as partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Disability Studies
in the Graduate College of the
University of Illinois at Chicago, 2016

Chicago, Illinois

Defense committee:

Joy Hammel, Chair and Advisor
Carol Gill
Glenn Fujiura
Carolyn Baum, University of Washington in St. Louis
Trudy Mallinson, George Washington University

ACKNOWLEDGEMENTS

The dissertation would not have been possible without the help and support of people around me. Above all, I would like to thank my mentor and committee chair, Dr. Joy Hammel for her support, encouragement, guidance, and scholarly mentoring. I would also like to thank my committee members, Drs. Carolyn Baum, Glenn T. Fujiura, Carol Gill, and Trudy Mallinson for their invaluable input and support throughout the study.

I recognize and thank all of the participants of the study for spending their time to share their experience, insights, and expertise with me. Thanks also go to my fellow graduate students at Dr. Hammel's research lab for their camaraderie and support. Finally, I would like to thank my husband and family for their unconditional support and love during my endeavor.

Following are funding sources that supported this dissertation.

- Dissertation Pilot Grant by the Midwest Roybal Center for Health Promotion and Translation (Grant # P30AG022849)
- Chancellor's Graduate Research Fellowship from the Graduate College at University of Illinois at Chicago
- Provost's Award for Graduate Research from the Graduate College at University of Illinois at Chicago
- Occupational Therapy Doctorate Research Scholarship from the Department of Occupational Therapy at University of Illinois at Chicago

TABLE OF CONTENTS

<u>CHAPTER</u>	<u>PAGE</u>
I. INTRODUCTION.....	1
II. BACKGROUND.....	7
A. Complexity of Participation for People with Stroke	7
B. Gap in Participation Focused Assessments.....	9
C. Use of Mixed Methods Design for Instrument Development in Disability Research	11
III. METHODS.....	16
A. Phase 1: Defining The Target Construct and Conceptual Model	18
1. Literature review.....	18
2. Grounded theory focus groups.....	18
3. In-depth individual interviews	20
4. Analysis to inform a conceptual model and generate an item pool	21
B. Phase 2: Item Refinement	22
1. Expert review	22
2. Cognitive interviewing	22
C. Phase 3: Testing The Psychometric Property of Community Participation Activation Scale.....	24
1. Sampling.....	24
2. Data collection.....	24
3. Data analysis.....	26
IV. RESULTS.....	30
A. Paper 1 - Facilitators to Active Community Participation Experienced by People with Stroke: A Qualitative Study.....	30
1. Abstract.....	30
2. Introduction	31
3. Methods	33
4. Results.....	36
5. Discussion.....	53
B. Paper 2 - Development of the Community Participation Activation Scale (CPAS): Conceptualization and Item Development	58
1. Abstract.....	58
2. Introduction	59
3. Methods	61

TABLE OF CONTENTS (continued)

<u>CHAPTER</u>	<u>PAGE</u>
4. Results	65
5. Discussion.....	77
C. Paper 3 - Validation of The Community Participation Activation Scale: A Measure of Attitudes And Actions Activating Community Participation in Persons with Stroke.....	81
1. Abstract.....	81
2. Introduction	82
3. Methods	85
4. Results	89
5. Discussion.....	99
6. Conclusions.....	103
V. DISCUSSION	104
A. Discussion of Findings	104
1. Conceptualizing community participation activation	104
2. Content validity and accessibility of the Community Participation Activation Scale items	109
3. Psychometric properties of the Community Participation Activation Scale	110
4. Implications for rehabilitation practice and research	111
B. Limitations and Future Direction	113
VI. CONCLUSION.....	116
APPENDICES	118
Appendix A	119
Appendix B	121
Appendix C	123
Appendix D	124
Appendix E	136
Appendix F.....	140
REFERENCES	143
VITA	160

LIST OF TABLES

<u>TABLE</u>	<u>PAGE</u>
I. DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS (N=13)	37
II. SELECTED QUOTES THAT SUPPORT EACH DOMAIN	66
III. CHARACTERISTICS OF EXPERT PANEL (N=8)	75
IV. CHARACTERISTICS OF COGNITIVE TESTING PARTICIPANTS (N=5).....	75
V. SELECTED COMMENTS FROM THE COGNITIVE TEST.....	77
VI. DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS (N=93)	90
VII. RASCH SUMMARY PSYCHOMETRICS.....	92
VIII. FINAL ITEM STATISTICS FOR ACTION ITEMS	93
IX. FINAL ITEM STATISTICS FOR ATTITUDE ITEMS.....	94
X. CONSTRUCT VALIDITY OF THE COMMUNITY PARTICIPATION ACTIVATION SCALE.....	97

LIST OF FIGURES

<u>FIGURE</u>		<u>PAGE</u>
1.	Research procedure.....	17
2.	Interview guide for focus group and individual interview	35
3.	Three levels of participation and influencing factors.....	50
4.	Conceptual model describing community participation activation.	74
5.	The Wright maps for action and attitude domains	96
6.	Action and attitude person measures plot.....	98

LIST OF ABBREVIATIONS

CPA	Community Participation Activation
CPAS	Community Participation Activation Scale
CPI	Community Participation Indicators
DIF	Differential Item Function
ICF	International Classification of Functioning, Disability and Health Model
I-CVI	Item level Content Validity Index
MnSq	Meansquare
RNLI	Reintegration to Normal Living Index
RSM	Andrich Rating Scale Model
S-CVI	Scale level Content Validity Index

SUMMARY

Much effort has been made to clarify the definition of participation and identify how to best measure the construct since the International Classification of Functioning, Disability and Health (ICF) model included participation as a major component. A growing body of literature supports that participation requires continuous management of individual and social needs and values. Enabling and activating people with stroke to be ready to participate in the community is a desired outcome of stroke rehabilitation; yet, no measures are available to assess how ready or activated a person is for community participation that can then inform participation-focused interventions tailored to the person's level of activation. Therefore, the aim of the study was to develop and validate a new measure called "Community Participation Activation Scale (CPAS)" that examines how activated a person is by assessing attitudes and actions facilitating community participation.

An exploratory mixed method design was used, in which the qualitative study (phase 1 and 2) complemented the quantitative study (phase 3). In phase 1, a conceptual model explaining factors activating participation was developed based on findings from focus groups, in-depth interviews, and literature review. The conceptual model showed that there is a dynamic interaction between attitudes and actions which activates and enables community participation post stroke.

In phase 2, the CPAS items were developed based on the conceptual model, then refined using expert reviews and cognitive testing. A pool of 41 items was examined by eight experts. The overall scale level content validity index was 0.90 after

SUMMARY (continued)

deleting five items based on ratings and comments from the experts. Then, 37 items were tested and revised based on findings from cognitive testing with five individuals with stroke. Revision included combining items, deleting irrelevant items, clarifying the meaning of ambiguous items, simplifying wording, and lowering the reading level.

In phase 3, a pool of 27 items were field-tested with 93 individuals with stroke living in the community. Rasch modeling and classic test theory were used to examine the psychometric property of the CPAS. After deleting a misfitting person and items, Rasch analysis supported the unidimensionality and monotonicity of 15 action items and 10 attitude items. Person separation reliabilities of the Action and Attitude domains were 0.75 and 0.72 respectively, and internal consistency reliabilities were 0.82 and 0.84 respectively. The CPAS showed low to moderate correlation with community integration and enfranchisement constructs ($r=0.39-0.55$).

The CPAS represents an important contribution to the literature for increasing our understanding of activation in the context of community participation. Although the assessment needs further development to improve precision, the initial findings demonstrated that CPAS can be explained by two distinct domains: Action and Attitude domains. The study provides preliminary findings supporting that CPAS can be used as an assessment to examine community participation activation in people with stroke and may help inform individually designed, participation-focused interventions.

I. INTRODUCTION

Since its inclusion in the International Classification of Functioning, Disability and Health (ICF) model as a major component of disability and health, participation has become central in discussion across all rehabilitation and health care professionals (World Health Organization [WHO], 2001). In the ICF, participation is defined as involvement in life situations (WHO, 2001), which encompasses a broader perspective of human life. In this model, participation interacts with health conditions, body functions and structures, activities, and environmental and personal factors. Some examples of participation categories include being a student, worker or economic participant, caregiving, homemaking for others, parenting, and engaging in organizational/community life, recreation and leisure, religious activities, and civic and political activities.

Although the ICF model moved away from an impairment based classification and provided a stepping stone for a paradigm shift, the ICF has been critiqued for its ambiguity in defining participation (Hammel et al., 2008; Hemmingsson & Jonsson, 2005; Whiteneck & Dijkers, 2009). In this model, activity and participation are described under one category, and therefore, there is a conceptual overlap between the two concepts (Hammel et al., 2008; Whiteneck & Dijkers, 2009). An activity is identified as the execution of a task or action, and participation is defined as performance within life situations; both concepts include the notion of “doing”. The ICF was also critiqued for

putting too much emphasis on individual performance. Individual performance and thus independence are seen as primary characteristics of participation. This idea penalizes people with disabilities who have their own way to participate in life situations by getting help from personal assistants or utilizing resources and services (Hammel et al., 2008). The ICF was also critiqued for not fully taking into account the lived experiences of people with disabilities and the impact of the environment on overall participation choice, control, and enfranchisement (Hammel et al., 2008; Hemmingsson & Jonsson, 2005; Shaw, Leyshon, & Liu, 2007)

Given these critiques, much effort has been done to clarify the definition of participation (Hammel et al., 2008; Trudy Mallinson & Hammel, 2010; Whiteneck & Dijkers, 2009; Whiteneck, Bogner, & Heinemann, 2011). Whiteneck and Dijkers (2009) argued that participation should be differentiated from activities. Activities are physical and cognitive tasks performed by an individual, and thus activities may be limited if an individual's capability required for the task is limited. Participation, on the other hand, is a sum of many individual activities and encompasses not only doing things but also managing the environment in which roles are performed. Participation also embraces the concept of choice. Individuals choose activities and social roles they want.

Therefore, a person with a disability who is restricted in doing activities may not be restricted in their participation if they choose not to engage in certain activities or if they do it in a different way. A person is also more likely to be able to participate in particular roles if supports such as assistive devices, personal assistants, or policy changes are provided, even though essential functions required for activities may be limited. In that sense, participation is more complex than just an individual performance and is

inclusive of the person's interaction with physical, social, emotional, societal, and environmental factors (Bouffioulx, Arnould, & Thonnard, 2011; Eyssen, Steultjens, Dekker, & Terwee, 2011; Whiteneck & Dijkers, 2009).

Mallinson and Hammel (2010) also pointed that participation occurs at the intersection of a person, task and environment. The transactional nature of participation lays emphasis on the complexity of participation and the need for negotiating resources and supports on person, activity, and environmental levels. The transactional nature was also confirmed in a study that elicited the qualitative experiences of people with disabilities from the insider perspective (Hammel et al., 2008). Conducting focus groups with 63 participants with disabilities, Hammel and her research team found that people with disabilities viewed participation as meaningful engagement or “being part of” an activity, context, or social group while having control and power over their choices and opportunities. Meaningful engagement was closely related to the sense of security and willingness to take a risk. They also defined participation as having access to resources and services as well as equal opportunities as a human and as an equal member of society as others. In this study, participation was defined as a “dynamic process that involved constant negotiation and balancing of competing needs and values across individual, social and societal levels, exerting a ‘push-pull’ influence on people's ability to participate in ways that they find meaningful and satisfying” (Hammel et al., 2008, p. 1455). By people with disabilities, participation was seen more as a process and access to opportunities than the actual performance.

Participation for people with stroke is also a complex process. Stroke is a life altering experience, and what was taken for granted before stroke requires new learning

and adaptation. Re-engaging in important activities and life roles may demand a continuous process of adaptation and strategizing (Charmaz, 2002; Clarke & Black, 2005). A systematic review about adjustment after stroke found that individual, interpersonal, and structural level factors interact while a person forms resilience after stroke (Sarre et al., 2013). People with stroke developed practical and mental strategies to compensate for their disability. Having a supportive social support fostered hope and motivation for recovery and helped them access resources. Sarre et al. (2013) also found that structural issues such as health system, information, public attitude, and employment policies played an important role in forming resilience. Another systematic review about post stroke social participation also found that social participation is a complex and multi-faceted process that is continuous and dynamic (Woodman, Riazi, Pereira, & Jones, 2014). The person's ability to accept stroke related issues and adapt attitudes and behaviors using self-management skills was central in facilitating social participation.

While it is evident that community participation is a dynamic and complex process of managing different individual and environmental factors influencing one's life, assessment tools for evaluating participation typically focus on capturing the frequency of engagement. There are several assessments that integrate the concepts of choice and enfranchisement or focus on the influence of the environment on participation (Heinemann, Magasi, Bode et al., 2013; Heinemann, Magasi, Hammel et al., 2013). These assessments focus on individual's satisfaction or perceived importance of certain activities, perceived acceptance in society, or environmental barriers and supports to participation. However, current assessments do not capture the complex and dynamic

nature of managing community participation experienced by individuals with stroke, such as the attitudes or actions that activate individuals to pursue participation goals.

The ability to manage multiple factors influencing community participation allows people with stroke to have control over their lives while living with a long-term disability. Thus, being able to determine a person's level of readiness would facilitate the process of supporting long-term community participation of people with stroke. Such readiness was measured as a construct called *activation* in the context of chronic disease management. Patient activation describes individual patient readiness and ability to manage their chronic conditions and to participate as an effective member of the health care team (Hibbard, Stockard, Mahoney, & Tusler, 2004). For rehabilitation clinicians, availability of an assessment that measures the activation level for community participation could allow better understanding of an individual's readiness and ability to reintegrate and participate into the community, which in turn, should enable clinicians to collaboratively design participation focused interventions that better meet individual needs. Such assessment would also facilitate research to identify whether activation can predict participation or quality of life outcomes, further providing larger scale evidence for programming for people with stroke.

While there is a need to develop an assessment that allows better understanding of readiness for community participation, no research has been done to understand the construct of *activation* in the context of community participation. The development of a measure should begin with establishing conceptual clarity of Community Participation Activation (CPA). The conceptualization of CPA then can guide the instrument development and validation process. Therefore, the study has three aims:

- Aim 1: To explore factors that activate people with stroke to participate in the community as desired and conceptualize activation in the context of community participation.
- Aim 2: To develop a new measure called Community Participation Activation Scale (CPAS) that assesses how activated a person with stroke is to participate in the community as desired.
- Aim 3: To test the preliminary psychometric properties of the CPAS.

II. BACKGROUND

A. Complexity of Participation for People with Stroke

Stroke is a leading cause of disability in the United States. The American Heart Association estimated that about 795,000 people experience a new or recurrent stroke in the United States every year (Go et al., 2014). Two thirds of them survive and most of them live with mild to moderate impairments (Wolf, Baum, & Connor, 2009). Although it occurs more likely among older adults, the age of onset of the first stroke is also decreasing, affecting more working age individuals (Wolf et al., 2009). People with stroke report difficulties in home activities, social relationship, work, education, mobility, and leisure, which may impact their quality of life and health outcomes (Edwards, Hahn, Baum, & Dromerick, 2006; Hammel, Jones, Gossett, & Morgan, 2006; Tellier & Rochette, 2009). For working age adults, stroke has a larger impact on employment, family relationship, sexual life, economic difficulties, and leisure activities, indicating the social implications of stroke among younger people (Daniel, Wolfe, Busch, & McKevitt, 2009).

Previous research has explored the complexity of participation among people with stroke, examining their experiences with community reintegration, resilience, recovery, and activity re-engagement. Research set forth that people with stroke evaluate and negotiate meanings, values, and importance of their activities while using their skills, abilities, resources, and supports to carry on what they want to do. This

multi-faceted and dynamic process of managing supports and barriers and meaning of activities continuously influenced participation outcomes (Anderson & Whitfield, 2011; Häggström & Lund, 2008; Rochette, Tribble, Desrosiers, Bravo, & Bourget, 2006; Sarre et al., 2013; Woodman et al., 2014).

Whether a person choose to resume or let go of an activity after the stroke was influenced by an evaluation of the value or importance of an activity, their satisfaction with their performance of the activity, willingness and ability to adapt, and availability of resources and supports (Häggström & Lund, 2008; Kubina, Dubouloz, Davis, Kessler, & Egan, 2013; Robison et al., 2009; Woodman et al., 2014). Many studies reported that the process of coping with the newly acquired disability is an important precondition to returning to meaningful life roles after stroke (Ch'ng, French, & McLean, 2008; Rochette et al., 2006; Woodman et al., 2014). In addition to the loss of functional ability, the negative stereotype of stroke in society or within their social group made them depressed or afraid of going out. Rejecting the stigma and stereotype and building a positive view about themselves kept them more positive and willing to participate in the community as they wanted (Anderson & Whitfield, 2013; Woodman et al., 2014).

People with stroke utilize various adaptation strategies to deal with the impact of stroke and the environment and to more actively participate in meaningful life situations. Pound, Gompertz, and Ebrahim (1999) explored social and practical strategies utilized by people with stroke, including mobilizing informal social support, creating new ways of doing, taking things slowly, initiating relearning, and exercising. Clarke and Black (2005) found that people with stroke report high quality of life when they have ways to adapt to their impairment. Prioritizing, utilizing existing resources, and building social supports

were some examples of adaptations and adjustments employed by people post-stroke. Some other studies found that people after stroke learn how to accept help and use technology to increase their engagement and participation in activities (Häggström & Lund, 2008; Larsson Lund, Lövgren-Engström, & Lexell, 2011; Robison et al., 2009). Hammel et al. (2006) found that people with stroke actively identify and implement environmental and system level strategies to increase their participation. People with stroke reported modification of the environment, access and use of information, use of equipment or adaptive devices, and advocacy as strategies to support their participation in the community.

Current literature supports that participation is facilitated when one is able to deal with the medical and societal implications of stroke and manage resources and supports available to enable what he/she wants to do. While social, societal, and structural supports need to be available for people with stroke to utilize, there is a strong management component including negotiating confidence, abilities, skills and resources, which people need to carrying out to fully participate in their lives after a stroke.

B. Gap in Participation Focused Assessments

Recent studies have paid much attention on how to measure participation with people with disabilities since participation has become a key outcome in rehabilitation and disability research (Augustine, Roberts, & Packer, 2011; Chang, Coster, & Helfrich, 2013; Heinemann et al., 2010; Kessler & Egan, 2012; Tse, Douglas, Lentin, & Carey, 2013; Whiteneck & Dijkers, 2009; Whiteneck et al., 2011). Several reviews examined participation focused measures for people with disabilities and people with stroke

(Chang et al., 2013; Eyssen et al., 2011; Kessler & Egan, 2012; Tse et al., 2013). These reviews found that the majority of participation measures focus on measuring the frequency and intensity of participation, variety of activities engaged, and required support level to capture the objective experiences of participation (Chang et al., 2013; Tse et al., 2013). Other measures focusing on the subjective experience assess satisfaction with participation, importance of participation, perceived level of limitations or disruption, quality of life, and participation enfranchisement (Heinemann et al., 2011; Heinemann, Magasi, Bode et al., 2013; Tse et al., 2013). Additional instruments found related to participation focused on the impact of environmental barriers and supports on participation (Gray, Hollingsworth, Stark, & Morgan, 2008; Heinemann et al., 2015; Whiteneck et al., 2004).

Several articles set out the challenges or considerations to measuring the concept of participation. As it is pointed out in literature conceptualizing participation, the challenge to measure participation is that participation is not clearly defined. While the ICF provides a framework, the construct of participation is not fully conceptualized, and there is no consensus on the operational definition of participation across different researchers. The reviews found that current participation measures differed in the operationalization of the concept and the covered content areas (Chang et al., 2013; Eyssen et al., 2011).

Related to the issue around the definition of participation, a challenge is that participation can be interpreted in different ways. While many instruments focus on the objective measure of participation as a way to compare different groups across different settings, some argue that objective measures focusing on the performance side of

participation cannot fully capture the meaning of individual's unique participation experience (Häggström & Lund, 2008; Hammel et al., 2008; Mallinson & Hammel, 2010). Participation includes a concept of choice and personal preferences which cannot be captured with objective measures. Objective measures are also limited in that they can only offer relative comparisons between groups without a normative standard. The frequency or intensity of participation cannot be used to judge the quality of participation because less frequent participation may be a result of personal choice.

Another challenge is to measure the interaction between the person, activity, and environment. Increasing literature support the complex and multi-faceted nature of participation that is influenced by the interaction between person, task, and environment (Mallinson & Hammel, 2010; Whiteneck et al., 2011). Mallinson and Hammel (2010) called for the need of measurement that attends to the transactional nature of participation across person, tasks, and environment. Along with the focus on the transactional nature of participation, the process of managing and negotiating the interaction of personal and environmental factors has been emphasized in different studies (Häggström & Lund, 2008; Woodman et al., 2014), which brings attention to the need for assessments focusing on the process and strategies facilitating participation. However, no assessment yet has focused on the management perspective of participation.

C. **Use of Mixed Methods Design for Instrument Development in Disability Research**

While disability studies scholars claim that both qualitative and quantitative methods should be used to push the agenda for people with disabilities, disability

research has preferred qualitative research approaches over quantitative methodology for capturing unique experiences of people with disabilities. Quantitative instruments have been criticized for poorly presented items, limiting responses, reinforcing the medical model, and providing limited understanding of people with disabilities (Kitchin, 2000). Instruments not developed to capture the reality of people with disabilities may produce a false image of people with disabilities reinforcing marginalization, powerlessness, and invisibility (Kitchin, 2000). Therefore, creating instrument items preserving the qualitative meaning of human experience is essential to improve the use of quantitative methodology in disability research.

Reflecting this concern, more attention has been put on how to create various items and scales that reflect the real picture of human experience. The focus on having instruments accurately indexing individual's reality and patterns of living have brought mixed methods to the fore in instrument development and validation studies. The benefit of integrating qualitative research into the otherwise quantitative research design is that it provides better understanding of the contextual factors laying the groundwork and helps preserving the meanings in the instrument items (Fleury, 1993; Kroll, 2011). Recent psychometric researches highlight the importance of understanding the meaning of constructs of interest and its authenticity for respondents (Gray, Hollingsworth, Stark, & Morgan, 2006; Hammel et al., 2008, 2015). In light of content validity, studies also started to integrate qualitative research methods to enrich the quality of research and to gain a more comprehensive picture of the construct of interest (Rowan & Wulff, 2007; Smith, Sosa, Tisone, & Mckyer, 2011).

There are different steps in instrument development research where qualitative approaches can be integrated. The first step is to conceptualize the construct of interest. This step is important as it lays the conceptual foundation that links the tool to evidence (Wolfe & Smith, 2007). To have a better conceptual foundation for the instrument, researchers can conduct literature reviews, real-world observations, and interviews and focus groups with expert panels and/or key informants (Onwuegbuzie et al., 2009; Wolfe & Smith, 2007). Interviews or focus groups with key informants are best to understand a construct from participant's own words describing their lived experience. Individual interviews are beneficial when exploring complex constructs because the interviewer can ask follow-up questions (Patton, 2001). Focus groups are effective and preferred over individual interviews because they help gather greater amounts of information while less demanding time and resources (Nassar-McMillan, & Borders, 2002; Smith et al., 2011). The group dynamic and synergy also fosters ranges of thoughts, and researchers can observe interaction between group members (Nassar-McMillan & Borders, 2002).

Grounded theory focus groups and interviews can be used for exploratory purposes when the conceptual definition and scope of the measure are not yet shaped. Qualitative data can help understand and refine existing information and elicit new insight in understanding the construct (Magasi & Heinemann, 2009; Nassar-McMillan & Borders, 2002). These data can also be used to confirm operational definition and identify common language related to the construct (Magasi & Heinemann, 2009). Data collected through reviews and interviews then are analyzed to identify behaviors underlying the construct of interest. Grounded theory analysis, constant comparison, or

axial coding can be utilized to identify common themes that become potential items in the next step (Onwuegbuzie, Bustamante, & Nelson, 2009).

The second step involves developing initial instrument items and refining them. Based on the behaviors identified, the instrument developer crafts items. In order to develop a relevant and meaningful instrument, items should reflect the language and expressions used by informants during the focus groups or interviews (Fleury, 1993). Ultimately, the items should be generated with help from experts and key informants – either by writing items together or receiving feedback from them. In this step, researchers can conduct cognitive interviews to ensure that the instrument items are perceived by the respondents as intended (Magasi & Heinemann, 2009). Cognitive interviews collect data on respondents' comprehension, thought process on decision-making, and response selection.

Item refinement can also be informed by focus groups. Nassar-McMillan and Borders (2002) particularly pointed to the flexibility of the focus group format to collect both quantitative and qualitative data to be used for item refinement (e.g., yes/no to need for revision question and qualitative feedback/description to the yes/no answer). The use of quantitative data (i.e., how many people said that this item needs revision) with qualitative explanation provides a valid method to justify removal or revision of items. While Nassar-McMillan and Borders (2002) suggested the use of experts, Fleury (1993) suggested having a participant rating panel consisting of participants who have been part of the instrument development process and new participants. Whereas new participants can offer novel perspectives, previous participants already know the items and can provide feedback on the revised versions which is potentially more candid

given the rapport built over time. The panel examines the instrument clarity, homogeneity of contents, and content validity (Fleury, 1993).

These strategies are useful as they engage people with disabilities in the research process and enhance the quality and applicability of the instrument. Inclusion of people with disabilities provides more opportunities for them to offer alternative explanations or verify researcher interpretation throughout the research. This is particularly important, because researchers often have a predetermined agenda based on socially constructed discourses that may alter the true meaning (Kitchin, 2000). People with disabilities' involvement in instrument development also elicit audience-appropriate language and formatting, increasing the usability and interpretability of the data.

III. METHODS

This study utilized an exploratory sequential mixed method design, in which the qualitative study complements a principally quantitative study (Creswell, Klassen, Plano, Clark, & Smith, 2011). An exploratory mixed method is commonly used in instrument development especially if the research area is new or unfamiliar (Kroll & Morris, 2009; Magasi & Heinemann, 2009). Such design increases the sample size, maximizes the appropriateness and utility of the instrument, and increases research integrity (Onwuegbuzie, Bustamante, & Nelson, 2009). In this study, data from focus groups, in-depth interviews, and literature review informed the development of a construct model and potential items of the instrument, which were quantitatively tested with a larger sample size. Figure 1 shows the procedures involved in the study. All research activities were approved by University of Illinois at Chicago, Office for the Protection of Research Subjects (Appendix A).

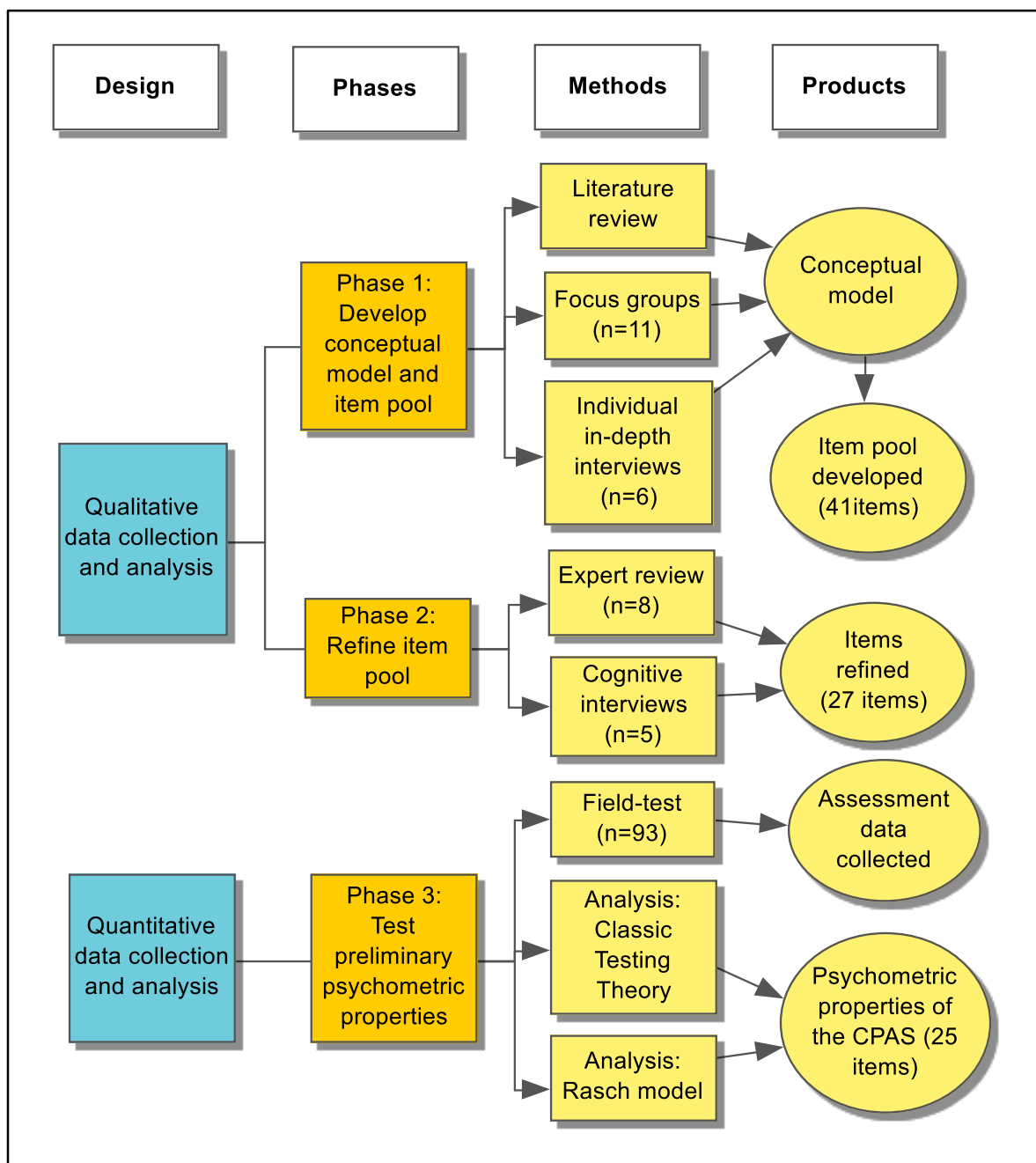


Figure 1. Research procedure.

A. **Phase 1: Defining The Target Construct and Conceptual Model**

A construct is “a theoretical concept that explains observable behaviors and refers to assumed latent (unobservable) characteristics of respondents” (Wolfe & Smith, 2007). Defining the target construct helps differentiate the construct from other similar or different constructs, which ensures the content validity of the instrument. Based on the construct and elements constituting the construct, a conceptual model is generated showing the relationship among elements (Wolfe & Smith, 2007). The conceptual model allows the researcher to define different aspects of the construct and identify potential indicators of the construct and potential means to observe the construct in one’s behaviors (Wolfe & Smith, 2007). This study used data from literature review, individual interview, and focus group interviews to develop the conceptual model.

1. **Literature review**

Comprehensive literature review was conducted to identify what factors influences participation in the community after stroke. Databases such as PubMed, CINAHL, and Google Scholar were utilized to search literature with following foci:

- Community participation after stroke
- Strategies used by the people with stroke
- Factors influencing post stroke participation in the community

2. **Grounded theory focus groups**

Focus groups were conducted to describe and frame perspectives and experiences regarding community participation. Using a convenience sampling method, individuals with stroke were recruited through flyers distributed to two local hospitals and through an existing registry from a previous research study. Interested participants

contacted the researcher. Participants were included if they: 1) had a stroke; 2) were 18 years or older; and 3) self-identified them as at least moderately active in participating in the community. Participants with stroke were recruited with consideration of diverse backgrounds in race, education level, and time since stroke, although they were not purposefully chosen to meet diversity. Individuals with severe cognitive impairment and aphasia were excluded from the study. A semi-structured interview guide was developed following a guideline by Krueger and Casey (2008) (Appendix B). Following questions were asked to further reveal the process of and factors influencing community participation activation (CPA).

- Opening question: Tell us your name and tell us how long ago you had a stroke.
- Introductory questions: What does “participation” mean to you? What comes to mind when you hear the word “activated”? How about the term “being active”?
- Transition questions: At what point after your stroke did you feel activated so you can participate in things you want to do? What was the turning point?
- Key questions: We would like to talk more about things that made you active again after your stroke. I learned from many people that, after a stroke, doing what you want to do takes management skills or strategies. I would like to learn more from you what factors influenced your level of participation after stroke. (follows with probes)

- Ending questions: We want to support others to become active again after having a stroke. Can you think of anything else that we haven't yet discussed that we should know about helping people become active? If you were to give a person with a new stroke one piece of advice to help him/her become active again, what would that be?

3. **In-depth individual interviews**

In-depth individual interviews were conducted to capture details of the key ideas identified during the focus groups (Patton, 2001). Five key informants from the focus groups were invited to participate in the follow-up interview. One additional participant was purposefully recruited to explore additional aspects not covered in the focus groups. A semi-structured interview guide was developed to facilitate the interviews (Appendix C). Following questions were asked to further reveal the process of and factors influencing CPA.

- Tell me the story of what your life was like after you came back home after your stroke.
- Compare when you first had a stroke and now, what has changed over time? At what point after your stroke did you feel comfortable going out and actively participate in things you want to do? In other words, what was the turning point?
- We would like to talk more about things that made you active again after your stroke. I learned from many people that, after a stroke, doing what you want to do takes management skills or strategies. I would like to learn

more from you what factors influenced your level of participation after stroke.

- Please list all the things that support your active participation
- This research study is about how people with strokes become active participators again in doing what they want to do. Can you think of anything else we should know about helping them become more active again in their lives?

4. **Analysis to inform a conceptual model and generate an item pool**

For triangulation, the focus group and interview data were combined and compared with the literature review (Patton, 2001). The focus group and interview data were transcribed verbatim and analyzed using a grounded theory model to inform the conceptual model (Jeon, 2004). The author who is a PhD candidate with a background in occupational therapy and disability studies analyzed the data. Iterative, constant, comparative, and thematic analysis was used to understand the phenomenon (Krueger & Casey, 2008; Patton, 2001). Data were coded using Atlas.ti. Codes were grouped and iteratively compared until patterns and theme emerged (Krueger & Casey, 2008; Patton, 2001). Maps of thematic codes were developed to conceptualize the emerging construct. These maps were shared and discussed with two other researchers who have a background in occupational therapy and disability studies. Codes and themes were refined based on feedbacks and comments from the discussion. Using the analysis result, the conceptual model was developed to depict the revealed relationship between elements constructing the concept. An item pool was generated in accordance with domains and indicators of the conceptual model.

B. **Phase 2: Item Refinement**

1. **Expert review**

An expert review helps to ensure the content validity of an instrument. Experts can provide feedback on whether the items represent the construct and whether the content of the item is accurate (Wolfe & Smith, 2007). Using purposive sampling, content area and outcome measurement experts were recruited to review the items. Experts were asked to rate the relevance of the proposed items using a 4-point ordinal rating scale (1= the item is not representative; 4= the item is representative) and provide feedback on contents and clarity, following a guideline (Appendix D) adapted from Grant and Davis (1997). The item-level CVI (I-CVI) was calculated using the proportion of experts who scored items with either 3 (relevant) or 4 (representative) (Grant & Davis, 1997; Polit & Beck, 2006). Scale level content validity index (S-CVI) was then calculated as the average of the I-CVI values as recommended by Polit and Beck (2006). An I-CVI of 0.75 and a S-CVI of 0.9 or higher were used as criteria to establish a content valid instrument. The I-CVI and S-CVI scores and qualitative comments from expert panel were used to revise the items and to meet the content validity criteria.

2. **Cognitive interviewing**

Cognitive interviews were utilized to understand how respondents interpret the items and refine the items (Jobe, 2003). Cognitive interviewing is a process to ensure that a questionnaire measures what is intended to measure (Magasi & Heinemann, 2009; Ryan, Gannon-Slater, & Culbertson, 2012). This process can also be

helpful with people with cognitive impairment because it can prevent an instrument from being vague, mentally fatiguing, or too abstract (Ongena & Dijkstra, 2007).

Five cognitive interviews were conducted with individuals with stroke, following the recommended guideline (DeWalt, Rothrock, Yount, & Stone, 2007). To cover “as much of a questionnaire’s conceptual terrain as possible” and represent some demographic variety, purposive sampling was utilized to select individuals with stroke with different ages, racial backgrounds, educational levels, and levels of cognitive impairment (Beatty & Willis, 2007, p. 295). Potential participants were identified through an existing research registry. As suggested by DeWalt, Rothrock, Yount, and Stone (2007), at least two participants with following criteria were recruited: 1) less than 12 years of education, and 2) cognitive impairment.

Cognitive interviews were conducted using the verbal probing approach (Ryan, Gannon-Slater, & Culbertson, 2012). Using semi-structured guides, participants were asked to repeat the item in their own words, explain the meaning of items, and offer alternate phrasing when comprehension was limited (Appendix E). The interviewer kept detailed notes and audio recorded the interviews. Data will were analyzed following an informal analysis process suggested by Willis (2005). A summary of interviewee’s response and general comments were typed into an electronic copy for each question. These results were compiled across interviews quantitatively and qualitatively. Comments and observations were summarized with a number of participants who reported same opinions or feedback. Based on the comments and feedbacks, the items were refined.

C. **Phase 3: Testing The Psychometric Property of Community Participation**

Activation Scale

1. **Sampling**

The refined item pool was field-tested with individuals with stroke. A sample size of 100 people has been suggested as the minimum size for validating an assessment using Rasch modeling (Reeve et al., 2007). Approximately 100 participants were recruited through flyers distributed to rehabilitation hospitals, stroke support groups, and a stroke research registry located in a Midwestern metropolitan area in the United States. Snowball sampling among individuals with personal networks of people with a stroke was also used (Patton, 2001). Participants were included if they met the following criteria: 1) had a stroke at least 1 month ago; 2) 18 years and older; and 3) living in the community. Participants were excluded if they had severe aphasia with no means to communicate.

2. **Data collection**

A 30- to 60-minute interview was conducted at a location of convenience or over the phone by the author. The interview battery included the new instrument, existing measures selected to examine the construct validity, and a questionnaire to collect demographic information of the participants. A visual aid was provided to assist the response process. If the interview was conducted over the phone, the visual aid was mailed to the participants in advance.

The interview battery included the CPAS, Reintegration to Normal Living Index (RNLI), Community Participation Indicators (CPI) Enfranchisement, and demographic questions.

The Community Participation Activation Scale (CPAS). The CPAS is designed to assess attitudes and actions among people with stroke that indicate the extent to which an individual is activated for community participation. The assessment consists of 27 items including 16 action items and 11 attitude items. The questionnaire was developed based on literature review and findings from focus groups and qualitative interviews. Researchers and clinicians with a background in stroke rehabilitation, measurement and testing, self-management, and health service research reviewed the items for content validity and five people who had experienced a stroke participated in cognitive testing to ensure clarity of items and relevance of item content. The CPAS uses a 4-point Likert-type scale: 1=this does not describe me at all; 2=this describes me somewhat; 3= this describes me quite well; and 4=this describes me exactly. To help respondents conceptualize community participation and focus on their community engagement activities in the past two weeks, the CPAS begins by asking: "Please tell me what you did outside your home in the past two weeks."

Reintegration to Normal Living Index (RNLI). The RNLI assesses perceived satisfaction with performance in areas such as activities of daily living, social participation, mobility, and social relationships (Wood-Dauphinee, Opzoomer, Williams, Marchland, & Spitzer, 1988). The scale consists of 11 items. Following Stark et al. (2005) we used a Likert scale of 0 to 10 (0=strongly disagree; 10=strongly agree) rather than the original visual analog scale. Previous research shows that the RNLI has excellent internal consistency (0.92 and 0.91) when tested with people with chronic stroke (Bluvol & Ford-Gilboe, 2004; Stark et al., 2005).

Community Participation Indicators (CPI) Enfranchisement. The Enfranchisement section of the CPI evaluates the extent to which a person feels that he or she is valued in society and that his or her full participation is respected by the community they want to participate in (Heinemann, Magasi, Bode et al., 2013). The assessment consists of two subscales: 15 items reflecting personal importance of participation and 13 items reflecting perception of control over participation. Items are scored on a 5-point rating scale from 1 to 5 (1=almost never, 2=seldom, 3=sometimes, 4=frequently, 5=all the time). Rasch modeling established the construct validity and person separation reliability of the importance and control subscales of the CPI with a sample with diverse disabilities. Both importance and control subscales showed good person separation (2.26 and 2.28, respectively)

3. **Data analysis**

A combination of Rasch modeling and Classical Test Theory approaches were used to examine the psychometric characteristics of the CPAS. Rasch model calibrates items along a hierarchy and describes the item difficulty or person ability in relation to other items or persons, by transforming ordinal data (raw scores) into interval level measures (logits). While comparison of raw scores indicates whether there is more or less, Rasch measurement allows comparison of person ability and item difficulty. The Rasch model also allows each item and person to retain its value even in a summary score. Since items were intended to share the same rating scale structure, the Andrich Rating Scale Model (RSM) was applied (Linacre, 2000).

The CPAS was evaluated in terms of rating scale structure (monotonicity), unidimensionality, reliability and precision (person separation reliability, internal

consistency), construct validity (item ordering, targeting, and association with related constructs), and differential item functioning (DIF).

a. **Rating scale structure (Monotonicity)**

Examining the function of rating scale categories is essential to ensure that interpretations of collected data are valid (Linacre, 2004). To assess and optimize the rating scale functioning, data had to meet following criteria: 1) each category's frequency count must be at least 10 observations; 2) category thresholds are ordered (e.g., observed thresholds increase monotonically across the trait); and 3) the rating scale outfit meansquare (MnSq) should be less than 2.0.

b. **Unidimensionality**

The underlying assumption of the Rasch model is unidimensionality. This assumption was tested by using fit analysis and Rasch-residual-based principal components analysis. The item fit to the Rasch model is an index of whether the items represent the construct, and person fit detects disconformity of a typical response pattern. Item and person fits are measured using infit (weighted) and outfit (unweighted) statistics. The ideal outfit MnSq value is 1.0. If the infit MnSq is greater than 1.0 (i.e., underfitting), it suggests that the items may reflect a different construct and are diverted from unidimensionality (Cervellione, Lee, & Bonanno, 2008; Wolfe & Smith, 2007). Items with an infit MnSq between 0.7 and 1.3 is acceptable and supports unidimensionality.

To supplement the fit statistics which is not always sensitive in detecting multidimensionality, principal component analysis of standardized residuals was examined using the percentage of variance explained by Rasch measures and the first

factor (Fendrich, Smith, Pollack, & Mackesy-Amiti, 2008; Wolfe & Smith, 2007). For this study, an eigenvalue <2.0 and $<10\%$ of variance explained on the first contrast was an indicator for sufficient unidimensionality.

c. **Precision and reliability**

Person separation reliability indicates how efficiently the assessment is able to separate persons into sufficient groups for the purpose of the test. A scale with person separation reliability greater than 0.85 is desired and indicates that the measure can reliably distinguish among three ability levels of sample participants (Tennant & Conaghan, 2007). In addition, the internal consistency reliability was assessed using Cronbach's coefficient alpha. Cronbach's coefficient alpha is an indicator of the extent items measure the same construct that is most commonly used (Cronbach, 1951).

d. **Construct validity**

The construct validity was examined using Pearson's correlation coefficient. It was hypothesized that actions and attitudes facilitating community participation would be associated with community integration and enfranchisement. CPI enfranchisement items (Heinemann et al., 2011; Heinemann, Magasi, Bode et al., 2013) and RNLI (Wood-Dauphinee, Opzoomer, Williams, & Spitzer, 1988) were used to examine the construct validity. A Pearson r falling into the range of 0.26-0.49 is low, 0.50 and 0.69 is moderate, and 0.70 or higher is high correlation (Plichta & Kelvin, 2012).

e. **Item bias**

DIF examines the extent to which item may be more or less easily endorsed by members of particular demographic groups. In this study, DIF was used to examine gender bias of the CPAS. DIF greater than 0.5 logits were flagged for further examination. The mere presence of DIF does not imply biased person measures. For items reflecting DIF, the impact on person measures was examined by comparing person measures calibrated with and without items demonstrating DIF (Smith, 2004).

IV. RESULTS

Three articles were generated to present the findings of each phase. The first article analyzed the data from the focus groups and in-depth interviews that were collected to better understand post-stroke community participation experiences of people with stroke. The second article conceptualized community participation activation (CPA) and described the process of item development and refinement of the Community Participation Activation Scale (CPAS). The third article presented findings from the validation process of the CPAS.

A. **Paper 1 - Facilitators to Active Community Participation Experienced by People with Stroke: A Qualitative Study**

1. **Abstract**

Purpose: To explore what factors facilitate active community participation for people with stroke.

Methods: A qualitative study utilizing three focus groups and six in-depth individual interviews. Twelve participants who had a stroke were recruited through flyers and existing registry database. Recorded focus groups and interviews were transcribed verbatim and analyzed using constant comparative analysis with Atlas.ti.

Results: Seven themes emerged: 1) Comfortable getting around in the community; 2) actively trying to engage in more community activities; 3) managing stroke related issues; 4) planning ahead; 5) accessing and managing community mobility; 6) asking for and accepting help from others; and 7) seeking and using information about

community resources and services. A cross-cutting theme arose summarizing different stages of community participation post stroke.

Discussion: The findings show that people with stroke experience changes in their attitudes and actions over time after their stroke that influence their level of community participation. By being able to manage the individual and social implications of their stroke, they gain sense of empowerment and confidence in participating in the community as they desire. The results emphasize the importance for rehabilitation professionals to provide an environment that supports the development of actions and attitudes facilitating community participation post-stroke.

Keywords: stroke, social participation, community participation, qualitative study

2. **Introduction**

Stroke is one of the major causes of impairments associated with disability in the United States. This life-altering experience affects people's ability to participate in various life roles. People with stroke frequently experience issues with mobility, cognition, communication, and fatigue. These impairments combined with environmental barriers and social biases may limit people's engagement in important activities and previous life roles (Sarre et al., 2013; Satink et al., 2013). Research has shown that people who had a stroke report difficulties in home activities, social relationship, work, finance, education, mobility, and leisure, which may impact their quality of life and their health outcomes (Daniel, Wolfe, Busch, & McKevitt, 2009; Edwards, Hahn, Baum, & Dromerick, 2006; Hammel et al., 2006; Tellier & Rochette, 2009).

Previous studies have established that participation is a complex process of negotiating and balancing needs and resources across individual and social levels (Hammel et al., 2008; Hemmingsson & Jonsson, 2005; Mallinson & Hammel, 2010; Whiteneck, Bogner, & Heinemann, 2011). A body of literature also explored the complexity of participation or engagement in activities experienced by people who had a stroke (Anderson & Whitfield, 2011; Hammel et al., 2006; Sarre et al., 2013; Woodman et al., 2014). Hammel et al. (2006) pointed out that participation after stroke requires more than just independent individual performances and is inclusive of managing person's interaction with micro and macro level environmental factors. Participation also includes sense of inclusion and respect from the community (Hammel et al., 2006). A systematic review about adjustment after stroke also revealed that individual, interpersonal, and structural level factors interact to influence resilience after stroke (Sarre et al., 2013). Sarre et al. (2013) found that people with stroke use mental and practical strategies to adjust to stroke on the individual level. Social relationships with family or friend and structural issues such as access to health system, information, public attitude, and employment policies also played an important role in forming resilience after stroke.

Because of the complexity and the influence of environmental factors, people with stroke need to be able to manage different individual and social implications of their impairments and disability. Existing research shows that people employ different ways to gain control over their lives. Woodman, Riazi, Pereira, and Jones (2014) found in their systematic review that the ability to accept stroke-related problems, modify behaviors and attitudes, and utilize self-management skills such as problem solving,

goal setting, and active decision making when facing barriers are essential to social participation. They found that people with stroke evaluate and negotiate meanings, values, and importance of the activities while using their skills, abilities, resources, and supports (Woodman et al., 2014). Häggström and Lund (2008) found that people with stroke adopted strategies to enhance engagement in activities including modifying performance and preferences, expressing and looking after ones' interests, seeking information, avoiding environments with hindrances, and explaining one's capability to others. Other studies also found that people after stroke learn how to revalue activities, accept help, modify the environment, and use technology to increase their engagement in activities (Lund, Lövgren-Engström, & Lexell, 2011; Robison et al., 2009).

Community participation is often overlooked as a domain of intervention for people with stroke, although it is a frequently reported area of disparity for people who had a stroke (Wolf, Baum, Lee, & Hammel, 2016). To better support the ability of people with stroke to manage participation in the community to do what they want to do, it is important to understand factors that activate people with stroke to manage the process of community participation. When informing interventions, it is critical to bring in the voice of the consumers and learn from their experiences. Therefore, the purpose of the study was to explore and identify facilitators that people with stroke report using to activate their participation in the community.

3. **Methods**

The study employed a qualitative research methodology utilizing focus groups and individual interviews.

a. **Recruitment and participants**

A total of 12 individuals with stroke were recruited through flyers distributed to two local hospitals and through an existing registry from a previous stroke self-management intervention study. Interested participants contacted the researcher. Participants were included if they: 1) had a stroke; 2) were 18 years or older; and 3) lived in the community. Participants were recruited with consideration of diverse backgrounds in race, education level, and time since stroke, although they were not purposefully chosen to reach full diversity. Potential participants were excluded if they had a severe cognitive impairment or aphasia. All participants signed an informed consent approved by University of Illinois at Chicago, Office for the Protection of Research Subjects.

b. **Data collection**

Focus groups and in-depth individual interviews were conducted to describe and frame perspectives and experiences regarding behaviors and strategies that facilitate community participation. Individual in-depth interviews followed the focus groups to capture details of key ideas shared during the focus groups. Both the focus group and individual interview used a semi-structured interview guide developed to reveal what is needed to actively participate in the community (Figure 2). The questions were developed based on information from literature review and previous participatory research studies the author was involved and followed the guideline by Krueger (2008).

Focus group

1. Opening question: Tell us your name and tell us how long ago you had a stroke.
2. Introductory questions: What does “participation” mean to you? What comes to mind when you hear the word “activated”? How about the term “being active”?
3. Transition questions: At what point after your stroke did you feel activated so you can participate in things you want to do? What was the turning point?
4. Key questions: We would like to talk more about things that made you active again after your stroke. I learned from many people that, after a stroke, doing what you want to do takes management skills or strategies. I would like to learn more from you what factors influenced your level of participation after stroke. (follows with probes)
5. Ending questions: We want to support others to become active again after having a stroke. Can you think of anything else that we haven’t yet discussed that we should know about helping people become active? If you were to give a person with a new stroke one piece of advice to help him/her become active again, what would that be?

Individual interview

1. Tell me the story of what your life was like after you came back home after your stroke.
2. Compare when you first had a stroke and now, what has changed over time? At what point after your stroke did you feel comfortable going out and actively participate in things you want to do? In other words, what was the turning point?
3. We would like to talk more about things that made you active again after your stroke. I learned from many people that, after a stroke, doing what you want to do takes management skills or strategies. I would like to learn more from you what factors influenced your level of participation after stroke. (follows with probes)
4. Please list all the things that support your active participation
5. This research study is about how people with strokes become active participators again in doing what they want to do. Can you think of anything else we should know about helping them become more active again in their lives?

Figure 2. Interview guide for focus group and individual interview

c. **Data analysis**

The focus groups and interviews were transcribed verbatim and analyzed using a constant comparative thematic analysis. The first author who is a PhD candidate with a background in occupational therapy and disability studies analyzed the data. First round of analysis was done using Microsoft Word where data were analyzed with preliminary codes. The data then were transferred to Atlas.ti software and recoded. Codes were grouped and iteratively compared until patterns and themes emerged (Krueger & Casey, 2008; Patton, 2001). Maps of thematic codes were developed to conceptualize the emerging construct. These maps were shared and discussed with two other researchers who have a background in occupational therapy and disability studies. Codes and themes were refined based on feedback and comments from the discussion.

4. **Results**

A total of three focus group sessions were conducted with 11 participants. Out of 11 participants, five key informants with rich information about the topic were invited for a follow-up individual interview to allow additional time to elaborate on their experience. In addition, one new participant was purposefully recruited for an individual interview to add a perspective that was not covered by other participants. Majority of the participants were female (n=7), African American (n=9), educated with at least a high school degree (n=12), and not married (n=8). The mean age was 59 years (SD=4.9), and the mean time since their primary stroke was 11 years (SD=8.2). Demographic characteristics of all 12 participants are listed in Table I.

TABLE I
DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS (N=12)

ID	Completed ^a	Age	Gender	Race	Education	Marital	Years since stroke
Q01	FG, INT	56	Female	Hispanic	Master's degree	Married	3
Q02	FG	57	Female	African American	Bachelor's degree	Divorced	15
Q03	FG	50	Female	African American	High school/GED	Divorced	1
Q04	FG	62	Female	African American	High school/GED	Single	28
Q05	FG	69	Male	African American	High school/GED	Divorced	21
Q06	FG, INT	59	Male	Caucasian	High school/GED	Married	9
Q07	FG, INT	56	Male	African American	Some college/associate degree	Married	5
Q08	FG	57	Male	African American	Some college/associate degree	Divorced	16
Q09	FG, INT	59	Male	African American	Some college	Divorced	2
Q10	FG	59	Female	African American	Some college/associate degree	Married	7
Q11	FG, INT	66	Female	African American	Some college/associate degree	Single	12
Q12	INT	58	Female	Caucasian	Bachelor's degree	Divorced	13

^a FG: Focus group; INT: In-depth interview

Seven themes were generated: 1) Comfortable getting around in the community; 2) actively trying to engage in more community activities; 3) managing stroke related issues; 4) planning ahead; 5) accessing and managing community mobility; 6) asking for and accepting help from others; and 7) seeking and using information about

community resources and services. In addition, a cross-cutting theme described the different stages of community participation by people with stroke.

a. **Feeling comfortable in public**

Getting around in the community involves constantly dealing with different environmental barriers. As illustrated in the following quote, even walking itself involved much negotiation when in the community:

You've always got to kind of analyze the good and the bad things. Can I do this? What will happen if I can't? I mean it's kind of like me walking down the street. I have to look, not straight ahead of me, but straight ahead and down so that I can see the surface that I'm on walking on. If it's uneven I have to know that. Otherwise, I'm going to be on my face. Especially if I'm tired because my left side gets tired and my foot drops. (Q06)

However, participating in the community involves more than negotiating with the impairments or physical environment. Participants frequently encountered attitudinal barriers in the community such as stigma or intolerance.

I guess kids didn't understand, I would go for a walk in the neighborhood and I'd hear the little kid, "Here she comes." I would just turn around and stare. Because I knew they were looking at me, but I was trying to make a joke of it. I'd go look like I was looking at them. And they eventually stopped, but I had to get used to it, the staring at me. (Q04)

Because of these challenges, it was important to be comfortable and confident so as not to be discouraged by those barriers. Accepting the changes to their lives, feeling safe and confident about walking, and feeling empowered not to care about public attitude were important factors that made them comfortable going out and participate in the community.

I can do stairs, but like I say, I have to rest after a few flights. But I can do them, it will take me a while. Hopefully there's not a lot of people behind me because they're going to have to wait. Or I'll just move to the side and have them go by. But for the most part people are pretty tolerant. (Q06)

I used to be scared to walk into a room that would be full of people. I was scared. But not no more. If I bump into you, I say excuse me, if they bump into me they say excuse me. And then it is okay. (Q05)

These personal changes occurred through different experiences. A few people mentioned their network with other people with disabilities through hospital affiliated exercise facilities and stroke support groups, and how those groups helped them feel more comfortable participating in the community. Modeling other people with shared experience and building a sense of community empowered them and built their confidence to pursue what they want to do despite attitudinal barriers and their own internalized stigma on disability.

I met at least seven people there who had strokes. And we would all sit around and talk. And they said, "On everybody's birthday we're going to go out and have lunch to celebrate your birthday. Just because you had a stroke, you don't have to stay at home." And I said, this is nice. And it motivated me. And I wasn't the only one walking funny. And it really motivated me. (Q04)

Like I went to a class, and it was ladies, we all had some kind of disability. A leg chopped off, or a stroke, or something that had to do with cancer. And I learned so much from these women about going out and not being afraid. (Q11)

In addition, while many people in this study highlighted walking as the first step to become active again, one participant made it clear that walking well was not enough to boost her confidence to go out in the community.

Safety [was more important for me than the quality of walking] because before [I felt safe], I was walking but I was really afraid to take it to the next level. I just felt that like "at least I can walk". But then I would see people out with a cane or walker or whatever and they were just going. I was like, I can walk fast like that. That was my motivation (Q11)

b. **Actively trying to engage in more community activities**

Sometimes, trying out new activities meant that participants were willing to take risks if they thought the activity was personally important enough for them

to participate. Success in such trials boosted their confidence and motivation in participating in different activities in the community.

The things that my therapy was talking about. "Are you afraid of elevators?" I said, "Yep." "Are you afraid of the escalators?" "Yep." So I said, "I might as well do it." I went out to the [shopping mall], and rode the escalator. Got off, didn't fall, but I was scared. Rode the elevators, didn't fall. Went to shop by myself, bought myself some clothes, shoes, everything. Then I was motivated. So I could get out and do these things just like anybody else. (Q05)

Trying new things also helped them learn what they can do and cannot do.

Failure in trial could result in different ways: choosing to give up that activity, trying a different activity, or trying the activity in a modified way. These choices depended on personal preference, desire, and perception about certain activities and their participation.

When I first thought I can do this or I can do that, I really couldn't. So going out and trying bowling. I used to be an avid bowler, and because of my fingers I had a special ball. Now, I would bowl with my right hand and the thing wouldn't fit. The bigger ones, the ones that the bowling alley had were too big. So I tried that, couldn't do that. I used to like to go out stepping as we would call it, dancing and I would just go. There was this favorite bar that we would go to all the time..... I just tried different things in order for me to find out that I couldn't do them... (Q11)

I tried [riding a bike]. But with my spasticity, I just would keep going around in circles. Because I can't... So I went to the gym and I got in the... a hand cycle. I've tried the hand cycling, and they actually have what they call a cab-trike which is a three wheeler, and you can use your legs. And you're steering it down by your seat. So it's something that, you know, yeah it looks funny, but it gets the job done, you know. (Q08)

Like I love to play basketball. But I can't, I can go out there and shoot it up, you know, but I can't move like I want to. I got a heel, I've got a hip with arthritis, I got weak muscles. So I can't move the way I want to. (Q07)

Overall, participants reported that they try to engage in more community activities to stay active and keep themselves busy. This meant that they actively look into

potential activities to engage. Many participants noted how staying engaged in a variety of different activities helps them stay both physically and mentally healthy, and make them feel that they are contributing members in society. For many participants, social isolation was an issue and they actively tried to engage in different ways to keep busy and not to get depressed.

I know that I, for some odd reason, I think I learned to branch out because I would be lonely if I didn't. I look forward to going to work, maybe that's why I look for more challenges like going to school and everything. (Q09)

And then at home, my religious activities keep me busy in studying. So I'm always trying to, like somebody mentioned about being idle and not doing nothing, that really can cause you to get bored, and start being depressed about yourself because you're not out there like everybody else. And you can't do all the things. (Q07)

On Monday, I go to that [church] because it is a group of people who count the money. I like to be there because I feel useful counting singles. I feel everybody is having a good time. We laugh. We are concerned about each other - when is your next appointment? how do you feel? A sense of small group. Nobody is the boss all of us are the bosses no body dictates. Of course the business manager is the person who is responsible but in that group of people all of us are volunteers and it is a small group 4 or 5 people. (Q01)

c. **Managing stroke related issues**

Many participants showed a good understanding of how stroke impacted their body, which helped them understand how the impact can affect their participation in the community.

I can tell when I get tired, then my foot starts to drop, a lot of things going on in your mind. You have to be careful, look where you are walking what kind of obstacles you have in front of you. Things like that. (Q06)

My emotions are not the same. Sometimes I am too sensitive and I get angry and I get angry fast when something's bother me. When back in the past I would never really let [those things] bother me. My emotions are different. My sleep habits are different I do recognize that there is something mentally different with

me from having a stroke. At first I was in denial of that but now I have really come to understand there is something different with me. (Q07)

For them, it was important to manage their stroke related issues so those issues did not stop them from participating in activities they wanted or needed to do. Strategies such as exercising to strengthen their lower or upper body, resting to deal with fatigue, and taking medication were mentioned.

I think most of my exercise comes when I go to the grocery store. Walking around the store and people always, even now when I go to the store, strangers or people that work there, 'Don't you want a scooter?' 'No thank you.' (Q02)

Working out, you know, my legs were getting stronger going to the fitness center it makes my legs feel strong so that doing that kind of helps me feel more active. (Q07)

Well everybody's different. And for me, I found out I have to get rest. I have to take a nap. I cannot keep going because if I'm tired I'm not at my best. And if I'm more relaxed, I can do things, I guess more smoothly. But if I'm tired, it effects, you know, my progress. Even trying to walk I tend to get very tired. But if I'm rested up, I feel good, my mind is relaxed and everything. (Q04)

Managing stroke related impairments also included the ability to utilize strategies to compensate for impairments, particularly for cognitive impairments. Many participants reported using memos to assist with their memory loss. One participant talked about how she deals with memory issues in social contexts:

When I get my memory not back with me to remember names, I just say, "Hi, how's the family?" It's that. I don't remember who the family is, who are the children, or what is the name of the person? But I'm still trying to be nice. (Q01)

d. **Planning ahead**

Many participants noted how planning needed to happen whenever they left their homes or they engaged in activities. Planning included scheduling daily routines, checking for accessibility before visiting unfamiliar places, and preparing for emergency situations.

Well, I'm getting to the point now, I go some places, I have to call ahead to find out if they have stairs, is there a rail that I can hold onto to get up the stairs. It has to be a rail. I cannot walk a flight of stairs with no rail. I can't do that anymore. And so that's my first question. If I have to go downstairs to go to the lady's room, is there a rail, or a ramp, or anything. (Q04)

So like I got this leg brace to help me walk straight. So I know sometimes I need to use that even though I might wheelchair myself somewhere. But I make sure just in case this wheelchair might break or something, so I can just make sure I can hopple where I need to go. So I always got like a plan B for some reason. I keep a plan B behind me. (Q08)

Everything requires planning now. Sometimes you have to make a list and if you don't write it on paper, you definitely have to put it in your brain when you get up in the morning. Like you're lying in the bed, even as I'm eating breakfast, okay did I wash those dishes or did I put that, you know, plan that. Am I going to Walgreen today? (Q02)

Participants also planned for extra time to pace themselves because activities usually take more time than they used to before stroke. For some participants, planning involved making a decision about the time they engage in certain activities. For example, participants would go to movies during the day before it gets busy or go grocery shopping early in the morning when it is not crowded. One participant mentioned how he plans to do things around his transportation.

But having transportation, you know, I try to do as much as I can for myself. And I have my wife and my daughter, [but] I don't try to rely on them to do everything for me. So whenever I'm out with transportation, I take advantage of all the opportunities. Wherever I'm going, if there's a store, Walgreen, or whatever, I get what I need, I take care of, I get what I have to have (Q07)

Participants also talked about different ways of thinking through their activities by talking them through out loud or writing them down. Planning included an analysis of their ability and access within a given environment. A few participants mentioned that they examine what they can and cannot do, which helped them identify what supports or strategies they needed to pursue or plan in order to make participation possible.

At first you kind of forget you want to do something and you just think you can do it again and realize that you can't. Now, it's if I want to do something, first I have to think can I do it? If I think I can do it, how am I going to do it what do I need to get it done. Things like that. My thought process is a lot greater now than it used to be. When you're able bodied you are used to doing things you just do it. (Q06)

e. **Asking for and accepting help from others**

Many participants talked about the help they were receiving or not receiving from their social supports such as family and friends. Many participants acknowledged the need for asking for help and importance of having and accepting help when needed.

I mean [having people around you] boost your self-confidence in yourself. I mean you'd rather have your independence, but when you really need something, they'll be there for you as somebody able to do it. (Q08)

While they acknowledged the importance of having help at times, many participants expressed their desire to stay independent and do thing for themselves rather than receiving help from other. The sense of independence was a sensitive concept as participants appreciated help but felt strong about having control over their participation and the help they were receiving.

They [people who had a stroke]'ve come to the realization that, "I had a stroke, I need some help." And that's the way we are. We're very proud people. Like you said, you don't like anybody standing behind you, I don't like that either. Nobody wants any help. We know we need it, but we're very proud people. (Q11)

And sometimes he [my husband] cooks, or sometimes he tells me to take a nap, or take it easy. It is good because it helps me to be myself. But I don't want to get in the comfort side either and just leave everything for him. I want to be able to do stuff. Maybe not as fast as I used to, take my time and do it (Q01)

Receiving and asking for help from family also depended on the relationship with or attitude of the family. Participant Q08 talked about her family that wants to do everything for her, not allowing her independence when she can. Participant Q06

described a different situation in which his family tried to help him because they were impatient with him. Such interaction made participants not comfortable receiving help.

Now with me, maybe my self-conscious because I sense a lot of this patronizing, condescending. And it pisses me off. Because you're not giving me any credit for the recovery that I've done. It's like you prefer that I'm disabled than to be independent. Because they're always asking me, "Why don't you call me to do this?" "Because I can do it. And I want to be able to do it." (Q08)

So when I'm at home and my wife's around, or family, everybody thinks they have to help me. And I'm like, "If I need your help I'll ask for it. Otherwise just let me do it." See they get annoyed because it takes four times longer for us to do something. And [I say] just don't get annoyed. I'm going to do it, but it's going to take a lot longer than it's going to take you. And I think after right years, it's finally kind of getting through it. They're just going to have to wait until I'm done. So it's hard for everybody. (Q06)

On the other hand, there were families that did not treat participants differently, which allowed the relationship to stay equal and reciprocal.

I love the way my family treats me because they treat me like there ain't nothing wrong with me. And even though I'll look at them and think, don't they realize I had a stroke? They look at me like ain't nothing's changed, you can do this and you can do that. I'm like, what's wrong with ya'll? But in a way I'm glad they did treat me that way. Because I don't want them, you know, I love the way they treat me. They treat me like ain't nothing wrong with me. (Q07)

f. **Accessing and managing community mobility**

Managing transportation was reported as key in getting out in the community, and many participants talked about how access to transportation enabled them to do what they wanted and needed to do. One participant said, "Para Transit was picking me up in 2001. Driving me to work, and coming back home" (Q02). Another said, "Once I started driving I was able to get out a lot more" (Q06).

Participants mentioned the importance of both the availability of different modes of community mobility and the ability to manage those modes. First, it was important to

learn about door-to-door Paratransit services, driving rehabilitation, or vehicle modification services. Once services were established, it was important to manage the different modes of transportation. The door-to-door service users reported the need for planning their trip in advance because they needed to reserve their rides a day before an event. Some participants who relied on the door-to-door Paratransit service or public transportation also expressed frustration with the reliability, quality, and attitude of the service providers.

One problem with transportation is, the busses, the CTA busses. When you put your card in and get it out, and you start to walk to your seat, they guy like floors it and you go all over the place. Thank God they got those bars to grab onto. I mean I think they could wait till you get seated. I mean seeing as how the handicap seats aren't near the front anyways, they really, they need a lesson. (Q06)

The drivers need to tell these people [sitting in the seats for people with disabilities], "I'm not going to move this bus until you get out of those handicap seat." Because I don't think it's fair for me to get on there, and my balance is bad, and here they are acting like they're asleep. This is what I run into. They sit up there like, they're not asleep, they don't want to get up. (Q04)

Overall, participants with multiple means of community mobility (e.g., driving, public transportation, Paratransit, rides from others) expressed more freedom in getting around in the community.

...when I came home before I wasn't nearly in no condition to do that but now I will get in the car and I will drive within a quarter mile radius you know short distances. I go get my hair cut and if I want to go shopping I may call PACE [ADA Paratransit] to take me somewhere to buy some clothing or something. (Q07)

Like [ADA Paratransit], I don't go with them all the time, I'll take [public transportation]. You get the free bus pass and I use it. Someplace I want to go, so I got to go downtown now and get some Christmas presents. I'm going to go down there and get on the bus. (Q10)

Once in a while. Like if I drive my car to the service station, and it's going to be all day, or whatever, I'll take the bus back home and wait for it. (Q06)

g. **Seeking and using information about community resources and services**

Many participants talked about how they learned about resources and services available to support their participation in the community. Because most of the participants in the study had their stroke for a while and had established transportation options and financial supports (e.g., Supplemental Security Income, Social Security Disability Insurance) already, the resources they were seeking and utilizing were related to information about leisure or productive activities. Participants mentioned different means of accessing this type of information including computer or phones, but frequently, people found information through special events (e.g., disability fair) or referrals from local hospitals.

When my computer was working I looked up a lot of things to do with disabilities and stuff like that. In my searches and stuff, but now I do it on my phone rather. (Q11)

We came back in [from an outing] and they were holding a disability fair in the lobby [of the hospital]. And the sailing program was there. So with a little push from my wife, I signed up [for the sailing program] and went out. And have been doing it ever since. (Q06)

So I met a lady that had an employment agency. And she gave me a job as a telemarketer....My first job as a telemarketer, I really liked it. And that's a nice job, and I had a nice job when I became disabled. And I really enjoy getting up, going every day to the job. I met people. I learned to do that job. I said, "Oh I like this, selling stuff." And that's about it. I really liked it. (Q04)

Sometimes information was found through other people. Family and friends were often helpful in finding information and passing it on to the person with stroke. Some people found information through other people with stroke or disabilities and actively sought information through groups like that.

Well somebody telling me that there was a para transit company that was going to pick me up at my door, and carry me to work. It's like, "Yeah we'll get you information." Or my sister did. Because she worked for the Department of Aging. And that was unbelievable, so that was a great resource. And then I started back to work in March, and I was riding the Paratransit bus, and this young Caucasian lady says, "You just had a blood clot on your brain, maybe you might want to go down to [the hospital fitness center]. And then that's when I started going.....And that was a resource there that greatly benefitted me. Because after working, I would go to the fitness center after work. And they had a stroke program there. And you know, we would use the machines and they would keep up on what we were doing. Then I found out that they had stroke support group meetings. (Q02)

And my sister, she made the flight reservations and all of that, which I felt like I could do. But she found out there were things that she thought about that I didn't think about. Things like meet me at the gate and ride on this big baggage claim thing. And they take you to the gate...You get on the plane first, you get off the plane, there's somebody waiting for you. I was like, this is the best way to travel. (Q11)

Basically what I did for myself personally on the internet was that I joined a young person's stroke survivor exercise group. The woman's out of Texas. These are young people and much more into this than I am. I did find out about new therapies and I did find out about something called a 'Fit Bit' which I had never heard about. (Q12)

h. **Different levels of community participation**

Analysis across the themes suggested that participants experienced different levels of community participation that were affected by attitude, actions, and environment (Figure 3). Community participation was activated by the interaction between *attitudes*, such as willingness to take risks and reclaiming a sense of independence, and *actions*, such as trying new activities, using resources and help, planning, and problem-solving. Environmental factors, such as the peer support from the stroke community, family attitudes, social prejudice, and community resources strongly influenced how attitudes and actions were shaped. Depending on the attitudes and actions developed, individuals were differently activated in their community participation. Three different levels included: 1) not being confident or comfortable going

out and participating in the community; 2) being confident going out but having limited and/or unsatisfactory participation; and 3) actively seeking and managing supports and resource and participating in the community as desired.

Not confident or comfortable going out and participating in the community. Most participants expressed that they were not comfortable participating in the community first after they had their stroke because of the fear and uncertainty with their new body and public reaction to their impairment. Their experience at this level was mainly explained by their rehabilitation experience. For many, therapy sessions or doctor's visits using transportation provided through insurance or from family were their sole activities outside their home because functional improvement was seen as a precondition to participation in any other community activities.

The physical therapy that I go after I had the stroke kind of got me back active trying to do things. So I followed that up after the physical therapy. I was in the hospital, then I followed up with out-patient physical therapy. So all of that kept my body moving and I carried that home with me after that. And then I started walking, you know, taking my walks. And I move around in my house all the time. So that's how it all started, with the physical therapy. It kind of got me back in the groove of doing things. (Q07)

I kept thinking, I'm not going out like this. I'm lying in the bed, or getting in a wheelchair doing all of this. And I just kept saying, God please just let me walk again. Just let me walk. And me being the hard head that I am, I got up one night at two o'clock in the morning. All the nurses and staff were on the floor, and I said, "I'm going to walk to the bathroom." And I fell out the bed. And that's what motivated me to, "Okay what kind of therapy do you have, arms, legs, mental?" Whatever therapy they were giving I took (Q11).



Figure 3. Three levels of participation and influencing factors

However, in addition to their functional impairment, they stated that they had to deal with their body image and stigma around disability because of the negative public attitude as well as their own stereotype towards disability. Participant Q4 mentioned about the staring of the public, while participants Q10 and Q5 talked about their own stereotype towards disability which affected their comfort level and confidence.

I had trouble going out. I didn't like it because I was all crooked. My face was crooked. I didn't like it. I didn't like it at all. My arm, I couldn't move it right. So I'd just want to stay in the house. (Q10)

Well first of all, I had a hard time getting used to this word called handicap. I knew what it was, but I didn't know I was handicap. And you said, "If you think about handicap, look in the mirror." That's when I found out I was handicap. And I said, "Oh God, I can't believe I'm handicap." You know, I was a kid at one time, I used to make fun of people like this. And I'm handicap. I mean, what does handicap mean? Look in the mirror and you'll see. I said, "No, no." (Q05)

Confident going out but having limited and/or unsatisfactory participation. Several factors then helped them continue building their confidence and comfort level with going out into the community and participate in necessary activities such as grocery shopping, exercising, family visits, or doctor's visits. At this level, participant reported gaining confidence from functional improvement, being able to problem solve barriers, and using the environment and resources as supports to participating in necessary activities. Help from family and friends and/or networking with other people with stroke or disabilities encouraged and empowered them to participate in the community. Along with their functional recovery, continuous trials and errors and experiences with failures and successes in daily activities facilitated their activity choices and understanding of their ability. This process also allowed them to understand the importance of modifying the way they do things. In addition, arrangement of transportation options and necessary community services expanded their mobility in the community and access to

needed resources for community participation. However, despite the confidence they gained and their participation in activities, people in this stage were limited in the breadth of their participation due to their self-consciousness on their impairment or limited social network. Although people were able to fulfill their basic daily activities and necessary activities in the community, they felt “stuck” with not being able to perform certain things in a way they want, felt disconnected from their community, and/or expressed loneliness, isolation, or boredom.

At work, I used a cane to walk because I don't want them to see me in a wheelchair. Because it's very egotistic at the TV station. They don't care if you had a stroke or not, or they don't care about your handicap. So they're going to try to have one over on you and everything. Plus sometimes I'm shy. And going out, I'm like, I'm through going out in a way because I used to be a DJ for like 20 years. And sometimes I see the public, and seeing it before the stroke and after the stroke, it's like, you know. (Q09)

When I want something you know when I want something from the store I am not going to sit here and not have what I want. I'll just get up and walk to the store you know. Or if there is something that is in the vanity that's close by that I want if I want a haircut if I need a haircut I will get and get in the car and drive 4 blocks to the barber shop.....The socializing has dwindled down quite a bit.....Yeah I am okay with it. I am still struggling with the boredom. You are still in the house by yourself. My wife and my daughter they socialize on a different level. I am sure you know what I mean. So obviously I feel like an outcast, I feel like really by myself a lot so what I do with that I have the pool table. I have my music and I have the games on TV so that's how I deal with that. (Q07)

Actively seeking and managing participation in the community as desired. Then there were a few participants who went beyond necessary activities and sought various activities in the community. As opposed to people who were confident but not satisfied with their participation, people at this level found resources and supports to engage in activities they wanted to and were less conscious of their disability and more satisfied with their level of community participation. They seemed empowered in a sense that they were not unsatisfied with being unable to do certain things and/or needing to

modify activities. As mentioned above in quotes by participants Q4 and Q11, this sense of empowerment derived from bonding with and being part of a community of other people with stroke or disabilities. The disability community provided participants with a safe environment to share strategies and information, to try various activities, and to feel that it is okay to do things in a different way or to not succeed.

Participants with such sense of empowerment also reported confidence in participating in other activities in the community without being part of a group of people with disabilities. Such attitude then allowed participants to pursue different activities as they desired. Although such pursuit did not always lead to satisfactory participation, those participants did not feel discouraged by not being able to perform in a way others do it. For example, participant Q11 tried bowling and stepping and learned that she could not do them, however, she tried line dancing at a slower pace with a group of other people with disabilities instead. The following quote illustrates her resilience to challenges and confidence in trying out different activities.

It's changed so much then, because now where I was doing things individually I look more for group sessions.....,I just tried different things in order for me to find out that I couldn't do them. The [fitness] center gave me enough confidence to go out and try these things. But now, pretty much anything that I want to do, as far as like going out. I still go out. As far as dancing, I take line dancing for the disabled and I just go at a slower pace. Shopping, I still do that. So everything that I wanted to do that I wouldn't do before. I've got enough confidence and stuff in myself. (Q11)

5. **Discussion**

The findings show that people who had a stroke take different approaches and strategies to be able to actively participate in the community. Seven themes related to attitudes and actions evolved out of the three focus groups and six individual

interviews: 1) comfortable getting around in the community; 2) actively trying to engage in more community activities; 3) managing stroke related issues; 4) planning ahead; 5) accessing and managing community mobility; 6) asking for and accepting help from others; and 7) seeking and using information about community resources and services. An additional cross-cutting theme described how people become activated to participate in the community.

The result of the study supports and extends previous studies that highlighted the importance of using skills, resources, and supports to manage restrictions or barriers to community participation (Clarke & Black, 2005; Hammel et al., 2006; Sarre et al., 2013; Woodman et al., 2014). The study showed that a sense of empowerment is integral in making people with stroke resilient in the face of attitudinal challenges and stigma in public and comfortable participating in community activities. While many studies identified walking or functional ability as predictors for community participation (Algurén, Fridlund, Cieza, Sunnerhagen, & Christensson, 2012; Chau, Thompson, Twinn, Chang, & Woo, 2009; Desrosiers et al., 2006; Desrosiers et al., 2008; Gadidi, Katz-Leurer, Carmeli, & Bornstein, 2011), this study showed that walking was an important part but not enough to make people go out and do what they want to do in the community. Even when they were able to walk, many participants had a negative perspective about disability that made themselves conscious about public attitude and reaction. This self-consciousness prevented them from doing what they want to do in the community. These findings suggest that improving physical functions is not enough and that there is a need to facilitate the empowerment process during rehabilitation so they feel more comfortable with their impairments earlier on.

At the time of the interviews, none of the participants were at the level of not being comfortable to go out but there was a difference between people proactively seeking and participating in a variety of things they wanted and people who were only participating in necessary community activities and not fully satisfied with their participation. Previous studies found that functional impairments, social attitudes and perception, physical and cognitive access, policy issues, and financial barriers prevent people from further seeking community participation goals (Anderson & Whitfield, 2011; Hammel et al., 2006; Sarre et al., 2013). One of the biggest differences observed in this study between proactive and passive participants was having a close social support, including a peer group. Anderson and Whitfield (2013) pointed to the importance of having a supportive social support that does not make one feel different or isolated. This study also found the importance of having family or friends who accept them as they are, however, there was also a strong emphasis on connecting with others with similar experiences and having a role model. Active participants pointed to their participation in different group activities with friends or peers with disabilities, which provided them a safe environment to try new things and also fail. Such environment helped them become more confident and willing to pursue other community participation opportunities.

Another difference between the passive and proactive group was the willingness and ability to make changes to how they participate in the community. Proactive participants were more willing and acceptant to do activities differently instead of trying to be “normal” again. Kubina, Dubouloz, Davis, Kessler, and Egan (2013) noted that lowering the expectation leads to activity adaptation, however, this study also found that

the openness for modifications was a result of empowerment and confidence. People who positively felt that it is okay not to do everything the way others do it were also willing to try new things and open to different ways of getting things done. They reconstructed normalcy and embraced their difference as what is normal to them. Murugami (2009) noted that such reconstruction rejects the medical model that presents disability as tragedy and accepts the social model of disability in which disability is a social construct created by the oppressive society designed for able-bodied. To support people with stroke to reconstruct their perception on disability and impairment and to build their disability identity, the process of empowerment is critical. Peer support and mentoring, engagement in the disability advocacy community, and programs introducing the social model of disability have shown to be effective methods in empowering and raising consciousness of people with disabilities (Anderson & Whitfield, 2013; Fawcett et al., 1994; Freire, 1993; Lee, Hammel, & Wilson, 2016) and may represent promising intervention strategies to also promote community participation goals.

As the cross-cutting theme revealed, active management of community participation is a result of the interaction between *attitudes* and *actions*. It was noticeable that the participants were knowledgeable and skillful with how to problem solve stroke related issues, plan in advance, manage barriers with resources and supports, and deal with transportation to participate in their favorite activities in the community. Attitudes such as acceptance to changes and willingness to try new things also facilitated their readiness to participate in the community. The specific attitudes and actions identified as facilitators to community participation in this study can inform participation focused interventions and outcome measures for people with stroke. The

ultimate goal of stroke rehabilitation is to enable the clients to live their lives fully, so an emphasis on living life well with a disability, instead of only trying to remediate impairments, is indicated. It is critical to support people with stroke in how to strategize ways to improve their participation and integration in society. The findings can provide a guideline for participation-focused rehabilitation interventions and a basis for a measure that can evaluate outcomes related to community participation.

The study has limitations. Although participants showed diversity in age, time since stroke, marital status, and gender, the majority of the participants were African American and educated with a high school degree. All of them were community-dwelling not including a sample living in institutions. In addition, many of them were connected to a rehabilitation hospital that offers a variety of resources and programs for people with disabilities. The availability of resources that provide opportunities for people to engage in activities and network with other people with disabilities may not be experienced by people with stroke located in rural areas or people without access to these types of programs. The data were also mainly analyzed by the first author, adding potential bias originated from her background and personal experience with people with stroke.

In conclusion, the findings show that people with stroke experience changes in their attitudes and actions over time that influence their level of community participation. By being able to manage the individual and social implications of their stroke and reconstructing their perception of disability, individuals gain sense of empowerment and confidence which results in active seeking and participating in the community. The results emphasize the importance for rehabilitation professionals to provide an

environment that supports the development of actions and attitudes facilitating community participation post-stroke.

B. Paper 2 - Development of the Community Participation Activation Scale (CPAS): Conceptualization and Item Development

1. Abstract

Purpose: The purpose of this study was two-fold: 1) to conceptualize community participation activation; and 2) to develop and refine an item pool of the Community Participation Activation Scale (CPAS).

Methods: Instrument development including conceptualization (literature review, focus groups, qualitative in-depth interviews), item writing, expert reviews, and cognitive interviewing. Adults who had a stroke informed the development through focus groups and qualitative interviews (n=12) and cognitive interviews (n=5). Content area and outcome measurement experts participated in expert reviews (n=8).

Results: The findings show that activated people with stroke are likely to attain attitudes and actions that make them actively seek and maintain community participation. A pool of 41 items was examined by experts, and 37 items were used for cognitive testing. Items were revised based on the feedback from cognitive interviews. A total of 27 items were developed.

Conclusion: The CPAS is a new measure assessing attitudes and actions activating community participation after stroke that can be used as a participation measure in stroke rehabilitation and research. The process of conceptualization, expert reviews and cognitive testing ensured content validity of the measure. Findings from psychometric testing will be described in another article.

Key words: stroke, social participation, outcome assessment, expert review, cognitive testing

2. **Introduction**

The concept of participation has become central in the discussion across all rehabilitation and health care professionals since it was included in the International Classification of Functioning, Disability and Health (ICF) model as a major component of disability and health (World Health Organization, 2001). In the ICF, participation is defined as “involvement in life situations” (WHO, 2001), which encompasses a broad perspective of human life. While the ICF model attempted to define participation, it has been critiqued for being ambiguous in differentiating participation from activity and lacking a clear conceptualization (Hammel et al., 2008; Hemmingsson & Jonsson, 2005; Whiteneck & Dijkers, 2009).

Given these critiques, much effort has been done to clarify the definition of participation. Many researchers agree that participation is more than performing a sole activity but rather a meaningful engagement or “being part of” an activity, context, or social group while having control, choice, and access to opportunities (Hammel et al., 2008; Trudy Mallinson & Hammel, 2010; Whiteneck & Dijkers, 2009; Whiteneck et al., 2011). Existing literature also pointed to the transactional nature of participation which lays emphasis on the influence of the intersection among a person, task and environment on participation (Hammel et al., 2008; Hemmingsson & Jonsson, 2005; Mallinson & Hammel, 2010; Whiteneck & Dijkers, 2009). This intersection points to the complexity of participation and the importance of managing personal and environmental level factors that influence participation. Thus, participation is a “dynamic process that

involved constant negotiation and balancing of competing needs and values across individual, social and societal levels, exerting a ‘push-pull’ influence on people’s ability to participate in ways that they find meaningful and satisfying” (Hammel et al., 2008, p. 1455).

For people who had a stroke, participation in everyday life is also a complex process that takes significant management. A body of qualitative research shows that people become active in their lives and resume activities as they recover from stroke and learn how to strategize their newly acquired impairments in the environment (Hammel, Jones, Gossett, & Morgan, 2006; Kubina, Dubouloz, Davis, Kessler, & Egan, 2013; Sarre et al., 2013; Woodman, Riazi, Pereira, & Jones, 2014). People after stroke go through a process of adaptation by reappraising their new situations, relearning activities, and making modifications to their tasks and surroundings (Rochette et al., 2006; Woodman et al., 2014). They use different skills and strategies such as goal-setting, problem solving, trying out new solutions, utilizing resources and services, learning from health care professionals, and accepting help from others to adapt and to build confidence (Hammel et al., 2006; Kubina et al., 2013; Woodman et al., 2014).

A growing body of research supports that participation is a multi-faceted and complex process and that various attitudes, skills, and strategies take into a play to enable individuals with stroke to participate in the community in a way they want. Yet, current measures assessing participation mainly focus on the observable performance outcomes of participation. Participation is most frequently measured in forms of frequency and intensity of engagement in different activities, limitations and supports to participation, and importance or satisfaction with activities (Chang et al., 2013; Eyssen

et al., 2011; Kessler & Egan, 2012; Tse et al., 2013). Given the emphasis on choice, control, and opportunities and their role in participation, new measures have emerged to integrate concepts such as enfranchisement (Heinemann, Magasi, Bode et al., 2013). However, the process of participation and ability to manage different factors affecting participation are yet overlooked in participation measures. A measure with that focus would provide a participation outcome that explains areas one needs support with to participate in the community.

Development of a measure begins with establishing conceptual clarity of the construct. Recent measurement and testing literature suggest the use of qualitative methods to inform the conceptual model and item development (Magasi & Heinemann, 2009; Velozo, Seel, Magasi, Heinemann, & Romero, 2012). Such design increases the sample size, maximizes the appropriateness, validity, and utility of the instrument, and increases research integrity (Onwuegbuzie, Bustamante, & Nelson, 2009). Since no research has been done to quantify behaviors that enable participation, the study used a mixed method design to conceptualize the construct and to ensure validity in developing and refining the new measure, called “Community Participation Activation Scale (CPAS)”. The aims of the study were: 1) to develop a conceptual model to inform the item development; and 2) to develop and refine items that assess factors enabling community participation.

3. **Methods**

This study utilized an exploratory sequential mixed method design, in which the qualitative study complement a principally quantitative study (Creswell, Klassen, Plano, Clark, & Smith, 2011). An exploratory mixed method is commonly used

in instrument development especially if the research area is new or unfamiliar (Kroll & Morris, 2009; Magasi & Heinemann, 2009). This article entails three phases including conceptualization and development of a conceptual model, item development, and item refinement. Validation data of the measure will be reported in another article. All activities were approved by University of Illinois at Chicago, Office for the Protection of Research Subjects.

a. **Phase 1: Development of a conceptual model and an item pool**

Literature review. A comprehensive literature review was conducted to identify what factors influences participation in the community after stroke. Databases such as Pubmed and CINAHL were used to search literature with following foci:

- Community participation after stroke
- Strategies used by the people with stroke
- Factors influencing post stroke participation in the community

Focus groups and qualitative interviews. Focus groups and individual interviews were conducted to describe and frame perspectives and experiences regarding attitudes, behaviors, and strategies facilitating community participation. Semi-structured interview guides were used to reveal the process of and factors influencing community participation. Using a convenience sampling method, individuals with stroke were recruited through flyers distributed to local hospitals and through an existing registry from a previous stroke self-management intervention study. Individuals who had a stroke and living in the community were included. Individuals with severe cognitive impairment and aphasia were excluded from the study.

A constant comparative approach was used to analyze data from the literature review, focus groups, and qualitative in-depth interviews (Patton, 2001). Data were coded using Atlas.ti, and emerging patterns and themes were discussed with two other researchers. These data were used to develop a conceptual model. Domains and elements of the conceptual model informed the development of an item pool.

b. **Phase 2: Expert review**

An expert review was conducted to ensure the content validity of the instrument. Using purposive sampling, content area and outcome measurement experts were recruited to review the items. Experts were asked to rate the relevance of the proposed items using a 4-point ordinal rating scale (1=the item is not representative; 4=the item is representative) and provide feedback on contents and clarity, following a guideline adapted from Grant and Davis (1997). The item-level content validity index (I-CVI) was calculated using the proportion of experts who scored items with either 3 (relevant) or 4 (representative) (Grant & Davis, 1997; Polit & Beck, 2006). Scale level content validity index (S-CVI) was then calculated as the average of the I-CVI values as recommended by Polit and Beck (2006). An I-CVI of 0.75 and a S-CVI of 0.9 or higher were used as criteria to establish a content valid instrument. The I-CVI and S-CVI scores and qualitative comments from expert panel were used to revise the items and to meet the content validity criteria.

c. **Phase 3: Cognitive interviewing and reading level analysis**

Cognitive interviewing. Cognitive interviewing was used to understand how respondents interpret the items and refine the items to ensure that a questionnaire measures what is intended to measure (Jobe, 2003; Magasi &

Heinemann, 2009; Ryan, Gannon-Slater, & Culbertson, 2012). To cover “as much of a questionnaire’s conceptual terrain as possible” and represent some demographic variety, purposive sampling were utilized to select individuals with stroke with different ages, racial backgrounds, educational levels, and levels of cognitive impairment (Beatty & Willis, 2007, p. 295). At least two participants with one of the following criteria were recruited: 1) less than 12 years of education; and 2) cognitive impairment (DeWalt, Rothrock, Yount, & Stone, 2007).

Cognitive interviews were conducted using the verbal probing approach (Ryan, Gannon-Slater, & Culbertson, 2012). Using semi-structured guides, participants were asked to repeat the item in their own words, explain the meaning of items, and offer alternate phrasing when comprehension was limited. The interviewer kept detailed notes and audio recorded the interviews. Data were analyzed following an informal analysis process suggested by Willis (2005). The items were refined, based on the comments and feedbacks,

Reading level analysis. The reading level of each item was examined using the Simple Measure of Gobbledygook readability measure. The Simple Measure of Gobbledygook readability measure is gold standard measure that demonstrates strong correlation with the required reading level (Sharma, Tridimas, & Fitzsimmons, 2014). This readability measure is also recommended as a preferred measure when evaluating consumer-orientated health care materials (Fitzsimmons, Michael, Hulley, & Scott, 2010; Sharma et al., 2014). Items were reworded if the reading level was above the eighth grade level.

4. **Results**

a. **Phase 1: Construct and conceptual model**

Thirteen participants were recruited. Majority of the participants were female (n=7), African-American (n=9), educated with at least a high school degree (n=13), and not married (n=8). The mean age was 59 years old (SD=4.9) ranging from 60 to 69. The mean time since stroke was 11 years (SD=8.2) ranging from 1 to 21 years. Through three focus groups, six individual qualitative interviews, and a literature review, behavior domains were developed that explain attitudes and actions activating community participation. Table II shows selected quotes for each domain.

TABLE II
SELECTED QUOTES THAT SUPPORT EACH DOMAIN

Attitude domain	
<i>Belief that being active keeps healthy</i>	<p>It's a lot of planning. Putting a lot of thought into doing things. My ability to do things, I have a greater strength and I can, I don't as tired as fast. I've built up my endurance.</p> <p>So I'm always trying to, like somebody mentioned about being idle and not doing nothing, that really can cause you to get bored, and start being depressed about yourself.</p>
<i>Comfortable being in public</i>	<p>"Well I used to do a lot of walking of course before I had my stroke. I was always walking around the village and things like that...But now I don't go out so much now because to be honest, I don't really want to so much. I get very...a bit self-conscious about hobbling around the place you know." (Robison et al., 2009, p. 1560)</p>
<i>Willing to take risks and try new things</i>	<p>My therapist was talking about. "Are you afraid of elevators?" I said, "Yep." "Are you afraid of the escalators?" "Yep." So I said, "I might as well do it." I went out to the shopping mall, and rode the escalator. Got off, didn't fall, but I was scared. Road the elevators, didn't fall. Went to shop by myself, bought myself some clothes, shoes, everything. Then I was motivated.</p>
<i>Focusing on strengths and keeping positive</i>	<p>My thinking is always going to be, I'm confident, I can get it done. I'm always going to think that way. And I may wind up doing it and failing, but in my mind, it's going to be "I can get it done." And if I fail, my next thing is going to be that I can do it better next time. That's just the way I am, I'm always a positive thinker.</p>
<i>Redefining and re-evaluating self and reality</i>	<p>It took me quite a while to realize I was handicap. So once I got that down pat, everything was smooth sailing.</p>
<i>Being in control</i>	<p>"I think that it is very important for me...to be involved in decision-making...even if I can't manage to do the activity by myself." (Häggström & Lund, 2008, p. 92)</p>
Action domain	
<i>Managing the impact of stroke related impairments</i>	<p>Well, when I feel myself getting real tired, I take a little nap. Then I get and I feel good now.</p> <p>Working out. My legs were getting stronger. Going to the fitness center. It makes my legs feel strong, so doing that kind of things helps me feel more active.</p>
<i>Testing/trying new things</i>	<p>"When I first came out (of hospital) , I went to the clubhouse to play...and just started knocking a few balls and the I just took my time really to gradually get into it until I could start to walk the course again...I found it a bit of a struggle at first but I think that's only to be expected. Then I started getting into the swing of things." (Robison et al., 2009, p. 1561)</p>
<i>Planning</i>	<p>Well, I'm getting to the point now, I go some places, I have to call ahead to find out if they have stairs. is there a rail that I can hold onto to get up the stairs...And so that's my first question. If I have to go downstairs to go to the lady's room, is there a rail, or a ramp, or anything.</p> <p>You've always got to kind of analyze the good and bad things. Can I do this? What will happen if I can't?</p>

TABLE II (continued)
SELECTED QUOTES THAT SUPPORT EACH DOMAIN

Action domain	
<i>On-the-go/in-the-moment problem solving</i>	When the problem arises, I look at it, try it out and see what happens. I have to look, not straight ahead of me, but straight ahead and down so that I can see the surface that I'm on walking on. If it's uneven I have to know that otherwise I'm going to be on my face. Especially if I'm tired because my left side gets tired and my foot drops.
<i>Utilizing an adapted way of participating in activities</i>	As far as dancing, I take line dancing for the disabled and I just go at a slower pace. "Go (to the club) from about 9 until 11 or about half eleven, and I know then that I can go through that period without having to struggle off to the toilet or something like that, and have a drink. I enjoy it – music there, friends there..and then I come home and look forward to the next one." (Robison et al., 2009, p. 1561)
<i>Asking for help and accepting help from others</i>	I mean you'd rather have your independence, but when you really need something, they'll be there for you as somebody able to do it. So [asking for help] that's really important. Because I'm learning to deal with life in another way. And I'm able to do it. But sometimes I feel tired and I don't want to cook. My children are old enough to take care of themselves.....So it is only my husband and myself. And he's very understanding. And sometimes he cooks, or sometimes he tells me to take a nap, or take it easy.
<i>Comfortable being in public/ getting around in the community</i>	But now, pretty much anything that I want to do, as far as like going out. I still go out...Shopping, I still do that. So everything that I wanted to do that I wouldn't do before. I've got enough confidence and stuff in myself. "We've gone through various stages and I've reached a point where I got to be able to walk alone without feeling that I can't or I need someone with me. I'm most certainly at this stage now and it has to be done, and we did it and I feel comfortable with it." (Kubina et al., 2013, p. 240)
<i>Accessing community mobility when needed</i>	Well what has changed is that I have been using the [Paratransit] service. Now I get around I do things that I wanted to do...I pretty much handle my own. I even drive short distances....I go get my hair cut and if I want to go shopping I may call [Paratransit] to take me somewhere to buy some clothing or something.
<i>Seeking and utilizing information and community resources</i>	I don't have any family or nothing. The thing of it is that I did call [local grocery stores] and see if they would deliver and stuff. I get into that a little more. Then I got to talk to my people, [local pharmacy] to see if I can get medication, my meds delivered. I do like to take my dog for a walk in the forest preserves. But there is really no place to sit down except for like a fallen log, or a tree, or something. Maybe I can petition the county to start putting benches in.

i. **Attitude domain**

The attitude domain includes beliefs, opinions, and values that activate community participation post stroke.

1. *Belief that being active keeps people healthy:* Existing literature and data from the focus groups and in-depth interviews noted how staying engaged in activities and keeping busy helped them stay both physically and mentally healthy (Kubina et al., 2013; Woodman et al., 2014). The belief that doing things important to them as a way to keep them healthy drove them to participate in the community.
2. *Comfortable being in public:* The process of becoming comfortable getting around in the community involved attitudinal aspects (Ch'ng et al., 2008; Clarke & Black, 2005; Kubina et al., 2013; Robison et al., 2009). Activated people were not self-conscious about their disability and were able to deal with negative public attitude. The comfort level and confidence in getting around in the community allowed them to participate in activities as they wanted to.
3. *Willing to take risks and try new things:* Activated individuals with stroke try new things or test out new ways of doing things to explore more opportunities and pursue a desired active life style. Many participants from phase 1 talked about how trying new activities enhanced their participation in a variety of new activities. In previous studies, stroke survivors reported examples such as trying to get on the bus, get on the escalator at a shopping mall, and engage in exercise and leisure activities (Ch'ng et al., 2008; Kubina et al., 2013; Robison et al., 2009; Woodman et al., 2014). Their attempt to take the risk to try new activities or activities they used to participate

in helped them develop realistic expectations or better understanding on how to modify an activity or find the right level of supports to participate.

4. *Focusing on strengths and keeping positive:* Keeping a positive attitude was identified as a facilitator to community participation by phase 1 participants and literature (Ch'ng et al., 2008; Robison et al., 2009; Sarre et al., 2013; Woodman et al., 2014). People with stroke acknowledged that focusing on strengths increased their confidence and enabled them to try to do more activities. In addition, community participation was maintained and pursued when they had a positive outlook on resuming activities.
5. *Redefining and re-evaluating self and reality:* From study participants and literature review, it was shown that the process of re-evaluating the recovery expectation and rebuilding identity was central in deciding what roles and activities people with stroke were going to pursue and participate (Clarke & Black, 2005; Sarre et al., 2013; Woodman et al., 2014). People with stroke started to shift their focus from remediation to compensation when they redefined their expectation of their recovery. This shift to compensation made them actively strategize how to use the environment and supports to achieve their participation goals regardless of impairment or disability.
6. *Being in control:* Community participation is a subjective experience, and thus it is critical for persons with stroke to exert choice and control over what they want to do. Previous studies showed that the feeling of being in charge and having control leads to engagement in activities (Häggström & Lund, 2008; Woodman et al., 2014). Control was also closely related to the sense of autonomy and interdependence.

While people with stroke found help and support important, they wanted to keep control over activities and maintain their sense of independence as much as possible, including control over asking for help if needed.

ii. **Action domain**

The action domain includes strategies and actions performed and employed by people with stroke that makes them active in community participation.

1. *Managing the impact of stroke related impairments:* Previous literature and data from phase 1 showed that managing stroke related impairments preceded community participation (Pound, Gompertz, & Ebrahim, 1999; Robison et al., 2009; Satink et al., 2013). Examples of managing stroke related impairments included exercising, taking a rest when fatigued, taking medication, and being upfront about their cognitive or speech related impairments to reduce potential frustration. Having a sense of control over their health and impairments helped people with stroke gain confidence as well as strategies to compensate for their impairments.
2. *Planning:* Planning was one of the major results from the focus groups and individual interviews. Planning includes thinking through potential barriers, preparing for those barriers, and using strategies to make activities easier. Planning often occurred before one participated in activities and involved examination of potential environmental barriers in relation to their ability and identification of potential environmental supports to enable full participation (Robison et al., 2009; Woodman et al., 2014).

3. *On-the-go/in-the-moment problem solving:* The difference between having strategies in place before facing barriers and dealing with unexpected ones in the moment, both were identified as key strategies in the literature and qualitative data. People active in the community are capable of finding solutions when a problem arises. The ability to deal with problems when they arise helped people gain confidence and activated them to participate in the community as they wanted.
4. *Utilizing an adapted way of participating in activities:* Adaptation was key in participation and frequently mentioned in previous literature (Ch'ng et al., 2008; Clarke & Black, 2005; Häggström & Lund, 2008; Robison et al., 2009; Rochette et al., 2006; Woodman et al., 2014). Taking more time, pacing activities by taking rest, and using adaptive equipment or devices were ways stroke survivors modified their participation in activities. The use of adaptation and compensatory strategies was echoed by the focus group and interview participants. By adapting, stroke survivors identified alternative ways of enjoying previously engaged or new activities which enhanced their participation and their satisfaction (Clarke & Black, 2005).
5. *Asking for help and accepting help from others:* This domain is a result of previous studies and data from participants. Support from spouses or family has been reported as a key facilitator for participation after stroke (Häggström & Lund, 2008; Robison et al., 2009; Rochette et al., 2006; Satink et al., 2013). Studies noted how stroke survivors developed a new pattern of interdependence in community participation over time (Satink et al., 2013; Woodman et al., 2014). While initially stroke survivors felt reluctant in asking for and/or accepting help, they learned how to balance their desire to be independent with the need for help or supports. They

built a kind of interdependence that made using supports or asking for help acceptable if it could lead to desired participation.

6. *Getting around in the community when needed:* Phase 1 participants and previous studies pointed to the importance of physically getting comfortable getting around in the community (Ch'ng et al., 2008; Clarke & Black, 2005; Kubina et al., 2013; Robison et al., 2009). The ability and confidence to get around in the community made them feel ready to participate in community activities.
7. *Accessing and managing community mobility when needed:* In the focus groups, interviews and literature, the ability to drive, take public transportation, or arrange rides was noted as key to community participation (Hammel, Jones, Gossett, & Morgan, 2006). Most participants reported using paratransit or driving to go to places when they wanted. Accessing and managing different modes of transportation added flexibility in mobility in the community.
8. *Seeking and utilizing information and community resources:* Accessing information about community resources and supports is an important part of community participation for individuals with stroke (Clarke & Black, 2005; Hammel et al., 2006; Sarre et al., 2013; Woodman et al., 2014). People with stroke reported getting information about adaptive leisure activities or other community activities through health care professionals, other stroke survivors, internet and other community places (e.g., hospital resource center, library, local stores). Activated people with stroke showed the ability to negotiate access to needed resources and services. When resources or services were not readily available, people reported that they advocated for their needs.

iii. **Conceptual model**

The conceptual model presented in Figure 4 shows that attitudes and actions interact with each other and activate a person to develop behaviors and strategies to facilitate community participation. The conceptual model shows that community participation is not a result of the capacity to perform certain activities but a result of the interaction between attitudes such as willingness to take risks, and reclaiming a sense of independence and control and actual strategies and actions such as trying new activities, using resources and help, planning, and problem-solving. These practices increase individuals' confidence and skills required for community participation.



Figure 4. Conceptual model describing community participation activation.

b. **Phase 2. Item development and expert review**

Forty-one items were developed and reviewed by eight experts with expertise in measurement and testing, self-management, stroke rehabilitation, and health services (Table III). The I-CVI ranged between 0.50 and 1. Items with an I-CVI lower than 0.75 were dropped. After deleting five items, the S-CVI was 0.90. The qualitative comments from expert panel on clarity then were used to revise the items.

TABLE III
CHARACTERISTICS OF EXPERT PANEL (N=8)

Experience	Count	Length of experience (years)	
		Mean (SD)	Range
Health care professionals	5	28.0 (14.20)	7-50
Occupational Therapist	1		
Physical therapist	1		
Psychologist			
Researcher	5	18.8 (12.80)	3-33
Faculty	6	15.7 (12.37)	1-33

c. **Phase 3: Item refinement and cognitive interviewing**

Five participants with stroke were recruited to test 36 items that were revised after the expert review (Table IV). Participants covered diverse backgrounds in terms of age, race, education, and time since stroke.

TABLE IV
CHARACTERISTICS OF COGNITIVE TESTING PARTICIPANTS (N=5)

	Age	Gender	Racial background	Education	Time since stroke (months)	Short blessed score ^a
A*	43	Female	African American	High school (HS)	5	2
B*	66	Male	African American	Less than HS	24	12
C	47	Male	Caucasian	Associate's	2	0
D	69	Male	Asian	Bachelor's	9	0
E*	46	Male	Hispanic	Less than HS	12	2

* Participants who participated in the cognitive interview twice.

^a Minimal impairment <9, Moderate impairment 9-19

Items were revised after the first round of cognitive interview. Revision included combining items, deleting irrelevant items, clarifying the meaning of ambiguous items, simplifying wording, and lowering the reading level. For example, “I use resources and services that are available for people with disabilities,” and “I use resources and/or services that help me do more things” were combined after testing it with participants as participants were not able to describe the difference. Two response scales were given: one was a Likert scale of 1 to 4 (1=I agree completely, 4=I disagree completely); the other was a Likert scale of 1 to 4 (1=this does not describe me at all, 4=this describes me exactly). The second response scale was selected because it provided more variation in responses. The revised items (n=27) were then re-tested with three participants. The second revision included simplifying wording. Some examples can be found in Table V.

TABLE V
SELECTED COMMENTS FROM THE COGNITIVE TEST

Original items	Selected comments	Revision
Tell me about things that you do in the community	<ul style="list-style-type: none"> · "I go to the library and take walks. I don't do many things in my community...Oh, you mean what I do outside?" 	<ul style="list-style-type: none"> · Tell me about things that you do outside your home.
I seek and utilize services, people, and information to help me engage in activities that I want.	<ul style="list-style-type: none"> · "I seek and engage... That's not what a person with a stroke would say. I would pick words that I can pronounce" · "Oh, you mean resources?" · "If there is something I need or I want to do, I look it up or I ask around." 	Broke into two items: <ul style="list-style-type: none"> · I look up information that I need to do activities I care about. · I use community resources to help me engage in activities I care about.
I advocate for services, information, and supports when they are not readily available.	<ul style="list-style-type: none"> · "What supports? What do you mean"? · "Can you repeat?" 	<ul style="list-style-type: none"> · I advocate for services and resources when they are not readily on hand.

5. **Discussion**

The study aimed to conceptualize CPA and develop an assessment that can evaluate CPA of people with stroke. The findings show that activated people with stroke are likely to develop and show ability in strategizing attitudes and actions that enable them to manage and seek meaningful participation in the community. The conceptual model showed that there is a dynamic interaction between attitudes and actions which influences a person's level of CPA. A pool of 41 items was developed based on the conceptual model of CPA. This pool was examined by experts, and 37 items were used for cognitive testing. Items were revised based on the feedback from

expert review and cognitive interviews. The CPAS contained a total of 27 items after examining the content validity and receptivity of the items with experts and people with stroke.

Community participation activation shares similar domains with the concept of “patient activation,” which refers to the extent a patient has the knowledge, beliefs, skills, and behavioral repertoire to manage chronic conditions (Hibbard et al., 2004). The domains of attitude and action from this study were comparable to beliefs and skills/behavioral repertoire as identified in patient activation. Although different, in both concepts, it was important to have the belief, values, skills, and strategies that support the desired behavioral outcomes. These components are also highlighted as essential in models such as self-efficacy theory, empowerment model, or resilience theory that describe how people with chronic conditions or disabilities form behaviors or become empowered to take actions necessary to manage their lives (Bandura, 1994; Fawcett et al., 1994; Masten & Wright, 2009).

Patient activation literature shows that higher activation leads to changes in self-management behaviors and better health outcomes (Greene & Hibbard, 2012; Hibbard & Greene, 2013; Hibbard, Mahoney, Stock, & Tusler, 2006; Hibbard et al., 2004). It is possible that higher community participation activation leads to more active participation. However, community participation entails the concept of choice and is strongly influenced by societal and system level barriers that people have less control over. Therefore, having the belief, confidence, and behaviors may not always lead to more frequent participation although it may lead to higher satisfaction with participation, because one with the ability to manage and choose what he or she wants to do may be

more satisfied with their choice and level of engagement. More examination needs to be done to further understand the relationship between community participation activation and other participation outcomes such as engagement, satisfaction, and enfranchisement.

The validity of the CPAS was increased through different steps that were integrated into the item development and refinement processes. First, a conceptual model was developed based on findings from focus groups and in-depth interviews with people who had a stroke. This approach ensured that the model was grounded in people's experiences (Magasi & Heinemann, 2009; Velozo et al., 2012). The conceptual model also helped conceptualize the target construct and differentiate the construct from other similar or different constructs such as community reintegration, resilience or coping, which improved the content validity of the instrument.

Second, focus groups, individual interviews, and cognitive testing provided opportunities to learn the language that the target group speaks, which is important information to authentically ground the wording of the items in people's experiences. Questions can be difficult to comprehend when the construct is abstract and the language used is unfamiliar to the target group. In addition, using the language the target group speaks provides them with cues to retrieve their memory and increase the validity of the instrument (Schaeffer & Presser, 2003). Items were developed using the language spoken by stakeholders, and cognitive testing allowed stakeholders to then test the items and provide input for revision or removal.

Third, the study used an expert assessment to examine the content validity (Polit & Beck, 2006). Experts were recruited through thoughtful selection to cover different

backgrounds and perspectives. To minimize bias, the expert review assessment included detailed instruction about the underlying constructs, hypothesis, and rating task (Grant & Davis, 1997). Polit and Beck (2006) suggested to use a criterion of .78 for I-CVI which allows one out of eight experts to disagree. However, this study used .75 as a minimum criterion for the I-CVI, allowing maximum two out of eight experts to disagree. Adding flexibility to the criterion was a deliberate decision taking into account the complexity of understanding community participation and potential incongruity around the new concept of community participation activation. Using a criterion of 0.75 expanded the item pool with items that were deemed important by people with stroke.

This study has several limitations. Due to limited resources, qualitative data were collected from a small sample size. More instruments are developed based on large sample focus groups or interviews to ensure saturation of data (Hammel et al., 2008). However, collected data were compared and triangulated with existing literature, enriching data to support the conceptual model. Another limitation was that the expert review was only conducted once. Items were revised and improved after the first expert review and cognitive testing which may warrant another round of expert review (Polit & Beck, 2006).

The CPAS assessment offers a tool that measures the activation aspect of community participation that other current participation assessments do not. The CPAS was developed and refined based on data from qualitative interviews, literature, expert reviews, cognitive testing, and readability test. This process affirms that the CPAS is designed to be conceptually valid and well-received by people with stroke. Although future study is needed to examine the psychometric property, the study shows that the

CPAS has potential to be used to examine CPA and complement existing participation assessments to help further understand the status of community participation of people with stroke.

C. **Paper 3 - Validation of The Community Participation Activation Scale: A Measure of Attitudes And Actions Activating Community Participation in Persons with Stroke**

1. **Abstract**

Objective: To examine the psychometric properties of the Community Participation Activation Scale (CPAS) in persons with stroke.

Method: A total of 93 persons with stroke living in the community completed the CPAS, a self-reported assessment of attitudes and actions activating community participation. The CPAS was evaluated in terms of rating scale structure, unidimensionality, reliability and precision, construct validity, and differential item functioning.

Results: Rasch analysis supported the unidimensionality of the 15 action items and 10 attitude items. The rating scale structure was monotonic for both domains. Person separation reliabilities of the Action and Attitude domains were 0.75 and 0.72, respectively, but internal consistency reliabilities were good (>0.80). The CPAS showed low to moderate correlation with community integration and enfranchisement constructs (0.39-0.55).

Conclusion: The study provides preliminary findings supporting that CPAS can be used as an assessment to examine community participation activation in people with stroke and may help inform individually-designed, participation-focused interventions.

Keywords: Stroke, patient activation, social participation, outcome assessment, Rasch model

2. **Introduction**

Since the inclusion of participation as a main component within the International Classification of Functioning, Disability, and Health (ICF) model (World Health Organization, 2001) there has been greater emphasis and prioritization of participation outcomes in both healthcare and rehabilitation research (Chang, Coster, & Helfrich, 2013; Heinemann, 2010; Heinemann et al., 2010; Kessler & Egan, 2012; Whiteneck & Dijkers, 2009). Disability scholars have also expanded the definition of participation by including concepts of choice, control, freedom, and access to opportunities as critical components to participation (Hammel et al., 2008; Hemmingsson & Jonsson, 2005; Mallinson & Hammel, 2010; Whiteneck & Dijkers, 2009). These personal and environmental factors are thought to influence an individual's participation in life situations. For any given person, successfully managing these multiple factors can be crucial for achieving desired community participation goals (Hammel et al., 2008; Hemmingsson & Jonsson, 2005; Mallinson & Hammel, 2010; Whiteneck & Dijkers, 2009).

The complex experiences of achieving participation for people with stroke are well documented in existing literature. A body of qualitative studies reveals how people with stroke continuously evaluate and negotiate their needs, values, abilities, and supports to do what they want to do in a way they want (Häggström & Lund, 2008; Hammel et al., 2008; Woodman et al., 2014). In addition, people with stroke go through a complex process of adaptation in lifestyle in order to re-engage in personally

meaningful activities in their communities. Those adaptations include modifying tasks and preferences, seeking information, working around environmental barriers, focusing on strengths, and getting help (Häggström & Lund, 2008; Hammel et al., 2006; Kubina et al., 2013; Sarre et al., 2013; Woodman et al., 2014). By constantly negotiating personal and environmental factors, people with stroke participate in the things they want to do in the community.

The term “activation” originated in the context of chronic disease management to describe as individual patient readiness and ability to manage their chronic conditions and to participate as an effective member of the health care team (Hibbard et al., 2004). Recently, Lee (2016) applied thematic analysis of qualitative interviews among persons with stroke to identify factors that define activation in the context of community participation. Results suggest community participation activation (CPA) can be conceptualized as the interaction between *attitudes*, such as willingness to take risks and reclaiming a sense of independence, and *actions* such as trying new activities, using resources and help, planning, and problem-solving. The assumption is that people who show activated attitudes and actions will better manage community participation by gaining confidence and skills. An activated person, in the context of community participation, has the ability to manage the personal and social implications of stroke and to utilize strategies, resources and supports to participate in the community as desired.

While it is evident that community participation is a dynamic and complex process of managing different individual and environmental factors influencing one’s life, assessment tools for evaluating participation typically focus on capturing the frequency

of engagement. There are participation assessments such as the Community Participation Indicators or the Environmental Factors Assessment that integrate the concepts of choice and enfranchisement or focus on the influence of the environment on participation (Heinemann, Magasi, Bode et al., 2013; Heinemann, Magasi, Hammel et al., 2013). These assessments focus on individual's satisfaction or perceived importance of certain activities, perceived acceptance in society, or environmental barriers and supports to participation. However, current assessments do not capture the complex and dynamic nature of managing community participation experienced by individuals with stroke, such as the attitudes or actions that activate individuals to pursue participation goals.

The ability to manage multiple factors influencing community participation allows people with stroke to have control over their lives while living with a long-term disability. Thus, being able to determine a person's level of activation would facilitate the process of supporting long-term community participation of people with stroke. For rehabilitation clinicians, availability of a CPA assessment could allow better understanding of an individual's readiness and ability for community participation, which in turn, should enable clinicians to collaboratively design interventions that better meet individual needs. A CPA assessment would also facilitate research to identify whether activation can predict participation or quality of life outcomes, further providing larger scale evidence for programming for people with stroke. The Community Participation Activation Scale (CPAS) was developed to respond to the gap in knowledge and practice. The aim of the study was to evaluate the CPAS that assesses attitudes and actions facilitating community participation.

3. **Methods**

a. **Sampling**

A sample size of 100 people has been suggested as the minimum size for validating an assessment using Rasch modeling (Reeve et al., 2007).

Approximately 100 participants were recruited through flyers distributed to rehabilitation hospitals, stroke support groups, and a stroke research registry located in a Midwestern metropolitan area in the United States. Snowball sampling among individuals with personal networks of people with a stroke was also used (Patton, 2001). Participants were included if they met the following criteria: 1) had a stroke at least 1 month ago; 2) 18 years and older; and 3) living in the community. Participants were excluded if they had severe aphasia with no means to communicate.

b. **Data collection**

Thirty to 60-minute structured interviews were conducted in person or over the phone by the author. A visual aid stating the four response options was provided to assist participants. If the interview was conducted over the phone, the visual aid was mailed in advance. The interview battery included the CPAS, Reintegration to Normal Living Index (RNLI), Community Participation Indicators (CPI) Enfranchisement, and demographic questions.

The Community Participation Activation Scale (CPAS). The CPAS is designed to assess attitudes and actions among people with stroke that indicate the extent to which an individual is activated for community participation. The assessment consists of 27 items including 16 action items and 11 attitude items. The questionnaire was developed based on literature review and findings from focus groups and qualitative interviews

(Lee, 2016). Researchers and clinicians with a background in stroke rehabilitation, measurement and testing, self-management, and health service research reviewed the items for content validity and 5 people who had experienced a stroke participated in cognitive testing to ensure clarity of items and relevance of item content. The CPAS uses a 4-point Likert-type scale: 1=this does not describe me at all; 2=this describes me somewhat; 3= this describes me quite well; and 4=this describes me exactly. To help respondents conceptualize community participation and focus on their community engagement activities in the past two weeks, the CPAS begins by asking: "Please tell me what you did outside your home in the past two weeks."

Reintegration to Normal Living Index (RNLI). The RNLI assesses perceived satisfaction with performance in areas such as activities of daily living, social participation and relationships, and community mobility (Wood-Dauphinee, Opzoomer, Williams, Marchland, & Spitzer, 1988). The scale consists of 11 items. Following Stark et al. (2005) we used a Likert scale of 0 to 10 (0=strongly disagree; 10=strongly agree) rather than the original visual analog scale. Previous research shows that the RNLI has excellent internal consistency (0.92 and 0.91) when tested with people with chronic stroke (Bluvol & Ford-Gilboe, 2004; Stark et al., 2005).

Community Participation Indicators (CPI) Enfranchisement. The Enfranchisement section of the CPI evaluates the extent to which a person feels that he or she is valued in society and that his or her full participation is respected by the community they want to participate in (Heinemann, Magasi, Bode, et al., 2013). The assessment consists of two subscales: 15 items reflecting personal importance of participation and 13 items reflecting perception of control over participation. Items are scored on a 5-point rating

scale from 1 to 5 (1=almost never, 2=seldom, 3=sometimes, 4=frequently, 5=all the time). Rasch modeling established the construct validity and person separation reliability of the importance and control subscales of the CPI with a sample with diverse disabilities. Both importance and control subscales showed good person separation (2.26 and 2.28, respectively)

c. **Data analysis**

A combination of Rasch modeling and Classical Test Theory approaches were used to examine the psychometric characteristics of the CPAS. Since items were intended to share the same rating scale structure, the Andrich Rating Scale Model (RSM) was applied (Linacre, 2000). The CPAS was evaluated in terms of rating scale structure, unidimensionality, reliability and precision (person separation reliability, internal consistency), construct validity (item ordering, targeting, and association with related constructs), and differential item functioning (DIF).

Rating Scale Structure. Examining the structure of rating scale categories is essential to ensure interpretations of collected data are valid (Linacre, 2004). The rating scale functioning was assessed using the following criteria: 1) each category's frequency count must be at least 10 observations; 2) category thresholds are ordered (e.g., observed thresholds increase monotonically across the trait); and 3) the rating scale outfit meansquare (MnSq) should be less than 2.0.

Unidimensionality. The Rasch model assumes a unidimensional structure to the items. We tested this assumption by examining item-level fit statistics and eigenvalues from principal components analysis of residuals. Item infit MnSq values greater than 1.0 (i.e., underfitting) suggests the pattern of person responses is not consistent with model

expectations and may indicate the item is tapping a different construct from other items. For this study, items with an infit MnSq between 0.7 and 1.3 were considered acceptable (Wilson, 2004).

In addition, principal component analysis of standardized residuals was examined using the percentage of variance explained by of Rasch measures and the first factor (Fendrich et al., 2008; Wolfe & Smith, 2007) was examined. For this study, we considered an eigenvalue <2.0 and $<10\%$ of variance explained on the first contrast as indicating sufficient unidimensionality.

Precision and reliability. Person separation reliability indicates how effectively the assessment is able to distinguish among persons of varying abilities. A scale with person separation reliability greater than 0.85 is desired and indicates that the measure can reliably distinguish among three ability levels of sample participants (Tennant & Conaghan, 2007). Internal consistency reliability was estimated using the Cronbach's coefficient alpha (Plichta & Kelvin, 2012).

Construct validity. In Rasch measurement, the ordering of the items from easiest to hardest to endorse describe the operational definition of the construct being measured. The ordering of the items should reflect patient and clinician experience and also what is known from current literature.

We also examined the extent to which the range of item difficulties matched the range of person abilities (Wolfe & Smith, 2007). The person-item map, known as the Wright map, illustrates the correspondence between the item difficulty and the person trait levels (Wilson, 2011). The greater the overlap, the better the items capture all levels of respondents on the trait.

We also examined the relationship between scores on the CPAS and RNLI and CPI enfranchisement subscales, respectively. For this study, we considered a Pearson Product-Moment correlation coefficient of 0.5 as indicating moderate association between the construct of CPA, enfranchisement, and community reintegration (Plichta & Kelvin, 2012).

Item Bias. Differential Item Functioning (DIF) examines the extent to which item may be more or less easily endorsed by members of particular demographic groups. We examined the extent to which gender may bias responses to the CPAS. DIF greater than 0.5 logits were flagged for further examination. The mere presence of DIF does not imply biased person measures. For items reflecting DIF, the impact on person measures was examined by comparing person measures calibrated with and without items demonstrating DIF (Smith, 2004).

4. **Results**

a. **Sample characteristics**

A total of 93 participants were recruited. The majority of participants (67.7%, n=63) were African Americans, reflecting the demographics of the geographic area and institutions from which the sample was recruited. Most participants were unemployed with very low income despite their high level of education. The majority of participants (62.4%, n=58) had their stroke more than 5 years before study enrollment. Most people had experienced one stroke but experience of stroke ranged from 1 to 5 times. The mean age of participants was 58 years (SD=9.2) with a range of 25 to 85 (Table VI).

TABLE VI
DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS (N=93)

Characteristics		Count	Percent
Gender	Male	41	44.1
	Female	52	55.9
Racial background	Caucasian/White	20	21.5
	African American/Black	63	67.7
	Hispanic/Latino	4	4.3
	Asian American	6	6.5
Education	Less than high school	7	7.5
	High school/GED	8	8.6
	Some college	33	35.5
	2 year college degree	12	12.9
	4 year college degree	23	24.7
	Graduate degree	10	10.8
Marital status	Married/ partner	37	39.8
	Single, never married	34	36.6
	Widowed, divorced, separated	22	23.7
Employment status	Employed, full time	1	1.1
	Employed, part time	12	12.9
	Employed, on leave	2	2.2
	Unemployed, not seeking	57	61.3
	Unemployed seeking	21	22.6
Income	\$15,000 or less	33	35.5
	\$15,001-\$25,000	22	23.7
	\$25,001-\$50,000	18	19.4
	\$50,001-\$100,000	11	11.9
	\$100,001 or more	9	9.7
Mobility aids	None	19	20.4
	Cane	48	51.6
	Walker	10	10.8
	Manual wheelchair	5	5.4
	Power wheelchair	11	11.8
Years since stroke	Less than 1 year	12	12.9
	1-3 years	9	9.7
	3-5 years	14	15.1
	5- 10 years	30	32.3
	10 year or more	28	30.1
Stroke occurrence	1 time	82	88.2
	2 times	6	6.5
	3 times or more	5	5.4
		Mean (SD)	Range
Age (years)		58 (9.2)	25-85
		Median (IQR)	Range
Time since stroke (months)		74 (38.5-140.5)	3-362

b. **Psychometric analysis**

Jointly, the 27 items did not form a unidimensional scale with 11 items showing misfit. The majority of these items were from the action domain. Removing these misfitting items caused further items to misfit in the subsequent analysis. This effect is generally found when items do not cohere to form a single construct. In subsequent analyses, the Action and Attitude items were analyzed separately.

Rating scale structure. Frequency counts for the rating scale categories generally exceeded 10 observations however, for three items (#11, 14, and 25) rating scale step 1 was rarely used. The observed average measures and thresholds increased in order, indicating that the rating scale steps reflect increasing activation across both the Action and Attitude domains.

Unidimensionality. One item misfit in each of the Action and Attitude domains. Item 7 "I use devices when it seems they make doing activities easier" misfit in the Action domain (infit MnSq=1.49) and Item 22 "I have no problem accepting help when I need it" in the Attitude domain misfit (infit MnSq=1.50). One person showed extreme misfit for the Action domain (infit zstd=4.3) and a different person showed extreme misfit for the Attitude domain (infit zstd=3.4). Misfitting items and persons were sequentially removed from subsequent analyses resulting in higher person separation reliability at each step (Table VII) suggesting improved measurement precision. In the final analyses, there were no misfitting items for either domain (Table VIII and Table IX).

TABLE VII
RASCH SUMMARY PSYCHOMETRICS

Process	Items	# of misfitting items	Item infit MnSq range	Person separation index	Person separation reliability	Variance explained	Eigen value
1. Selection of action items	16	1	0.75-1.49	1.68	0.74	30.8	2.3
2. Removal of misfitting item 7 (infit mnsq=1.49)	15	0	0.74-1.20	1.61	0.74	32.5	2.2
3. Removal of one misfitting person (infit ztsd=4.3)	15	0	0.82-1.22	1.71	0.75	33.5	2.0
1. Selection of attitude items	11	1	0.79-1.50	1.55	0.71	39.1	2.1
2. Removal of misfitting item 22 (infit mnsq=1.5)	10	0	0.84-1.21	1.56	0.71	42.0	2.1
3. Removal of one misfitting person (infit ztsd=3.4)	10	0	0.82-1.22	1.59	0.72	42.9	2.0

TABLE VIII
FINAL ITEM STATISTICS FOR ACTION ITEMS

Action items	Measure	SEM	Infit MnSq
16. I advocate for services and resources when they are not readily on hand.	0.78	0.14	0.96
15. I use community resources to help me engage in activities I care about.	0.61	0.14	1.13
2. I modify my activities to make up for what I cannot do.	0.57	0.14	1.13
1. I actively try to engage in more activities outside my home.	0.25	0.14	1.20
11. I handle problems in the moment when they arise when I am out in the community.	0.20	0.15	0.74
13. I always get to where I need to go even if something unplanned comes up.	0.14	0.15	0.94
5. I ask for help when I need it.	0.08	0.15	1.24
8. I manage health conditions from my stroke so they do not prevent me from doing activities I care about. (Examples of health conditions are weakness, fatigue, and pain)	-0.04	0.15	0.84
10. I always think through how things in the community can get in my way before I leave my home.	-0.04	0.15	1.22
6. I accept help when I need it.	-0.18	0.16	1.00
14. I look up information that I need to do activities I care about.	-0.23	0.16	0.99
9. I get around in the community when I need to	-0.28	0.16	0.79
4. I allow myself plenty of time and pace myself to get things done.	-0.52	0.17	0.92
3. I plan ahead to make it easier to do things I care about.	-0.64	0.18	0.76
12. I arrange transportation to get where I need to go when I need it.	-0.70	0.18	1.08

Note: SEM=Standard Error of Measurement

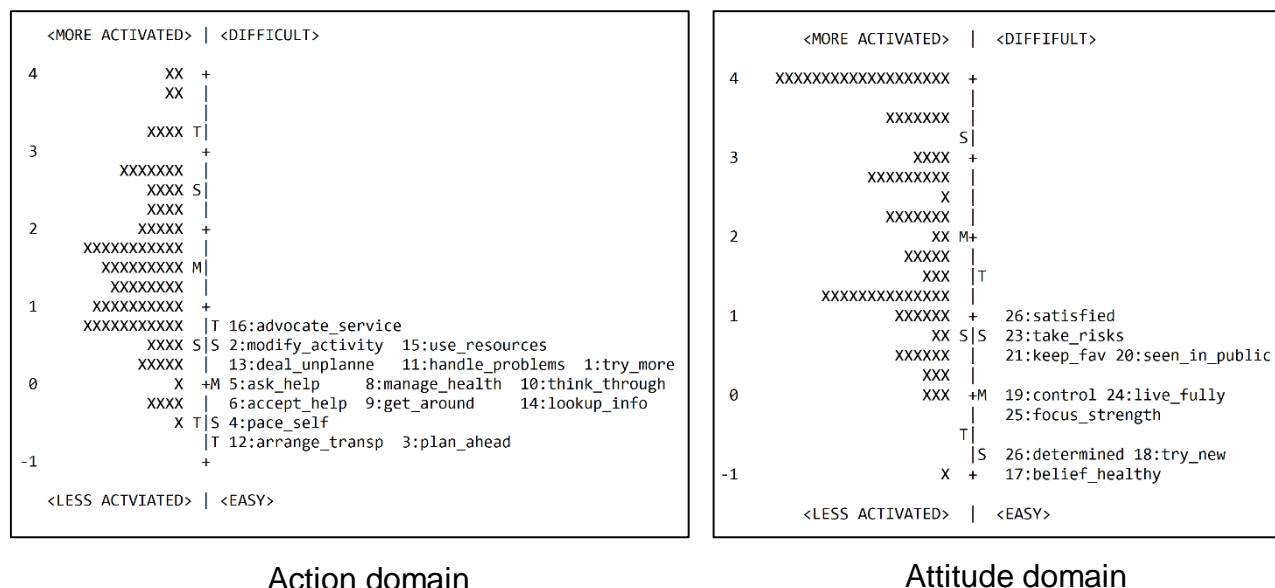
TABLE IX
FINAL ITEM STATISTICS FOR ATTITUDE ITEMS

Attitude items	Measure	SEM	Infit MnSq
26. I am satisfied with the way I do things even though it may not be the same way as others do it.	1.11	0.17	1.22
23. I am willing to take risks to try out a new activity if it is important to me.	0.63	0.17	0.96
21. I am sure that I can keep on doing my favorite activities.	0.57	0.17	1.20
20. I am comfortable being seen by others I don't know	0.54	0.17	1.18
24. I learned how to fully live my life with my disability	0.04	0.18	0.85
19. I believe I am in control of what I want to do during the day, even if I get help.	0.04	0.18	0.86
25. I focus on my strengths and successes rather than my limitations and failures.	-0.29	0.19	0.82
27. I am determined in the face of challenges.	-0.70	0.20	0.95
18. I am willing to try out new activities if there is a chance they will enhance my daily life.	-0.71	0.20	1.04
17. I believe doing things that are important to me helps me stay healthy.	-1.21	0.23	0.96

Note: SEM=Standard error of measurement

Reliability and precision. The final item sets for the Action and Attitude domains produced person separation reliabilities of 0.75 and 0.72, respectively. This translates into a G-index of 1.7 and 1.6, respectively, suggesting the measures discriminate the sample into about two ability levels (Fisher, 1992). Internal consistency evaluated with Cronbach's alpha showed good reliability in both Action and Attitude domains (0.82 and 0.84, respectively).

Construct validity. Item ordering and targeting of items against the range of participants are displayed in the Wright map (Figure 5). For the Action domain, the easiest items were items 12 “I arrange transportation to get where I need to go when I need it” (-0.7 logits) and 2 “I plan ahead to make it easier to do things I care about” (-0.64 logits). The most difficult Action item was item 16 “I advocate for services and resources when they are not readily on hand” (0.78 logits). For the Attitude domain, the easiest item was item 17 “I believe that doing things that are important to me helps me stay healthy” (-1.21 logits). The most difficult Attitude item was item 26 “I am satisfied with the way I do things even though it may not be the same as others do it” (1.11 logits). In general, the ordering of the items in both domains, from easiest to hardest to endorse reflect what would be expected from existing literature. In both domains, a ceiling effect was observed. In the Action domain, 67 participants (72%) were more activated than what the most difficult item can measure. In the Attitude domain, 73 participants (78.5%) showed higher ability than the ability the most difficult item can measure.



Note: X=one person; M=mean; S=one standard deviation; T=two standard deviation

Figure 5. The Wright maps for Action and Attitude domains.

Table X presents the associations between the CPAS domains and two assessments measuring related constructs, the CPI and the RNLI. There was a significant moderate positive correlation between the Attitude domain and the two subscales of the CPI enfranchisement items ($r=0.50$ Importance of Participation subscale; $r=0.55$ Control Over Participation subscale) and a significant low correlation between the Actions domain and these two CPI subscales ($r=0.44$ Importance of Participation subscale; $r=0.39$ Control Over Participation subscale). The RNLI total score showed positive but low associations with the Action and Attitude domains ($r=0.41$ and $r=0.49$, respectively).

TABLE X
CONSTRUCT VALIDITY OF THE CPAS

Scales	Pearson's <i>r</i>	
	Action	Attitude
<i>Community Participation Indicators (CPI) Enfranchisement</i>		
Importance of participation subscale	.44*	.50*
Control over participation subscale	.39*	.55*
<i>Reintegration to Normal Living Index (RNLI)</i>		
Total score	.41*	.49*

* Correlation is significant at Bonferroni adjusted $p=0.008$

Comparing Action and Attitude domains. Figure 6 shows the relationships among person measures for the Attitude and Action domains. Participants showed a strong positive correlation between Action and Attitude domains ($r=0.74$). However, some participants showed inconsistency between the two domains. Seven participants had high Attitude but low Action measures (measures outside of 95% CI). Three participants showed low Attitude but high Action measures. In addition, nine people with the highest person measures in the Attitude domain (≈ 6 logits) showed Action measures ranging from 1 to 5 logits.

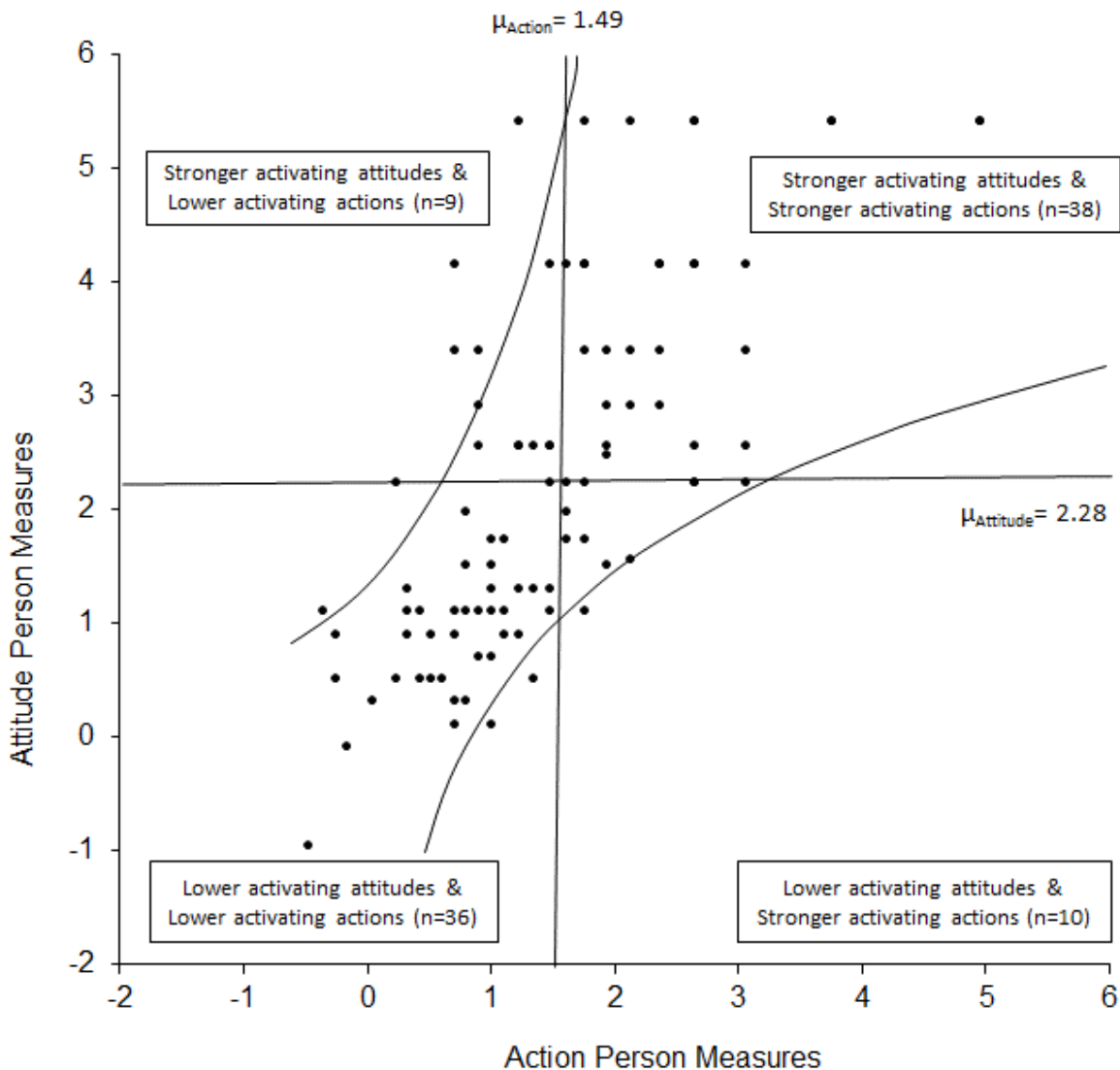


Figure 6. Action and Attitude person measures plot

Differential item functioning (DIF). For the Action domain, items 10 “I always think through how things in the community can get in my way before I leave my home” and 16 “I advocate for services and resources when they are not readily on hand” showed bias for gender. Female participants were more likely to think through barriers before leaving

home, while male participants were more likely to advocate for services when services were not readily available. However, the presence of this DIF did not affect the person measures so neither of the two items were removed (analyses not presented here). No gender bias was detected in the attitude items.

5. **Discussion**

The aim of this study was to examine the psychometric properties of the CPAS, a measure evaluating attitudes and actions activating a person with stroke to participate in the community. After running separate analyses, the 15 action items and 10 attitude items showed minimal evidence for multidimensionality, providing evidence of distinct hierarchies in both the Action and Attitude domains across people with stroke. The items in each domain also showed good internal consistency reliability. However, the precision of the assessment to locate people along the domains based on their activation was low. The Pearson's correlation showed that there is a low to moderate association between each of the domains and community participation enfranchisement and community reintegration constructs, providing modest support for the construct validity of the CPAS.

This study indicates that the CPAS comprises of two distinct constructs: the Attitude and Action domains. Existing literature about participation describes a dynamic and close interrelationship between actions and attitudes, suggesting that CPA may also constitute two different dimensions (Kubina et al., 2013; Woodman et al., 2014). Findings from this study also indicate that two domains are substantially correlated while also describing important differences among people with stroke. Specifically, having strong activating attitudes does not necessarily mean that the person also

perceives him/herself as taking actions activating community participation and vice versa. This finding accords with previous literature supporting that attitudes and actions do not always correspond (Ajzen & Fishbein, 2014). Our study suggests that neither domain alone is sufficient to explain the CPA. The two domains may differentially contribute to CPA suggesting that assessing both domains is required to understand an individual's community engagement. This also argues for developing individually focused interventions that can better support the person's development of CPA. A clinician may use information from CPAS to tailor individual interventions with a focus on building specific strategies or tactics to develop activating attitudes and actions for active community participation. For example, clients with low activating attitudes may need more peer interaction or professional support to help them feel more accepting their disability and need for making modifications. Clients who perceive difficulty with activating actions may need more help with practical strategies to use social resources or to access community mobility.

For each domain, the hierarchy of items generally follows what is described in the activation literature, yet allows for a deeper understanding of how people with stroke develop actions and attitudes to become activated in the community. The most challenging item in the Attitude domain was to be satisfied with the way things are done. Even people who were willing to take risks, felt like they had control, and had learned how to live fully with their disability, reported feeling less satisfied with the way they do things because they still felt different from others. This dissatisfaction may be a psychosocial consequence of an ablest culture that stigmatizes and discriminates people with disabilities with pity, fear, and uneasy social interaction (Anderson &

Whitfield, 2013). Activating actions appear to begin with arranging transportation, planning and pacing, and extend towards the more challenging elements of accepting and asking for help, using resources, and advocating for services. We found that “modifying activities” was one of the hardest Action items to endorse. This finding aligns with previous studies that found that people are less likely to make modifications in community activities and rather choose to participate in activities that they can do without modifications (Brady, Clark, Dickson, Paton, & Barbour, 2011; Kubina et al., 2013).

We found low person separation reliability but good internal consistency reliability for both the Action and Attitude domains. This inconsistency between the person separation reliability and internal consistency reliability may be due to poor targeting (Mallinson & Stelmack, 2001). Over 70% of participants reported activation levels beyond what the items can measure (i.e., a ceiling effect). Ceiling effects have been shown to artificially inflate Cronbach’s alpha (Thorndike & Thorndike-Christ, 2010). To improve targeting and enhance measurement precision, future studies of the CPAS should involve participants with a broader range of activation. Despite concerted efforts, the majority of the participants in this study were connected to a large urban rehabilitation hospital and were engaged in the substantial community resources and disability networks offered by that setting. Most participants contacted the researcher directly to participate in the study after reading a flyer posted in the rehabilitation setting, suggesting that they were motivated to pursue opportunities to participate in research and were able to arrange transport to come to the location of the interview. The sampling method may have led to selection bias, enrolling participants who were

already highly activated in community participation. However, future studies should also consider to what extent adding more challenging items would also help to discriminate among the highly activated participants.

We found low to moderate associations between the CPAS domains and community participation enfranchisement and community reintegration constructs. Enfranchisement identifies whether people feel fully integrated and included in society, which may be related to individual perceptions and attitudes. Because of the similarity in the items between the CPAS attitude items and CPI items, we expected to see a stronger association. The moderate correlation we found suggests that the two measures assess two different constructs despite the similarity of the items. Indeed, the CPI rating scale reflects how often respondents perceive being enfranchised during participation in activities, while the CPAS scale captures a perception of coherence with various aspects of community activation. The action items of the CPAS showed significant but lower correlation with the RNLI items suggesting that engaging in life activities per se as measured in RNLI is indeed a distinct from the concept of perception of actions captured by the CPAS.

The study has several limitations that moderate the interpretation of our findings. The study was a preliminary evaluation with a minimum sample size of participants from one geographic region, which may not generalize to the experiences of persons with stroke in other areas. The study used convenience sampling and snowball sampling which resulted in a self-selected group of participants who have social connections and community resources and with higher activation levels. The sample was predominantly African American and White and findings may not generalize to the experience of adults

with stroke from other ethnic backgrounds. Future work to improve the precision of the CPAS with a more representative sample should be conducted. In addition, examining the test-retest reliability and sensitivity to change of the CPAS would enhance its utility as a clinical outcome measure.

6. **Conclusions**

The CPAS represents an important contribution to the literature for increasing our understanding of activation in the context of community participation. Although the assessment needs further development, the initial findings demonstrated that CPAS can be explained by two distinct domains: Action and Attitude domains. The two domains showed substantial correlation while also describing two important differences among people with stroke. The study provides preliminary findings supporting that CPAS can be used as an assessment to examine CPA in people with stroke and may help inform individually designed, participation-focused interventions.

V. DISCUSSION

A. Discussion of Findings

The study conceptualized Community Participation Activation (CPA) and developed and validated an assessment that measures the construct. In phase 1, the qualitative study revealed different factors that influence CPA. The findings showed that an activated person, in the context of community participation, has the ability to manage the personal and social implications of stroke and to utilize strategies, resources and supports to participate in the community as desired. Results of phase 2 described a conceptual model of CPA that informed construction of CPAS items. Expert review and cognitive testing were conducted with the initial items to ensure the content validity and receptivity of the CPAS items. The analysis in phase 3 shows that the 15 action items and 10 attitude items supported unidimensionality, providing evidence of distinct hierarchies in both the Action and Attitude domains across people with stroke. The rating scale structure was monotonic for both domains. Person separation reliabilities of the Action and Attitude domains were 0.75 and 0.72, respectively while internal consistency reliabilities were 0.82 and 0.84, respectively. The CPAS showed low to moderate correlation with community integration and enfranchisement constructs ranging from 0.39 to 0.55.

1. **Conceptualizing community participation activation**

The study provides important evidence for understanding the construct of CPA. Qualitatively, the findings from phase 1 provide an understanding of how people

become activated to participate in the community after a stroke. The thematic analysis of qualitative interviews among persons with stroke suggests that community participation is activated when someone acquires activating attitudes and takes actions that help manage participation barriers and supports in the community. *Environmental factors, actions, and attitudes* were critical parts that influenced the level of community participation. While *environmental factors*, such as the peer support from the stroke community, family attitudes, social prejudice, and community resources influence how an individual shape attitudes and actions, the critical interaction influencing CPA was between *attitudes*, such as willingness to take risks and reclaiming a sense of independence, and *actions* such as trying new activities, using resources and help, planning, and problem-solving. People who accepted their disability as a normal part of their life (attitude) and took actions using strategies to deal with barriers and supports (actions) were more activated to participate in their life as they wanted.

In phase 3, the CPAS measure further confirmed that *actions* and *attitudes* constitute CPA. The analyses in phase 3 indicated that the CPAS comprises of two distinct constructs: the attitude and action domains. Findings from this study indicate that although the two domains strongly correlate, they describe important differences among people with stroke. Specifically, having strong activating attitudes does not necessarily mean that the person perceives themselves as taking activating actions and vice versa. This study suggests that neither domain alone is sufficient to explain the CPA. The two domains may not equally contribute to CPA suggesting that assessing both domains can increase understanding of an individual's CPA. This finding highlights that, in order to improve CPA, it is important to provide interventions that are individually

focused. For example, clients with low activating attitudes may need more peer interaction or professional support to help them accept their disability and the need for making modifications. Clients who perceive difficulty with activating actions may need more help with practical strategies to use social resources or to access community mobility.

The findings about the concept of CPA can be compared to existing literature about patient activation in chronic disease management. The attitudes and actions taken by people after a stroke to actively manage community participation have similarity with what people with chronic conditions do to actively manage their health conditions. Although they are different in their scopes, both concepts accounted for the importance of having the belief, skills, and strategies that support the desired behavioral outcomes. Concerning the scope of each concept, however, CPA expands the concept of activation to life management beyond health, whereas patient activation focuses more on the individual ability to manage health conditions (e.g., taking medication, maintain healthy diet, exercising, communicating with health care professionals). There is a health management component to community participation that patient activation and CPA share. However, participation is a more complex and dynamic process than symptom management that involves constant negotiation of needs and desires on personal and social level. CPA is not simply about improving function or managing health, but about managing the social implications of stroke (e.g., impact on roles and socializing, discrimination experienced due to disability) and managing macro and meta level environmental influences on life (e.g., public attitude, physical and cognitive

accessibility, available community resources and services). Therefore, CPA covers a broader scope of attitudes and actions affecting participation in everyday life.

In addition, the required level of empowerment seems to differ between CPA and patient activation. While both concepts aim to empower an individual to have control over his/her care or life, CPA involves a sense of empowerment originated from critical awareness on the sociopolitical bearing of disability, whereas patient activation empowers patients through skills, knowledge, and confidence about their own condition and care. Like in patient activation, many participants with stroke in the study reported that they felt empowered from functional recovery and the feeling of gaining control over their body or impairment, which made them start feeling comfortable in participating in activities. Literature also agrees that the initially people with stroke often feel empowered from their internal strength, confidence, motivation for recovery, and positive outcomes from rehabilitation (Kubina et al., 2013; Rochette et al., 2006; White et al., 2012). The analysis of the qualitative interviews, however, revealed that highly activated participants reached a level of empowerment that is beyond confidence from recovery and control over health and body. The group of highly activated people identified in phase 1 seemed to have reconstructed normalcy and embraced their difference as what is normal to them. Such reconstruction allowed them to free themselves from internal conflict and social discomfort. People with disabilities frequently need to deal with the idea that disability is inherently bad and sad. They face daily barriers to participation on physical environment level or on attitudinal level. Without critical consciousness about the oppressive environment or disability as a social construct, they may feel shame, continue to live with an expectation to become

“normal,” and only try to improve their function to assimilate to the majority. It is likely that they will continue to see disability as a negative trait and have internal identity conflict because of their desire to be “like others.” Such internal conflict can also lead to discomfort in the interaction with others in society. Gaining critical awareness and sense of empowerment leads proud identification with the disability group and true acceptance to differences (Gill, 1997). By doing so, people become activated to fully live their lives in the community with their impairments instead of feeling uncomfortable in the community in shame of having a disability or in fear of discrimination and social stigma.

However, there are limited opportunities that can trigger critical changes that allows people to move to the next level of empowerment. While peer support and mentoring, engagement in the disability advocacy community, and programs introducing the social model of disability have shown to be effective methods in raising critical consciousness of people with disabilities (Anderson & Whitfield, 2013; Fawcett et al., 1994; Freire, 1993; Lee et al., 2016), there is little effort in exposing people with stroke to such interventions or disability culture. The priority of organizations or interventions for people with stroke is often to prevent or cure disability from stroke, rather than to advocate for civil rights or a better system to support people who had a stroke (Anderson & Whitfield, 2013). More collaboration between the medical community or organization with the disability advocacy community needs to happen to strategize ways to enhance peer support and education opportunities and to change the culture from cure to advocacy and systems change for people who had a stroke.

2. **Content validity and accessibility of the Community Participation Activation Scale items**

The CPAS items were developed based on substantive input from people with stroke throughout the item development process to reflect their lived experiences. Integrating qualitative research is increasingly called for in measurement development as a way to increase the social and ecological validity by reflecting the reality of people's experiences (Magasi et al., 2011; Magasi & Heinemann, 2009; Velozo et al., 2012). The CPAS items directly integrated the attitudes and actions identified through qualitative data and existing literature. However, because the items were written by the researchers, it needed a further measure to ensure that the items are well perceived and understood by people who had a stroke. Because responding to a question requires judgment, abstract thinking, organizing, sequencing, processing, and problem-solving (Krosnick, 1991), the process of answering questions can be challenging for people with cognitive impairment, if proper support is not provided.

The design incorporated methods such as cognitive testing and readability testing to support people with stroke to easily and accurately understand and respond to the questions. The cognitive testing was effective in learning where to combine items, clarify meaning of items, and simplify wording. However, it is noteworthy that the format of cognitive testing was challenging to people with stroke even when they had with minimum cognitive impairment. Additional prompting, rephrasing of the questions, and a supportive attitude to reduce embarrassment and frustration facilitated the process of cognitive testing among people with stroke. The approaches used in this study affirmed

a robust and accessible measurement development process which should be considered in psychometric studies including people with disabilities.

3. **Psychometric properties of the Community Participation Activation**

Scale

The psychometric evaluation in phase 3 allowed to examine the psychometric function of the CPAS and helped identify areas that need to be taken into account in the next step of the development. We found low person separation reliability but good internal consistency reliability for both the Action and Attitude domains. This inconsistency between the person separation reliability and internal consistency reliability may be due to poor targeting (Mallinson & Stelmack, 2001). Over 70% of participants reported activation levels beyond what the items can measure (i.e., a ceiling effect). Ceiling effects have been shown to artificially inflate Cronbach's alpha (Thorndike & Thorndike-Christ, 2010). In this study, the ceiling effect may have occurred because of the highly activated sample. Despite concerted efforts, the majority of the participants in this study were connected to a large urban rehabilitation hospital and were engaged in the substantial community resources and disability networks offered by that setting. Most participants contacted the researcher directly to participate in the study after reading a flyer posted in the rehabilitation setting, suggesting that they were motivated to pursue opportunities to participate in research and were able to arrange transport to come to the location of the interview. To improve targeting and enhance measurement precision, future studies of the CPAS should involve a larger sample size with participants with a broader range of activation.

We found low to moderate associations between the CPAS domains and community participation enfranchisement and community reintegration constructs. Enfranchisement identifies whether people feel fully integrated and included in society, which may be related to individual perceptions and attitudes. Because of the similarity in the items between the CPAS attitude items and CPI items, we expected to see a stronger association. The moderate correlation we found suggests that the two measures assess two different constructs despite the similarity of the items. Indeed, the CPI rating scale reflects how often respondents perceive being enfranchised during participation in activities, while the CPAS scale captures a perception of coherence with various aspects of community activation. The action items of the CPAS showed significant but lower correlation with the RNLI items suggesting that engaging in life activities per se as measured in RNLI is indeed a distinct from the concept of perception of actions captured by the CPAS.

4. **Implications for rehabilitation practice and research**

While the findings from the psychometric examination suggest that there is need to further develop the CPAS, the assessment has potential in offering a unique tool to assess CPA. The CPAS can be used by health care professionals to inform client-centered, participation-focused interventions in clinical or community settings. Current participation measures show whether individuals engage in activities, how satisfied they are with their engagement, and what outside supports and barriers influence their engagement. The CPAS offers a measure that examines attitudes and actions that people with stroke develop to activate community participation. The CPAS is unique in providing information on how activated a person is to do what he/she wants

to do in the community. Using that information, health care professionals can develop a care plan tailored to the areas that a person with stroke is less prepared for. Using the CPAS to inform individually designed interventions also may initiate a shift of the focus of rehabilitation from remediation to capacity building for long term management of community participation. The ultimate goal of stroke rehabilitation is to enable clients to live their life fully with their impairments long term. It is critical to teach them how to strategize ways to improve their participation and integration in society. Using the CPAS, the desired outcome becomes promoting readiness for community participation, thus the focus of intervention may shift to long term management and self-efficacy building.

The assessment also has potential to enrich rehabilitation research regarding CPA of people with stroke and its relationship with other participation outcomes. First, the CPAS allows quantitative long term tracking of CPA among people with stroke. This new knowledge can help better understand changes in CPA over time among people with stroke at a population level. Further analysis will also allow understanding of participation. The assessment also enables researchers to explore the impact of CPA on other participation or quality of life outcomes. Participation is a complex process and is strongly influenced by personal and environmental factors. Individuals with stroke may have developed attitudes and actions activating their participation but choose not to participate in certain activities. Activated individuals may also be prevented from pursuing their participation goals because of societal and system level barriers that cannot be strategized despite their advocacy skills. It is also plausible that highly activated people with stroke may not frequently participate in the community but show

higher satisfaction with their status of participation. Given the complexity of participation, further examination of the relationship between participation activation and other participation related outcomes may be beneficial to fully understand community participation of people with stroke. Better understanding of CPA can help identify how to best support people with disabilities to promote their participation in the community. The CPAS provides an assessment to carry out such research.

B. Limitations and Future Direction

The study has several limitations. In the qualitative phase, the majority of the participants were African American and educated with at least a high school degree. In addition, many of them were connected to a rehabilitation hospital that offers a variety of resources and programs for people with disabilities. The availability of resources that provide opportunities for people to engage in activities and to network with other people with disabilities may not be experienced by people with stroke located in rural areas or people without access to these types of programs. Because this was a dissertation study, the qualitative data were analyzed by the author only. Although results were shared and discussed with two other researchers, the coding and analysis were conducted by one person, adding potential bias originated from the researcher's background and personal experience with people with stroke.

Another limitation was with the expert review. The revised items were not examined by the experts again. Another round of expert review could have provided a more accurate content validity based on the revisions made after the first round of expert review and the cognitive testing. In addition, although the cognitive testing was conducted twice, the second testing was done only with three participants. It is

recommended to have at least five participants to test whether the instrument is perceived as intended and to improve the clarity (DeWalt et al., 2007).

The psychometric testing of the CPAS was preliminary and also has several limitations. The study was a preliminary evaluation with a minimum sample size of participants from one geographic region, which may not generalize to the experiences of persons with stroke in other areas. The study used convenience sampling and snowball sampling which resulted in a self-selected group of participants who have social connections and community resources and with higher activation levels. The sample was predominantly African American and White and findings may not generalize to the experience of adults with stroke from other ethnic backgrounds. To improve the study design and enhance measurement precision of the CPAS, future studies of the CPAS should involve a larger sample size with participants with a broader range of activation. Future studies should also consider to what extent adding more challenging items would help to discriminate among the highly activated participants. To increase the utility of the CPAS as a clinical outcome measure, future study may also include examination of the test-retest reliability, sensitivity to change, and criterion validity. Ultimately, the measure could also be modified and tested with other disability groups or aging population given the shared experience of people with stroke and other long term disabilities.

Lastly, while the study attempted to ground the item development process within the lived experience of people with stroke, there were shortcomings in true collaboration. People with stroke were included as research participants rather than research partners. Disability research has been criticized for having a strict researcher

and participant relationship (Gill, 1999; Kitchin, 2000). A collaborative relationship does not only give people with disabilities control over research and facilitate empowerment of people with disabilities, but also make research more rigorous and produce more useful interpretation (Kitchin, 2000). In the future, participants with stroke should be involved as collaborators or consultants who can monitor the research project and provide constructive feedback at different stages.

VI. CONCLUSION

The study describes the process of the development, refinement, and validation of the Community Participation Activation Scale (CPAS). The scale was developed based on a conceptual model showing the interaction between attitudes and actions that activates community participation of people with stroke. Expert review, cognitive testing, and readability review were conducted to refine the items and increase content validity. Finally, 27 items were field-tested with people with stroke living in the community, resulting in two domains with 15 action items and 10 attitude items.

The initial findings show that the CPAS needs improvement in its precision and validity to be used as a clinical outcome measure. Yet, the study represents an important contribution to the literature for increasing the understanding of activation in the context of community participation. The analysis shows that CPAS can be explained by two distinct domains: Action and Attitude domains. This result confirms the conceptual model constructed based on the qualitative findings, showing that the two constructs are strongly correlated while also describing two important differences among people with stroke. The CPAS offers a measure that assesses aspects of community participation that other existing measures do not. The CPAS can be used to inform client-centered, participation-focused interventions and to further explore community participation activation on a larger scale.

While quantitative research is often criticized for not capturing the reality of people with disabilities, the instrument development process of the CPAS was aligned

with the values and ideas of disability studies. Although true partnership was not established, the instrument was developed based on qualitative information from people with stroke and refined through stakeholders' input and critique. The study provides a model for rigorous instrument design that integrates and reflects the lived experience of people with stroke.

APPENDICES

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

May 3, 2016

Danbi Lee, B.S.
Occupational Therapy
1919 W. Taylor
Occupational Therapy, M/C 811
Chicago, IL 60612
Phone: (312) 996-9655 / Fax: (312) 413-0256

RE: Protocol # 2014-0628
“Assessing Community Participation Management after Stroke: Developing and Validating the Participation Activation Measure (PAM)”

Dear Ms. Lee:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and/or consent form under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: May 3, 2016

Amendment:

Summary: Amendment #3 dated and received April 20, 2016 is an investigator-initiated amendment submitting a revised data collection instrument (PAS Validation Interview Guide, v2, 4/20/16).

Approved Subject Enrollment #: 200

Performance Sites: UIC

Sponsor: Midwest Roybal Center for Health Promotion,
Provost's Award for Graduate Research

Appendix A (continued)

PAF#: Not available, Not available
Grant/Contract No: Not available, Not available
Grant/Contract Title: Not available, Not available

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
04/20/2016	Amendment	Expedited	05/03/2016	Approved

Please be sure to:

→ Use your research protocol number (2014-0628) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website at,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"
 (<http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>)

Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 355-0816. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Alison Santiago, MSW, MJ
 Assistant Director, IRB # 2
 Office for the Protection of Research Subjects

Enclosure(s): None

cc: Joy Hammel (Faculty Advisor), Occupational Therapy, M/C 811
 Yolanda Suarez-Balcazar, Occupational Therapy, M/C 811

Appendix B

Focus Group Interview Guide

1. Opening question: Tell us your name and tell us how long ago you had a stroke
2. Introductory questions: What does “participation” mean to you? What comes to mind when you hear the work being active? How about the term “being active” ?
3. [Summarize what people shared.] In this group when I say participation, I mean “being able to do what you want to do, when you want it, the way you want it and who you want to do it with” We would like to talk about things that “activated” you to “participate”.
4. Transition questions: At what point after your stroke did you feel activated so you can participate in things you want to do? What was the turning point?
5. Key questions: We would like to talk more about things that made you active again after your stroke. I learned from many people that, after a stroke, doing what you want to do takes management skills or strategies. I would like to learn more from you what factors influenced your level of participation after stroke.
 - What kind of skills did you need in order to actively participate in what you want to do?
 - What strategies/tactics did/do you use to help you participate in the community?
 - What kind of beliefs do you think an active participator has/needs to have?
 - Tell me about the importance of confidence. In what areas did you need confidence in in order to actively participate in what you wanted to do?
 - What kind of information/knowledge did you need to know? What information/resources were useful?
 - What was/is the role of your family, friends, and other social networks you have in supporting your participation?
 - How did you manage your social network? What did you do to make them support you the way you wanted?
 - What are the things that you are still having difficulties with? Please tell me what makes them difficult
 - [If time allows] Going back to the first question, you said you had a turning point, what made you feel that you were not activated or ready to actively participate before that point?

Appendix B (continued)

6. Ending questions: We want to support others to become active again after having a stroke. Can you think of anything else that we haven't yet discussed that we should know about helping people become active? If you were to give a person with a new stroke one piece of advice to help him/her become active again, what would that be?

Appendix C

Qualitative Individual Interview Guide

1. Tell me the story of what your life was like after you came back home after your stroke.
2. Compare when you first had a stroke and now, what has changed over time? At what point after your stroke did you feel comfortable going out and actively participate in things you want to do? In other words, what was the turning point?
 - What made you feel that you were not ready to actively participate before that point?
3. We would like to talk more about things that made you active again after your stroke. I learned from many people that, after a stroke, doing what you want to do takes management skills or strategies. I would like to learn more from you what factors influenced your level of participation after stroke.
 - 1) What kind of skills did you need in order to actively participate in what you want to do? What strategies/tactics did/do you use to help you participate in the community?
 - 2) What kind of beliefs or feelings did you need to have in order to become an active participator?
 - 3) Tell me about the importance of confidence. In what areas did you need confidence in order to actively participate in what you wanted to do?
 - 4) What kind of information/knowledge did you need to know? What information/resources were useful?
 - 5) How did your family, friends, and other social networks support your participation?
 - 6) In terms of doing the things you want to do in your life, what are the things that you are still having difficulties with? Please tell me what makes them difficult
4. Please list all the things that support your active participation
5. This research study is about how people with strokes become active participators again in doing what they want to do. Can you think of anything else we should know about helping them become more active again in their lives?

Appendix D

Expert Review Survey

I am developing an instrument that measures how activated a person is to actively participate in life after stroke (called *Participation Activation*). In the International Classification of Functioning, Disability and Health (ICF), participation is defined as “involvement in a life situation.” For people with stroke, involvement in a life situation often requires a complex process that involves constant management of competing needs and values across individual, social and societal levels. Many researchers have been trying to figure out how to best measure people’s participation. Currently, participation focused instruments mainly measure how much people are involved in certain activities, however, there is no instrument that measures the “management” aspect of participation (i.e., to what extent people manage supports and barriers around them so they can do what they want to do).

In this new assessment, *Participation Activation* is measured as **the extent a person has acquired self-management strategies, knowledge, attitudes, and beliefs that make him/her actively participate in the community.**

The hypothesis is that an activated person (i.e., higher total score) is more likely to be an active participant seeking and maintaining meaningful life activities and roles.

Target population of the instrument: People who had a stroke with mild to moderate cognitive impairment who can answer the questionnaire without a proxy.

Setting: This assessment can be used as an evaluation tool or an outcome measure both in in-patient/out-patient rehabilitation systems and community based settings.

The following survey has three parts: 1) examination of the domains, 2) examination of the items, and 3) examination of the rating scale. Each part has its own instruction.

Please feel free to contact me if you have any questions regarding the survey.

Danbi Lee, PhD Candidate, OTD, OTR/L

dlee72@uic.edu; 312-996-9655

Appendix D (continued)

[Examination of the domains]

1. **Representativeness:** In the questionnaire, you are asked to judge how representative the domain and subdomains are of the construct *Participation Activation*.
2. Respond to questions at the end of the form related to evaluating the comprehensiveness of the domains and sub-domains.
3. Please provide comments/suggestions when appropriate.

Domains/Sub-domains	Representativeness 1= The domain is <u>NOT</u> representative of participation activation 2= The domain <u>is</u> representative of participation activation.	Comments
Domain: Attitude/Belief		
Sub-domain 1: Comfortable accepting help from others	1 2	
Sub-domain 2: Comfortable being in public	1 2	
Sub-domain 3: Belief that being active keeps you healthy and improves your function	1 2	
Sub-domain 4: Desire to be as independent/ autonomous as possible	1 2	
Sub-domain 5: Desire to feel useful/engage in meaningful activities	1 2	
Sub-domain 6: Positive outlook	1 2	
Sub-domain 7: Focus on strengths	1 2	
Sub-domain 8: Reevaluating meaning of activities	1 2	

Appendix D (continued)

Domains/Sub-domains	Representativeness 1= The domain is <u>NOT</u> representative of participation activation 2= The domain <u>is</u> representative of participation activation.	Comments
Domain 2: Knowledge	1 2	
Sub-domain 1: Understanding the impact of stroke related limitations	1 2	
Sub-domain 2: Understanding the impact of environment on activities	1 2	
Sub-domain 3: Knowing where to find information	1 2	
Sub-domain 4: Knowing your rights as a person with a disability	1 2	
Domain 3: Actions	1 2	
Sub-domain 1: Setting goals	1 2	
Sub-domain 2: Testing/trying new things	1 2	
Sub-domain 3: Prioritizing	1 2	
Sub-domain 4: Planning	1 2	
Sub-domain 5: On-the-go/in-the-moment problem solving	1 2	
Sub-domain 6: Utilizing an adapted way of participating in activities	1 2	
Sub-domain 7: Asking for help/utilize supportive network	1 2	
Sub-domain 8: Engaging with others who had a stroke	1 2	
Sub-domain 9: Utilizing community resources	1 2	
Sub-domain 10: Utilizing disability specific services/resources	1 2	

Appendix D (continued)

Domains/Sub-domains	Representativeness 1= The domain is <u>NOT</u> <u>representative</u> of participation activation 2= The domain <u>is representative</u> of participation activation.	Comments
Sub-domain 11: Accessing community mobility when needed	1 2	
Sub-domain 12: Navigating the disability system (e.g., medical/social service system)	1 2	
Sub-domain 13: Advocating for rights and resources for myself or other people with disabilities at large	1 2	

Comprehensiveness: Are there any domains that you think are inappropriate?

Comprehensiveness: Are there any domains that you think are missing?

Appendix D (continued)

[Examination of the items]

1. **Representativeness:** In the questionnaire, you are asked to judge how representative items are of the content domain of participation activation. In judging representativeness of the content items, please also evaluate whether the items are appropriate for people with mild to moderate stroke who are still in rehabilitation or living in the community after discharge.
2. **Clarity:** Following your evaluation on items' representativeness, you will be asked to rate the clarity of each item. Please judge whether the item is clearly written, distinct, and at an appropriate reading level for individuals with stroke.
3. Please provide comments/suggestions when appropriate.
4. Respond to questions at the end of the form related to evaluating the comprehensiveness of the entire instrument and addition or deletion of items.

Items	Representativeness 1= the item is <u>not representative</u> of participation activation. 2= the item <u>needs major revision</u> to be representative of participation activation. 3= the item <u>needs minor revisions</u> to be representative of participation activation (is relevant). 4= the item <u>is representative</u> of participation activation.	Clarity 1= this item is <u>well written, distinct, and at an appropriate reading level</u> for individuals with stroke 2= this item is <u>not clear</u> (comment suggestions for making the item clear)
Attitudes		
1. I am comfortable accepting help when needed.	<div style="text-align: center; margin-bottom: 10px;">1 2 3 4</div> Comment:	<div style="text-align: center; margin-bottom: 10px;">1 2</div> Comment:

Appendix D (continued)

Items	Representativeness 1= the item is <u>not representative</u> of participation activation. 2= the item <u>needs major revision</u> to be representative of participation activation. 3= the item <u>needs minor revisions</u> to be representative of participation activation (is relevant). 4= the item <u>is representative</u> of participation activation.	Clarity 1= this item is <u>well written, distinct, and at an appropriate reading level</u> for individuals with stroke 2= this item is <u>not clear</u> (comment suggestions for making the item clear)
2. I am comfortable being out in the community.	1 2 3 4 Comment:	1 2 Comment:
3. I am comfortable being seen out in the community.	1 2 3 4 Comment:	1 2 Comment:
4. I believe that participating in activities is what keeps me healthy.	1 2 3 4 Comment:	1 2 Comment:
5. I am in control of what I want to do, even if I get help.	1 2 3 4 Comment:	1 2 Comment:
6. Helping others is very important to me because it makes me feel useful.	1 2 3 4 Comment:	1 2 Comment:
7. I have a positive outlook about resuming new or previous activities.	1 2 3 4 Comment:	1 2 Comment:
8. I actively pursue my dreams and desires.	1 2 3 4 Comment:	1 2 Comment:
9. I focus on my strengths and successes rather than my limitations and failures.	1 2 3 4 Comment:	1 2 Comment:

Appendix D (continued)

Items	Representativeness 1= the item is <u>not representative</u> of participation activation. 2= the item <u>needs major revision</u> to be representative of participation activation. 3= the item <u>needs minor revisions</u> to be representative of participation activation (is relevant). 4= the item <u>is representative</u> of participation activation.	Clarity 1= this item is <u>well written, distinct, and at an appropriate reading level</u> for individuals with stroke 2= this item is <u>not clear</u> (comment suggestions for making the item clear)
10. I have accepted that I am not able to do some activities that I used to do before stroke.	1 2 3 4 Comment:	1 2 Comment:
11. I am satisfied with the way I do things even though it is not the same way.	1 2 3 4 Comment:	1 2 Comment:
Knowledge		
1. I understand how stroke related symptoms affect my ability to do what I want to do.	1 2 3 4 Comment:	1 2 Comment:
2. I am realistic in evaluating what I can do and cannot do.	1 2 3 4 Comment:	1 2 Comment:
3. I understand that my surroundings can either help or keep me from what I want to do.	1 2 3 4 Comment:	1 2 Comment:
4. I know of environmental barriers that can get in my way when I am out in the community.	1 2 3 4 Comment:	1 2 Comment:

Appendix D (continued)

Items	Representativeness 1= the item is <u>not representative</u> of participation activation. 2= the item <u>needs major revision</u> to be representative of participation activation. 3= the item <u>needs minor revisions</u> to be representative of participation activation (is relevant). 4= the item <u>is representative</u> of participation activation.	Clarity 1= this item is <u>well written, distinct, and at an appropriate reading level</u> for individuals with stroke 2= this item is <u>not clear</u> (comment suggestions for making the item clear)
5. I know where to get information I need (health professionals, community resources, other stroke survivors, etc).	1 2 3 4 Comment:	1 2 Comment:
6. I have a good understanding of my rights as a person with a disability.	1 2 3 4 Comment:	1 2 Comment:
Actions		
1. I set goals to try new things.	1 2 3 4 Comment:	1 2 Comment:
2. I work to attain my goals no matter how difficult the path is.	1 2 3 4 Comment:	1 2 Comment:
3. I try out new activities/tasks to figure out whether I can do them.	1 2 3 4 Comment:	1 2 Comment:
4. I have developed new preferences based on my strengths and weaknesses.	1 2 3 4 Comment:	1 2 Comment:
5. I plan ahead to make things easier.	1 2 3 4 Comment:	1 2 Comment:

Appendix D (continued)

Items	Representativeness 1= the item is <u>not representative</u> of participation activation. 2= the item <u>needs major revision</u> to be representative of participation activation. 3= the item <u>needs minor revisions</u> to be representative of participation activation (is relevant). 4= the item <u>is representative</u> of participation activation.	Clarity 1= this item is <u>well written, distinct, and at an appropriate reading level</u> for individuals with stroke 2= this item is <u>not clear</u> (comment suggestions for making the item clear)
6. I plan ahead to address unforeseen barriers.	1 2 3 4 Comment:	1 2 Comment:
7. I plan ahead to make sure needed accommodations are in place.	1 2 3 4 Comment:	1 2 Comment:
8. I have strategies to handle potential barriers in the community.	1 2 3 4 Comment:	1 2 Comment:
9. If I am in trouble, I can usually think of a solution.	1 2 3 4 Comment:	1 2 Comment:
10. I can effectively handle unexpected problems in the moment when things happen out in the community.	1 2 3 4 Comment:	1 2 Comment:
11. I allow myself more time and pace myself when completing a task or activity.	1 2 3 4 Comment:	1 2 Comment:
12. I do things in a different way to compensate for what I cannot do.	1 2 3 4 Comment:	1 2 Comment:
13. I use devices or equipment whenever needed to make things easier.	1 2 3 4 Comment:	1 2 Comment:

Appendix D (continued)

Items	Representativeness 1= the item is <u>not representative</u> of participation activation. 2= the item <u>needs major revision</u> to be representative of participation activation. 3= the item <u>needs minor revisions</u> to be representative of participation activation (is relevant). 4= the item <u>is representative</u> of participation activation.	Clarity 1= this item is <u>well written, distinct, and at an appropriate reading level</u> for individuals with stroke 2= this item is <u>not clear</u> (comment suggestions for making the item clear)
14. If the ways things are set up are making it difficult for me, I change the set up/environment.	1 2 3 4 Comment:	1 2 Comment:
15. I ask for help when I need it without hesitation.	1 2 3 4 Comment:	1 2 Comment:
16. I have a supportive network around me who I can ask for help if I need it.	1 2 3 4 Comment:	1 2 Comment:
17. I have a network of people with a stroke or other disabilities that I can relate to.	1 2 3 4 Comment:	1 2 Comment:
18. I have managed to have access to transportation to get where I need to go when I need it.	1 2 3 4 Comment:	1 2 Comment:
19. I can go out spontaneously and get where I need to go.	1 2 3 4 Comment:	1 2 Comment:
20. I use resources and/or services that help me do more things.	1 2 3 4 Comment:	1 2 Comment:
21. I actively use resources and services that are available for people with disabilities.	1 2 3 4 Comment:	1 2 Comment:

Appendix D (continued)

Items	Representativeness 1= the item is <u>not representative</u> of participation activation. 2= the item <u>needs major revision</u> to be representative of participation activation. 3= the item <u>needs minor revisions</u> to be representative of participation activation (is relevant). 4= the item <u>is representative</u> of participation activation.	Clarity 1= this item is <u>well written, distinct, and at an appropriate reading level</u> for individuals with stroke 2= this item is <u>not clear</u> (comment suggestions for making the item clear)
22. I can navigate the disability system (e.g., medical system, human services system) by myself or can get help with it.	1 2 3 4 Comment:	1 2 Comment:
23. I have been actively seeking and advocating for what I need (e.g., accessibility, services) when it was not readily available.	1 2 3 4 Comment:	1 2 Comment:
24. I have been part of a disability advocacy group that fight for disability rights and access to resources.	1 2 3 4 Comment:	1 2 Comment:

Comprehensiveness: Are there any items that you think should be deleted because they do not represent the content domain?

Comprehensiveness: Are there any items that you think are missing? In other words, are the items sufficient to represent the characteristics and behaviors of activated stroke survivors?

Appendix D (continued)

[Examination of the Rating scales]

1. Please indicate which rating scale seems most appropriate for the assessment (rank the rating scale options) and add comments/suggestions when appropriate.
2. Please suggest other ways to rate the items, if none of the options seem appropriate.

Rating Scales	Rank order	Comments
Same scale for all domains: 1= This does not describe me/my experience at all (This is not me) 2= This does not describe me/my experience very well (This is somewhat me) 3= This describes me/my experience somewhat (This sounds like me) 4= This describes me/my experience very well (This is definitely me)		
Same scale for all domains: 1= I completely disagree 2= I somewhat disagree 3= I somewhat agree 4= I completely agree		

Appendix E

Cognitive Testing Questionnaire

Items	Please repeat this question in your own word.	Response: Scale 1	Response: Scale 2	Explain the meaning of _____	Was the question difficult? Why?	Was it applicable to you? If not why?
1. I believe that participating in things that are important to me helps me stay healthy.						
2. I believe I am in control of what I want to do during the day, even if I get help.						
3. I am confident that I can get back to activities that are important to me.						
4. I actively pursue my dreams and desires.						
5. I focus on my strengths and successes rather than my limitations and failures.						
6. I have learned how to fully participate with my disability						
7. I ask for help when I need it without hesitation.						
8. I am comfortable accepting help when needed.						
9. I am satisfied with the way I do things even though it is not the same way as before my stroke.						
10. I understand how stroke related symptoms (e.g., cognitive, physical, fatigue) affect my ability to do what I want to do.				stroke related symptoms		
11. I am confident that I can manage stroke related symptoms (e.g., cognitive, physical, fatigue) so they do not prevent me from being active.						
12. I set goals that help me be more active and involved in life.						

Appendix E (continued)

Items	Please repeat this question in your own word.	Response: Scale 1	Response: Scale 2	Explain the meaning of _____	Was the question difficult? Why?	Was it applicable to you? If not why?
13. I work to meet my goals even though they may be hard to achieve.						
14. I am willing to try out new activities if there is a chance they will enhance my daily life.						
15. I am good at planning ahead to make things easier.						
16. Since the stroke, I allow myself more time and pace myself when completing an activity.						
17. Since the stroke, I do things differently to compensate for what I cannot do.						
18. I use devices whenever needed to make things easier.				devices		
19. I understand that my surroundings can either help or keep me from what I want to do.				surroundings		
20. I am comfortable being out in the community.						
21. I am comfortable being seen by others out in the community.						
22. I am aware of how things in the environment get in my way when I am out in the community.						
23. I plan ahead so things in the environment do not get in my way when I am out in the community.				things in the environment		
24. I am good at getting around in the community.						
25. I have ways to deal with accessibility when out and about.						

Appendix E (continued)

Items	Please repeat this question in your own word.	Response: Scale 1	Response: Scale 2	Explain the meaning of _____	Was the question difficult? Why?	Was it applicable to you? If not why?
26. I have arranged transportation to get where I need to go when I need it.						
27. I can get where I need to go if something unplanned comes up.						
28. I can handle unexpected problems in the moment when they arise when I am out in the community.				unexpected problems		
29. I know where to get information that helps me be more active (health professionals, community resources, other stroke survivors, etc).						
30. As a person who had a stroke, I have a good understanding of my civil rights to participate in the community.				civil rights		
31. I actively use resources and services to help me to do more activities.						
32. I actively use resources and services that are available for people with disabilities.						
33. I am confident that I can navigate the system (e.g., medical system, human services system) by myself or by getting help with it.						
34. I actively advocate for what I need (e.g., accessibility, services) when it is not readily available.						
35. I have a supportive network of friends and family around me from whom I can ask help if I need it.						

Appendix E (continued)

Items	Please repeat this question in your own word.	Response: Scale 1	Response: Scale 2	Explain the meaning of _____	Was the question difficult? Why?	Was it applicable to you? If not why?
36. I have a supportive network of people with a stroke or other disabilities that I can relate to.						
37. I have been part of a disability advocacy group that pushes for disability rights and access to resources.						

Appendix F

Community Participation Activation Scale (CPAS)

I am going to ask you questions about how you engage and participate in different community activities. Let me first ask you what community activities you are engaged.

Can you tell me things that you did outside your home in the past two weeks?

Now I am going to read you some statements. I want you to tell me to what extent each statement describes you. Here are the response options.

1= Does not describe me at all.

2= Describes me somewhat.

3= Describes me quite well.

4= Describes me exactly.

When you answer the questions, please think about the past 2 weeks and the activities you just mentioned.

Actions	Rating
1. You actively try to engage in more activities outside your home.	
2. You modify your activities to make up for what you cannot do.	
3. You plan ahead to make it easier to do things you care about.	
4. You allow yourself plenty of time and pace yourself to get things done.	
5. You ask for help when you need it.	
6. You accept help when you need it.	
7. You manage health conditions from your stroke so they do not prevent you from doing activities you care about. (Examples of health conditions are weakness, fatigue, and pain)	
8. You get around in the community when you need to	
9. You always think through how things in the community can get in your way before you leave your home.	
10. You handle problems in the moment when they arise when you are out in the community.	

Appendix F (continued)

Actions	Rating
11. You arrange transportation to get where you need to go when you need it.	
12. You always get to where you need to go even if something unplanned comes up.	
13. You look up information that you need to do activities you care about.	
14. You use community resources to help me engage in activities you care about.	
15. You advocate for services and resources when they are not readily on hand.	
Attitudes	Rating
16. You believe doing things that are important to you helps you stay healthy.	
17. You are willing to try out new activities if there is a chance they will enhance your daily life.	
18. You believe you are in control of what you want to do during the day, even if you get help.	
19. You are comfortable being seen by others you don't know	
20. You are sure that you can keep on doing your favorite activities.	
21. You are willing to take risks to try out a new activity if it is important to you.	
22. You learned how to fully live your life with your disability	
23. You focus on your strengths and successes rather than your limitations and failures.	
24. You are satisfied with the way you do things even though it may not be the same way as others do it.	
25. You are determined in the face of challenges.	

Appendix F (continued)

- 1= This does not describe me at all.
- 2= This describes me somewhat.
- 3= This describes me quite well.
- 4= This describes me exactly.

REFERENCES

- Ajzen, I., & Fishbein, M. (2014). The influence of attitudes on behavior. In D. Albarracin, B. T. Johnson, & M. P. Zanna (Eds.), *The handbook of attitudes* (pp. 173-221). New York, NY: Psychology Press.
- Algurén, B., Fridlund, B., Cieza, A., Sunnerhagen, K. S., & Christensson, L. (2012). Factors associated with health-related quality of life after stroke: A 1-Year prospective cohort study. *Neurorehabilitation and Neural Repair*, 26(3), 266-274.
- Anderson, S., & Whitfield, K. (2011). An ecological approach to activity after stroke: It takes a community. *Topics in Stroke Rehabilitation*, 18(5), 509-524.
<https://doi.org/10.1310/tsr1805-509>
- Anderson, S., & Whitfield, K. (2013). Social identity and stroke: "They don't make me feel like, there's something wrong with me". *Scandinavian Journal of Caring Sciences*, 27(4), 820-830. <https://doi.org/http://dx.doi.org/10.1111/j.1471-6712.2012.01086.x>
- Augustine, H., Roberts, J., & Packer, T. (2011). Everyday participation: Important outcomes for people with chronic conditions. *Occupational Therapy Now*, 13(5), 8-10.
- Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of human behavior* (vol.4, pp. 71-81). New York, NY: Academic Press. Retrieved from <https://www.uky.edu/~eushe2/Bandura/BanEncy.html>

- Beatty, P. C., & Willis, G. B. (2007). Research synthesis: The practice of cognitive interviewing. *Public Opinion Quarterly*, 71(2), 287-311.
- Bluvol, A., & Ford-Gilboe, M. (2004). Hope, health work and quality of life in families of stroke survivors. *Journal of Advanced Nursing*, 48(4), 322-332.
<https://doi.org/10.1111/j.1365-2648.2004.03004.x>
- Bogner, J. (2010). Community participation: measurement issues with persons with deficits in executive functioning. *Archives of Physical Medicine and Rehabilitation*, 91(9), S66-S71. <https://doi.org/10.1016/j.apmr.2009.11.032>
- Bouffoulx, É., Arnould, C., & Thonnard, J. L. (2011). Satisfaction with activity and participation and its relationships with body functions, activities, or environmental factors in stroke patients. *Archives of Physical Medicine and Rehabilitation*, 92(9), 1404-1410. <https://doi.org/10.1016/j.apmr.2011.03.031>
- Brady, M. C., Clark, A. M., Dickson, S., Paton, G., & Barbour, R. S. (2011). The impact of stroke-related dysarthria on social participation and implications for rehabilitation. *Disability and Rehabilitation*, 33(3), 178-186.
- Cervellione, K. L., Lee, Y. S., & Bonanno, G. A. (2008). Rasch modeling of the self-deception scale of the balanced inventory of desirable responding. *Educational and Psychological Measurement*, 69(3), 438-458.
<https://doi.org/10.1177/0013164408322020>
- Chang, F. H., Coster, W. J., & Helfrich, C. A. (2013). Community participation measures for people with disabilities: A systematic review of content from an International Classification of Functioning, Disability and Health perspective. *Archives of*

Physical Medicine and Rehabilitation, 94(4), 771-781.

<https://doi.org/10.1016/j.apmr.2012.10.031>

Charmaz, K. (2002). The self as habit: the reconstruction of self in chronic illness. *The Occupational Therapy Journal of Research*, 22, 31S-41S.

Chau, J. P. C., Thompson, D. R., Twinn, S., Chang, A. M., & Woo, J. (2009).

Determinants of participation restriction among community dwelling stroke survivors: A path analysis. *BMC Neurology*, 9(49), 1-7.

Ch'ng, A. M., French, D., & McLean, N. (2008). Coping with the challenges of recovery from stroke: Long term perspectives of stroke support group members. *Journal of Health Psychology*, 13(8), 1136-1146.

<https://doi.org/10.1177/1359105308095967>

Clarke, P., & Black, S. E. (2005). Quality of life following stroke: Negotiating disability, identity, and resources. *Journal of Applied Gerontology*, 24(4), 319-336.

Creswell, J. W., Klassen, A. C., Plano Clark, V. L., & Smith, K. C. (2011). *Best practices for mixed methods research in the health sciences*. Bethesda, MD: National Institutes of Health. Retrieved from https://tiger.uic.edu/jaddams/college/business_office/Research/Best_Practices_for_Mixed_Methods_Research.pdf

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests.

Psychometrika, 16(3), 297-334.

Daniel, K., Wolfe, C. D. A., Busch, M. A., & McKeivitt, C. (2009). What are the social consequences of stroke for working-aged adults? A systematic review. *Stroke*, 40(6), e431-e440.

Desrosiers, J., Demers, L., Robichaud, L., Vincent, C., Belleville, S., & Ska, B. (2008).

Short-term changes in and predictors of participation of older adults after stroke following acute care or rehabilitation. *Neurorehabilitation and Neural Repair*, 22(3), 288-297. <https://doi.org/10.1177/1545968307307116>

Desrosiers, J., Noreau, L., Rochette, A., Bourbonnais, D., Bravo, G., & Bourget, A.

(2006). Predictors of long-term participation after stroke. *Disability & Rehabilitation*, 28(4), 221-229.

DeWalt, D. A., Rothrock, N., Yount, S., & Stone, A. A. (2007). Evaluation of item

candidates: The PROMIS qualitative item review. *Medical Care*, 45(5 Suppl 1), S12-S21. <https://doi.org/10.1097/01.mlr.0000254567.79743.e2>

Edwards, D. F., Hahn, M., Baum, C., & Dromerick, A. W. (2006). The impact of mild

stroke on meaningful activity and life satisfaction. *Journal of Stroke and Cerebrovascular Diseases*, 15(4), 151-157.

Eyssen, I. C., Steultjens, M. P., Dekker, J., & Terwee, C. B. (2011). A systematic review

of instruments assessing participation: Challenges in defining participation. *Archives of Physical Medicine and Rehabilitation*, 92(6), 983-997. <https://doi.org/10.1016/j.apmr.2011.01.006>

Fawcett, S. B., White, G. W., Balcazar, F. E., Suarez-Balcazar, Y., Mathews, R. M.,

Paine-Andrews, A., ... Smith, J. F. (1994). A contextual-behavioral model of empowerment: Case studies involving people with physical disabilities. *American Journal of Community Psychology*, 22(4), 471-496.

- Fendrich, M., Smith, E. V., Pollack, L. M., & Mackesy-Amiti, M. E. (2008). Measuring sexual risk for HIV: A Rasch scaling approach. *Archives of Sexual Behavior*, 38(6), 922-935. <https://doi.org/10.1007/s10508-008-9385-2>
- Fisher, W. P. (1992). Reliability, separation, strata statistics. *Rasch Measurement Transactions*, 6(3), 238.
- Fitzsimmons, P. R., Michael, B. D., Hulley, J. L., & Scott, G. O. (2010). A readability assessment of online Parkinson's disease information. *The Journal of the Royal College of Physicians of Edinburgh*, 40(4), 292-296. <https://doi.org/10.4997/JRCPE.2010.401>
- Fleury, J. (1993). Preserving qualitative meaning in instrument development. *Journal of Nursing Measurement*, 1(2), 135-144.
- Freire, P. (1993). *Pedagogy of the oppressed*. (M. B. Ramos, Trans.). New York, NY: Continuum Publishing Company.
- Gadidi, V., Katz-Leurer, M., Carmeli, E., & Bornstein, N. M. (2011). Long-term outcome post-stroke: predictors of activity limitation and participation restriction. *Archives of Physical Medicine and Rehabilitation*, 92(11), 1802-1808. <https://doi.org/10.1016/j.apmr.2011.06.014>
- Gill, C. J. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation*, 9(1), 39-46.
- Gill, C. J. (1999). Invisible ubiquity: The surprising relevance of disability issues in evaluation. *American Journal of Evaluation*, 20(2), 279-287. <https://doi.org/10.1177/109821409902000209>

- Go, A. S., Mozaffarian, D., Roger, V. L., Benjamin, E. J., Berry, J. D., Blaha, M. J., ... Turner, M. B. (2014). Heart disease and stroke statistics—2014 update a report from the american heart association. *Circulation*, 129(3), e28-e292.
<https://doi.org/10.1161/01.cir.0000441139.02102.80>
- Grant, J. S., & Davis, L. L. (1997). Selection and use of content experts for instrument development. *Research in Nursing & Health*, 20(3), 269-274.
- Gray, D. B., Hollingsworth, H. H., Stark, S. L., & Morgan, K. A. (2006). Participation survey/mobility: psychometric properties of a measure of participation for people with mobility impairments and limitations. *Archives of Physical Medicine and Rehabilitation*, 87(2), 189-197.
- Gray, D. B., Hollingsworth, H. H., Stark, S., & Morgan, K. A. (2008). A subjective measure of environmental facilitators and barriers to participation for people with mobility limitations. *Disability & Rehabilitation*, 30(6), 434-457.
<https://doi.org/10.1080/09638280701625377>
- Greene, J., & Hibbard, J. H. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27(5), 520-526.
<https://doi.org/10.1007/s11606-011-1931-2>
- Häggström, A., & Lund, M. L. (2008). The complexity of participation in daily life: A qualitative study of the experiences of persons with acquired brain injury. *Journal of Rehabilitation Medicine*, 40(2), 89-95. <https://doi.org/10.2340/16501977-0138>
- Hammel, J., Jones, R., Gossett, A., & Morgan, E. (2006). Examining barriers and supports to community living and participation after a stroke from a participatory

action research approach. *Topics in Stroke Rehabilitation*, 13(3), 43-58.

<https://doi.org/10.1310/5X2G-V1Y1-TBK7-Q27E>

Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E.

(2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30(19), 1445-1460.

<https://doi.org/10.1080/09638280701625534>

Hammel, Magasi, S., Heinemann, A., Gray, D. B., Stark, S., Kisala, P., ... Hahn, E. A.

(2015). Environmental barriers and supports to everyday participation: A qualitative insider perspective from people with disabilities. *Archives of Physical Medicine and Rehabilitation*, 96(4), 578-588.

<https://doi.org/10.1016/j.apmr.2014.12.008>

Heinemann, A. W. (2010). Measurement of participation in rehabilitation research.

Archives of Physical Medicine and Rehabilitation, 91(9), S1-S4.

<https://doi.org/10.1016/j.apmr.2009.08.155>

Heinemann, A. W., Lai, J. S., Magasi, S., Hammel, J., Corrigan, J. D., Bogner, J. A., &

Whiteneck, G. G. (2011). Measuring participation enfranchisement. *Archives of Physical Medicine and Rehabilitation*, 92(4), 564-571.

<https://doi.org/10.1016/j.apmr.2010.07.220>

Heinemann, A. W., Magasi, S., Bode, R. K., Hammel, J., Whiteneck, G. G., Bogner, J.,

& Corrigan, J. D. (2013). Measuring enfranchisement: Importance of and control over participation by people with disabilities. *Archives of Physical Medicine and Rehabilitation*, 94(11), 2157-2165. <https://doi.org/10.1016/j.apmr.2013.05.017>

- Heinemann, A. W., Magasi, S., Hammel, J., Carlozzi, N. E., Garcia, S. F., Hahn, E. A., ... Jerousek, S. (2015). Environmental factors item development for persons with stroke, traumatic brain injury, and spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 96(4), 589-595.
<https://doi.org/10.1016/j.apmr.2013.11.024>
- Heinemann, A. W., Tulskey, D., Dijkers, M., Brown, M., Magasi, S., Gordon, W., & DeMark, H. (2010). Issues in participation measurement in research and clinical applications. *Archives of Physical Medicine and Rehabilitation*, 91(9), S72-S76.
<https://doi.org/10.1016/j.apmr.2009.11.031>
- Hemmingsson, H., & Jonsson, H. (2005). An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health—some critical remarks. *The American Journal of Occupational Therapy*, 59(5), 569-576.
- Hibbard, J. H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs*, 32(2), 207-214. <https://doi.org/10.1377/hlthaff.2012.1061>
- Hibbard, J. H., Mahoney, E. R., R. Stock, & Tusler, M. (2006). Do increases in patient activation result in improved self-management behaviors? *Health Services Research*, 42(4), 1443-1463.
- Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research*, 39(4p1), 1005-1026.

- Jeon, Y.H. (2004). The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Sciences*, 18(3), 249-256.
<https://doi.org/10.1111/j.1471-6712.2004.00287.x>
- Jobe, J. B. (2003). Cognitive psychology and self-reports: Models and methods. *Quality of Life Research*, 12(3), 219-227.
- Kessler, D., & Egan, M. (2012). A review of measures to evaluate participation outcomes post-stroke. *The British Journal of Occupational Therapy*, 75(9), 403-411. <https://doi.org/10.4276/030802212X13470263980757>
- Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research. *Disability & Society*, 15(1), 25-47.
<https://doi.org/10.1080/09687590025757>
- Kroll, T. (2011). Designing mixed methods studies in health-related research with people with disabilities. *International Journal of Multiple Research Approaches*, 5(1), 64-75.
- Kroll, T., & Morris, J. (2009). Challenges and opportunities in using mixed method designs in rehabilitation research. *Archives of Physical Medicine and Rehabilitation*, 90(11), S11-S16. <https://doi.org/10.1016/j.apmr.2009.04.023>
- Krosnick, J. A. (1991). Response strategies for coping with the cognitive demands of attitude measures in surveys. *Applied Cognitive Psychology*, 5(3), 213-236.
<https://doi.org/10.1002/acp.2350050305>
- Krueger, R. A., & Casey, M. A. (2008). *Focus groups: A practical guide for applied research* (4th ed.). Thousand Oaks, CA: Sage Publications.

- Kubina, L.A., Dubouloz, C.J., Davis, C. G., Kessler, D., & Egan, M. Y. (2013). The process of re-engagement in personally valued activities during the 2 years following stroke. *Disability and Rehabilitation*, 35(3), 1-8.
<https://doi.org/10.3109/09638288.2012.691936>
- Larsson Lund, M., Lövgren-Engström, A.L., & Lexell, J. (2011). Using everyday technology to compensate for difficulties in task performance in daily life: experiences in persons with acquired brain injury and their significant others. *Disability and Rehabilitation. Assistive Technology*, 6(5), 402-411.
<https://doi.org/10.3109/17483107.2011.574309>
- Lee, D. (2016). *Development and validation of the Community Participation Activation Scale*. Chicago, IL: University of Illinois at Chicago.
- Lee, D., Hammel, J., & Wilson, T. (2016). A community living management program for people with disabilities who have moved out of nursing homes: a pilot study. *Disability and Rehabilitation*, 38(8), 754-760.
<https://doi.org/10.3109/09638288.2015.1060266>
- Linacre, J. M. (2000). Comparing “Partial Credit Models” (PCM) and “Rating Scale Models” (RSM). *Rasch Measurement Transactions*, 14(3), 768.
- Linacre, J. M. (2004). Optimizing rating scale category effectiveness. In E. V. Smith & R. M. Smith (Eds.), *Introduction to Rasch measurement* (pp. 258-278). Maple Grove, MN: JAM Press.
- Magasi, S., & Heinemann, A. W. (2009). Integrating stakeholder perspectives in outcome measurement. *Neuropsychological Rehabilitation*, 19(6), 928-940.
<https://doi.org/10.1080/09602010902996414>

- Magasi, S., Ryan, G., Revicki, D., Lenderking, W., Hays, R. D., Brod, M., ... Cella, D. (2011). Content validity of patient-reported outcome measures: Perspectives from a PROMIS meeting. *Quality of Life Research*, 21(5), 739-746. <https://doi.org/10.1007/s11136-011-9990-8>
- Mallinson, T., & Hammel, J. (2010). Measurement of participation: Intersecting person, task, and environment. *Archives of Physical Medicine and Rehabilitation*, 91(9), S29-S33. <https://doi.org/10.1016/j.apmr.2010.04.027>
- Mallinson, T., & Stelmack, J. (2001). Going beyond unreliable reliabilities. *Rasch Measurement Transactions*, 14(4), 787-788.
- Masten, W., & Wright, M. O. (2009). Resilience over the lifespan. In J. W. Reich, A. J. Zautra, & J. S. Hall (Eds.), *Handbook of adult resilience* (pp. 275-299). New York, NY: Guilford Press.
- Murugami, M. W. (2009). Disability and identity. *Disability Studies Quarterly*, 29(4), 1-9.
- Nassar-McMillan, S. C., & Borders, L. D. (2002). Use of focus groups in survey item development. *The Qualitative Report*, 7(1), 1-12. Retrieved from <http://www.nova.edu/ssss/QR/QR7-1/nassar.html>
- Ongena, Y. P., & Dijkstra, W. (2007). A model of cognitive processes and conversational principles in survey interview interaction. *Applied Cognitive Psychology*, 21(2), 145-163. <https://doi.org/10.1002/acp.1334>
- Onwuegbuzie, A. J., Bustamante, R. M., & Nelson, J. A. (2009). Mixed research as a tool for developing quantitative instruments. *Journal of Mixed Methods Research*, 4(1), 56-78. <https://doi.org/10.1177/1558689809355805>

- Patton, M. Q. (2001). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Plichta, S. B., & Kelvin, E. (2012). *Munro's statistical methods for health care research* (6th ed.). Philadelphia, PA: LWW.
- Polit, D. F., & Beck, C. T. (2006). The content validity index: Are you sure you know what's being reported? Critique and recommendations. *Research in Nursing & Health*, 29(5), 489-497. <https://doi.org/10.1002/nur.20147>
- Pound, P., Gompertz, P., & Ebrahim, S. (1999). Social and practical strategies described by people living at home with stroke. *Health & Social Care in the Community*, 7(2), 120-128.
- Reeve, B. B., Hays, R. D., Bjorner, J. B., Cook, K. F., Crane, P. K., Teresi, J. A., ... Cella, D. (2007). Psychometric evaluation and calibration of health-related quality of life item banks: Plans for the Patient-Reported Outcomes Measurement Information System (PROMIS). *Medical Care*, 45(5), S22-S31.
- Robison, J., Wiles, R., Ellis-Hill, C., McPherson, K., Hyndman, D., & Ashburn, A. (2009). Resuming previously valued activities post-stroke: Who or what helps? *Disability & Rehabilitation*, 31(19), 1555-1566. <https://doi.org/10.1080/09638280802639327>
- Rochette, A., Tribble, D. S.-C., Desrosiers, J., Bravo, G., & Bourget, A. (2006). Adaptation and coping following a first stroke: A qualitative analysis of a phenomenological orientation. *International Journal of Rehabilitation Research*, 29(3), 247-249. <https://doi.org/10.1097/01.mrr.0000230051.24228.c8>

- Rowan, N., & Wulff, D. (2007). Using qualitative methods to inform scale development. *The Qualitative Report*, 12(3), 450-466.
- Ryan, K., Gannon-Slater, N., & Culbertson, M. J. (2012). Improving survey methods with cognitive interviews in small- and medium-scale evaluations. *American Journal of Evaluation*, 33(3), 414-430.
<https://doi.org/10.1177/1098214012441499>
- Sarre, S., Redlich, C., Tinker, A., Sadler, E., Bhalla, A., & McKevitt, C. (2013). A systematic review of qualitative studies on adjusting after stroke: Lessons for the study of resilience. *Disability and Rehabilitation*, 36(9), 716-726.
<https://doi.org/10.3109/09638288.2013.814724>
- Satink, T., Cup, E. H., Ilott, I., Prins, J., de Swart, B. J., & Nijhuis-van der Sanden, M. W. (2013). Patients' views on the impact of stroke on their roles and self: a thematic synthesis of qualitative studies. *Archives of Physical Medicine and Rehabilitation*, 94(6), 1171-1183. <https://doi.org/10.1016/j.apmr.2013.01.011>
- Schaeffer, N. C., & Presser, S. (2003). The science of asking questions. *Annual Review of Sociology*, 29(1), 65-88.
<https://doi.org/10.1146/annurev.soc.29.110702.110112>
- Sharma, N., Tridimas, A., & Fitzsimmons, P. R. (2014). A readability assessment of online stroke information. *Journal of Stroke and Cerebrovascular Diseases*, 23(6), 1362-1367. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2013.11.017>
- Shaw, L., Leyshon, R., & Liu, M. (2007). Validating the potential of the International Classification of Functioning, Disability and Health to identify barriers to and

- facilitators of consumer participation. *Canadian Journal of Occupational Therapy*, 74(3 Suppl), 255-266. <https://doi.org/10.1177/00084174070740S306>
- Smith, M. L., Sosa, E. T., Tisone, C. A., & Mckyer, E. L. J. (2011). Quality enhancement groups: A qualitative research method for survey instrument development. *Journal of Health Behavior and Public Health*, 1(1), 15-22.
- Smith, R. M. (2004). Detecting item bias with the Rasch model. In E. V. Smith & R. M. Smith (Eds.), *Introduction to Rasch measurement* (pp. 391-418). Maple Grove, MN: JAM Press.
- Stark, S. L., Edwards, D. F., Hollingsworth, H., & Gray, D. B. (2005). Validation of the Reintegration to Normal Living Index in a population of community-dwelling people with mobility limitations. *Archives of Physical Medicine and Rehabilitation*, 86(2), 344-345. <https://doi.org/10.1016/j.apmr.2004.03.020>
- Tellier, M., & Rochette, A. (2009). Falling through the cracks: A literature review to understand the reality of mild stroke survivors. *Topics in Stroke Rehabilitation*, 16(6), 454-462. <https://doi.org/10.1310/tsr1606-454>
- Tennant, A., & Conaghan, P. G. (2007). The Rasch measurement model in rheumatology: What is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis & Rheumatism*, 57(8), 1358-1362. <https://doi.org/10.1002/art.23108>
- Thorndike, R. M., & Thorndike-Christ, T. (2010). *Measurement and evaluation in psychology and education* (8th ed.). Boston, MA: Pearson.

- Tse, T., Douglas, J., Lentin, P., & Carey, L. (2013). Measuring participation after stroke: A review of frequently used tools. *Archives of Physical Medicine and Rehabilitation*, 94(1), 177-192. <https://doi.org/10.1016/j.apmr.2012.09.002>
- Velozo, C. A., Seel, R. T., Magasi, S., Heinemann, A. W., & Romero, S. (2012). Improving measurement methods in rehabilitation: core concepts and recommendations for scale development. *Archives of Physical Medicine and Rehabilitation*, 93(8, Supplement), S154-S163. <https://doi.org/10.1016/j.apmr.2012.06.001>
- White, J. H., Magin, P., Attia, J., Sturm, J., Carter, G., & Pollack, M. (2012). Trajectories of psychological distress after stroke. *The Annals of Family Medicine*, 10(5), 435-442. <https://doi.org/10.1370/afm.1374>
- Whiteneck, Bogner, J. A., & Heinemann, A. W. (2011). Advancing the measurement of participation. *Archives of Physical Medicine and Rehabilitation*, 92(4), 540-541.
- Whiteneck, G., & Dijkers, M. P. (2009). Difficult to measure constructs: Conceptual and methodological issues concerning participation and environmental factors. *Archives of Physical Medicine and Rehabilitation*, 90(11), S22-S35. <https://doi.org/10.1016/j.apmr.2009.06.009>
- Whiteneck, G., Harrison-Felix, C., Mellick, D., Brooks, C., Charlifue, S., & Gerhart, K. (2004). Quantifying environmental factors: A measure of physical, attitudinal, service, productivity, and policy barriers. *Archives of Physical Medicine & Rehabilitation*, 85(8), 1324-1335.
- Willis, G. B. (2005). *Cognitive interviewing: a tool for improving questionnaire design*. Thousand Oaks, CA: Sage Publications.

- Wilson, M. (2004). *Constructing measures: an item response modeling approach*. Mahwah, NJ: Lawrence Earlbaum Associates.
- Wilson, M. (2011). Some notes on the term: "Wright map." *Rasch Measurement Transactions*, 25(3), 1331.
- Wolf, T. J., Baum, C., & Connor, L. T. (2009). Changing face of stroke: Implications for occupational therapy practice. *The American Journal of Occupational Therapy*, 63(5), 621-625.
- Wolf, T. J., Baum, C. M., Lee, D., & Hammel, J. (2016). The development of the Improving Participation after Stroke Self-Management Program (IPASS): An exploratory randomized clinical study. *Topics in Stroke Rehabilitation*, 23(4), 284-292 <https://doi.org/10.1080/10749357.2016.1155278>
- Wolfe, E. W., & Smith, J., E. V. (2007). Instrument development tools and activities for measure validation using Rasch models: Part I—Instrument development tools. In E.V. Smith Jr. & R.M. Smith (Eds.), *Rasch measurement: Advanced and specialized applications* (pp. 202-242). Maple Grove, MN: JAM Press.
- Wood-Dauphinee, S. L., Opzoomer, M. A., Williams, J. I., & Spitzer, W. O. (1988). Assessment of global function: The Reintegration to Normal Living Index. *Archives of Physical Medicine and Rehabilitation*, 69(8), 583-590.
- Woodman, P., Riazi, A., Pereira, C., & Jones, F. (2014). Social participation post stroke: A meta-ethnographic review of the experiences and views of community-dwelling stroke survivors. *Disability and Rehabilitation*, 36(24), 2031-2043. <https://doi.org/10.3109/09638288.2014.887796>

World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva, Switzerland: World Health Organization.

VITA

NAME:	Danbi Lee
EDUCATION:	<p>B.O.T., Occupational Therapy, Yonsei University, Wonju, South Korea, 2005</p> <p>O.T.D., Occupational Therapy, University of Illinois at Chicago, Chicago, Illinois, 2009</p>
TEACHING EXPERIENCE	<p>Department of Occupational Therapy, University of Illinois at Chicago, Chicago, Illinois: Synthesis I and II for Occupational Therapy Students, 2009, 2011, 2014-2015</p> <p>Department of Occupational Therapy, University of Illinois at Chicago, Chicago, Illinois: Interventions for People with Dementia for Occupational Therapy Students, 2008-2015</p> <p>Department of Occupational Therapy, University of Illinois at Chicago, Chicago, Illinois: Working with Mothers with Disabilities for Occupational Therapy Students, 2014-2015</p>
HONORS	<p>ENGAGE-IL Summer Scholars Fellowship, HRSA Geriatrics Workforce Enhancement Program, University of Illinois at Chicago, Chicago, IL, 2016</p> <p>Dissertation Pilot Grant, Midwest Roybal Center Health Promotion and Translation, IL 2015</p> <p>Occupational Therapy Doctorate Research Scholarship, University of Illinois at Chicago, Chicago, IL, 2015</p> <p>Chancellor's Graduate Research Fellowship, University of Illinois at Chicago, Chicago, IL, 2013</p> <p>Provost's Award for Graduate Research, University of Illinois at Chicago, Chicago, IL, 2013</p> <p>Outstanding Poster Presentation Award, OT Summit of Scholars, 2013</p> <p>Doctorate of Occupational Therapy Achievement Award, University of Illinois at Chicago, Chicago, IL, 2010</p> <p>Lillian B. Torrance Scholarship, University of Illinois at Chicago, Chicago, IL, 2007</p>

PROFESSIONAL MEMBERSHIP	<p>The Illinois Occupational Therapy Association</p> <p>The American Occupational Therapy Association</p> <p>The Korean Association of Occupational Therapists</p>
ABSTRACTS	<p>Lee, D., Hammel, J., Baum, C., & Wolf, T. (2015). Improving participation after stroke: a self-management program for a healthy and active lifestyle after stroke. <i>Archives of Physical Medicine and Rehabilitation</i>, 96(12): e24.</p>
PUBLICATIONS	<p>Lee, D., Fogg, L., Hammel, J., Baum, C., & Wolf, T. (In press). Validation of the Participation Strategies Self-Efficacy Scale (PS-SES). <i>Disability and Rehabilitation</i>.</p> <p>Lee, D., Hammel, J., & Wilson, T. (2016). A community living management program for people with disabilities who have moved out of nursing homes: Pilot study. <i>Disability and Rehabilitation</i>, 38(8), 754-760.</p> <p>Gecht, M., Lee, D., Ehrlich-Jones, L., Bristow, M. (2016). Motivational interviewing: a tool to teach behavior change to third year medical students. <i>Family Medicine</i>, 48(2).</p> <p>Wolf, T., Baum, C., Lee, D., & Hammel, J. (2016). The development of the Improving Participation After Stroke Self-Management Program (IPASS): an exploratory randomized clinical study. <i>Topics in Stroke Rehabilitation</i>. DOI:10.1080/10749357.2016.1155278</p> <p>Hong I., Coker-Bolt, P., Anderson, K. R., Lee, D., & Velozo, C. A. (In Press). The relationship of physical activity to children who are overweight and obese: Findings from the 2012 NHANES National Youth Fitness Survey. <i>American Journal of Occupational Therapy</i></p> <p>Kielhofner, G. (2015). <i>Model of Human Occupation: theory and application</i> (S. Lee, E. Kim, D. Lee, & Y. Min, Trans.). Seoul, South Korea: Hanmi. (Original work published 2008)</p> <p>Hammel, J., & Lee, D. (2014). Aging and adults with intellectual and developmental disabilities: From health to participation. Haertl, K. (Ed.). <i>Adults with Intellectual and Developmental Disabilities: Strategies for Occupational Therapy</i>. Bethesda: AOTA Press.</p> <p>Hammel, J., Finlayson, M., & Lee, D. (2014). An organization-centered strategy: self-management: An evolving approach to maintain health, participation and wellbeing. In Christiansen, C. H., Baum, C. M., & J. Bass-Haugen. (Eds.). <i>Occupational Therapy: Performance, Participation, and Well-being</i>. (4th ed.). Thorofare, NJ: Slack Inc.</p>

PUBLICATIONS	<p>Hammel, J., Lee, D., Heffron, J., & Meskin, K. (In press). Self-management and self-determination. In Law, M., Baum, C., & Dunn, W. (Eds.). <i>Measuring Occupational Performance: Supporting Best Practice in Occupational Therapy</i>. Thorofare, NJ: Slack Inc.</p> <p>Lee, D., & Mahaffey, L. (In press). Community living and integration. In <i>Disability in American Life: An Encyclopedia of Concepts, Policies, and Controversies</i>. Santa Barbara, CA: ABC-CLIO</p>
--------------	---