

TITLE: Utilizing the “Experience Sampling Method” to Monitor Communicative Quality of Life during Treatment for a Single Subject with Chronic Aphasia

Objective: While research indicates that patients more than one-year post cerebral vascular accident may continue to benefit from communicative disorders (COMD) treatment (Robey et al., 1998), recent studies have begun to examine the efficacy of intensive treatment for this population (Hinkley & Carr, 2005; Hinkley & Craig, 1998; Hinkley et al., 2001). To determine treatment outcomes, investigators often assess life satisfaction along with cognitive and linguistic function (Cruice et al., 2003; Ross et al., 2006). Little exploration has been reported regarding the participant’s perceived quality of life during actual treatment administration. The Experience Sampling Method (ESM) is a technology utilized to measure variables such as variation in mood and/ or acceptance of condition in situations such as bipolar disorder, cancer or pain management. In this measure, participants responded on an ongoing basis throughout the day, across time or activities (Kubey & Larsen, 1996; Kubey et al., 1996; Scollon et al., 2003). The purpose of this study is to investigate the response of a single subject with chronic aphasia to an intensive treatment program utilizing ESM to compare the subject’s perceived communication comfort and well-being during daily treatment and other daily ancillary activities.

Participant and Methods: A 75 year old, college educated, Caucasian male who had sustained an ischemic event in the territorial distribution of the left middle cerebral artery 12 months earlier was investigated. This single participant participated in a 35 hour a week, 6 week, university based “Neuro Camp” for 6 adults with chronic brain damage. Communication focused activities included: individual treatment (5 hours), small group treatment (5 hrs), and large group treatment (2 hrs). Other weekly activities included: pantomime/improvisation (2 hrs), computer lab (2 3/4 hrs), music appreciation (2 hrs), wellness lecture (1 hr), psychological support (2 ¼ hrs), community integration (5 hrs), social lunch (5hrs), and either Tai Chi or watching funny videos (3hrs). Pre and post-testing with an assessment battery was conducted within one week prior and one week following the six week treatment to measure overall treatment outcomes. Additionally, in order to monitor any possible changes after discharge, post-post-testing was also performed 7 weeks following conclusion of post-testing. The assessment battery included: the ASHA Quality of Life Scale (ASHA QCLS), Spouse Quality of Life Scale (adapted from ASHA QLS), Communication Activities of Daily Living- 2nd Edition (CADL-2), the Aphasia Diagnostic Profile (ADP), and the Cognitive Linguistic Quick Test (CLQT) with the Physical Battery: the Berg Balance Scale (BBS), the Timed, Up and Go Test (TUG), and the Six Minute Walk Test (SMWT). Additionally, a B-A-A model was utilized to compare results of the Physical Battery following periods when Tai Chi was administered or withheld.

Pre-testing also verified that the subject had the necessary cognitive and reading function to participate in ESM. The first activity of the first day of Neuro Camp was ESM training by the investigator, a certified speech-language pathologist with master's clinicians providing individual cueing. At the beginning of the day and at the end of each activity, participants used a 5 point Likert scale to rate the following: happiness, fatigue, stress, and perceived communication function. At the end of the day, overall well-being was also assessed. PDAs were charged by the primary investigator each evening and data were periodically downloaded. Upon the completion of the study, data were analyzed by question in order to compare the mean difference in response to treatment with other ancillary activities.

Data Collection: During the first week, ESM responses were recorded on paper questionnaires using a 3 inch vertical line Likert scale with icons to reinforce responses. For example, the first question was "How happy do you feel right now?" A happy face was placed over the top choice "Really Happy". Descriptors, "Happy", "Okay", "Sad", and "Really Sad", corresponded with bars descending down the scale with an icon of an unhappy face below "Really Sad." Since the group adapted well to completing the questions upon request, a week later the group was re-trained to use individually assigned Palm, Tungsten PDAs. The identical questions were presented in the same order. Responses were presented vertically using check boxes (with PDA stylus). The ESM schedule remained consistent throughout the 6 week treatment program.

Results and Conclusions: While the primary focus of the study is the result of the ESM, it is worthwhile to briefly review the results of standardized testing. As provided in Table 1, participant performance in successive testing reflects overall gains following treatment for both the CLQT and the patient and spouse in Quality of Life. However, performance declined 7 weeks later at the post-post-testing, but, overall gains remained positive. Overall gains on the CADL-2 and ADP were variable at the post-testing period, but, were superior during the post-post-testing and remained positive overall. Although the subject falls within the range of Broca's aphasia on the ADP, speech intelligibility is his larger issue, compromised by both dysarthria and apraxic errors. It is suspected that cognitive/linguistic compensatory strategies (CLQT) generalized earlier. Qualitatively, at post-post, the respondents (patient and spouse) mentioned their disappointment that future intensive treatment was not an option which may have negatively impacted their Quality of Life score.

Physical results of the BBS and SMWT reflected overall gains across the study with the greatest gains occurring after the first 3 weeks of treatment in which he received a 3 hour a week Tai Chi program. This subject, previously an avid athlete, was highly motivated to regain independent ambulation and especially to play golf again. Therefore, his continual gains in function were not surprising, however, the marked increase following Tai Chi was notable.

Responses to the ESM questions concerning perceived communication, energy, happiness, stress, and overall well-being were sorted by the activity during which the data was gathered. The participant's mean responses across most sessions suggest that perception of communication responses were the most negative. Also, the standard deviation (S.D.) for perceived communication was the most stable. This result was not unexpected with the severity of the participant's communication difficulties. The participant's reporting of stress was consistently equal or second to communication in relatively negative responses across activities with a relatively stable S.D. Most surprising, however, is that the scores do not appear to reflect greater stress with increased communication demands, but, rather occurred during activities more prone to group conflict. Since the model included variation in severity and types of chronic brain damage, group programming was at times challenging due to wide cognitive variation and participant behavior. While this participant was one of the cognitively stronger, more tolerant patients, it appears that the impulsivity and non-compliance of others was bothersome to him. Perceived happiness, likewise, appears more related to more highly structured activities. The area of the most variable S.D. was energy which was not very surprising as this 75 year old, retired participant was involved in 7 hours of activities each day. Unfortunately, although the social lunch and watching funny videos were programmatically expected to provide a rejuvenative aspect, apparently they were relatively stressing.

In conclusion, it appears that ESM can be a beneficial adjunct to both the reporting of functional outcomes of treatment as well as for periodic program review/ modification. For instance, an area not examined in this study is the order of activity across the day/ week or comparison of the responses to activities across time. For participants with the cognitive, reading, and writing or vocal ability to answer the questions, the electronic ESM capability can lend a new efficient data collection and analysis option.