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Catherine A. Off

University of Montana - Missoula

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Patient Perspectives & Patient Reported Outcomes of an Intensive Comprehensive Aphasia Program

Catherine Off (PI)

Associate Professor

Department of Speech, Language, & Hearing Sciences

School of Speech, Language, Hearing & Occupational Sciences

College of Health Professions and Biomedical Sciences

University of Montana

BACKGROUND & SIGNIFICANCE

As health care continues to move in the direction of patient-centered care, researchers have begun to investigate the use of patient reported outcome measures (PROMS; Yorkston, 2015; deRiesthal & Ross, 2015). PROMs are designed to obtain the patient's perspective of their outcomes, thus complementing the traditionally administered psychometric (i.e., impairment-based) measures. PROMs also have the potential to better illustrate the impact that an acquired condition has on the patient's participation in life's roles, as recommended by the World Health Organization (WHO-ICF, 2010). Patient reported outcome measures are thought to be more sensitive and specific to therapeutic effects and may be more reflective of the impairment's influence on life participation than psychometric measures (Barrett, 2009/2010). These authentic "insider" perspectives have the potential to uncover the true impact of chronic impairments on quality of life, and to give a voice to people with acquired communication disorders such as aphasia. Patient perspectives and PROMs may reveal additional aspects of the recovery and intervention processes that should be measured to accurately document the improvements that are important to the patients themselves (Attard et al., 2015).

Approximately 655,000 people in the United States (US) survive a stroke each year (CDC, 2018) and approximately 2-4 million stroke survivors in the US suffer from aphasia, an impairment of language abilities that reduces the function of speaking, listening to spoken language, writing, and reading (AphasiaAccess, 2017). Approximately 180,000 Americans acquire aphasia each year (National Aphasia Association, 2018). Persons with aphasia (PWA) often experience limited communicative and social participation (Davidson et al, 2008), increased depression (Starkstein & Robinson, 1988), and reduced psychosocial well-being and quality of life (Code & Herrmann, 2003). Intensive comprehensive aphasia programs (ICAPs) are an emerging intensive, holistic health care model that has been developed to improve communication impairments as well as psychosocial well-being for PWA and their caregivers/support system (Babbitt, Worrall, & Cherney, 2013; 2015). ICAPs differ from traditional aphasia rehabilitation programs in that they target multiple speech, language, and cognition domains through a variety of evidence-based treatment approaches using high treatment intensity. ICAPs operate within a prescribed time frame (e.g., four weeks) with a cohort of PWAs and their families who enroll simultaneously (Rose, Cherney, & Worrall, 2013), thus providing a sense of community and numerous opportunities to generalize trained skills in natural, everyday social communication contexts. Intensive aphasia treatment is a preferred service delivery model over traditional, infrequent therapy, and has been shown to facilitate adaptive experience-dependent neuroplasticity and neuronal reorganization (Cramer et al., 2011; Kleim & Jones, 2008). Initial efficacy studies indicate positive patient outcomes across a variety of impairment-based and psychosocial domains as measured by psychometric assessment instruments (Rodriguez et al., 2013; Rose et al., 2013; Wenke et al., 2014).

AIMS

The purpose of this project was to explore patient perspectives and PROMs for stroke survivors with aphasia who participate in an intensive comprehensive aphasia program (ICAP) that was developed by the PI and is delivered at the University of Montana (Off, et al., 2015; 2017). Patient perspectives and PROMs were used to complement traditionally administered psychometric measures to document patient speech, language, cognition, and psychosocial outcomes following the ICAP. To date, no researchers have documented patient perspectives of their outcomes in the context of an ICAP.

METHODS

Study Design

A mixed-methods experiment was used to investigate patient perspectives of persons with aphasia (PWA) who participated in an ICAP that is based on the University of Montana campus. This ICAP provides four weeks of intervention, four days per week, for four and a half hours per day with pre- and post-intervention assessment the week before and after intervention, respectively. Outcomes include: (1) patient speech, language, and cognitive outcomes (i.e., psychometric measures); (2) patient reported outcome measures (PROMs) pertaining to communicative participation and psychosocial well-being/quality of life; and (3) patient perspectives and lived experiences, as documented by semi-structured interviews.

Participants

Participants included eight stroke survivors with aphasia enrolled in the University of Montana summer 2018 ICAP program. PWA ranged in age from 20-76 years of age.

Procedures

Once each participant was enrolled and consented to participate in the research, a graduate student researcher conducted two semi-structured interviews as follows: (1) the first interview took place during the four-week treatment period, and (2) the second interview took place during the week following treatment. Participants also completed patient-reported outcome measures (PROMs) to complement the qualitative data obtained from the interviews. PROMs and traditional psychometric measures were administered prior to and immediately following the ICAP.

Interviews. Participants were asked the same questions each time they were interviewed. Each participant received the written questions ahead of time in an aphasia-friendly/accessible format characterized by simplified syntax, increased font size, and an increased amount of white space on each page. Care was taken to ensure that the participants clearly understood the interview questions and were given every opportunity to respond using any modality of language. The interview questions sought to answer what the experience is like to go through the ICAP program when one is living with aphasia. These interviews allowed us the opportunity to explore the patient's lived experience in the context of our ICAP. The primary interview question asked was "tell me about your experience during the Intensive Comprehensive Aphasia Program"; the second question asked was "tell me about any changes in your aphasia, speech, language, cognition or psychosocial well-being you have noticed since beginning this program". Because the participants with aphasia necessarily have impaired receptive and expressive language, we provided interview questions in both verbal and written, aphasia-friendly form. Participants also used written language or alternative and augmentative communication devices (AAC) or other nonverbal strategies (i.e., gesture) to communicate their responses.

Patient-Reported Outcome Measures (PROMs). Participants completed three PROMs as follows: (1) the *Communicative Participation Item Bank* (Baylor et al., 2017); (2) the *Assessment of Living with Aphasia (ALA)*, (Simmons-Mackie, et al., 2014); and (3) the *Geriatric Depression Scale (GDS)*; (Sheikh & Yesavage, 1986). All PROMs were administered to the PWAs by the PI or other members of the research team to ensure that the PWA fully comprehended each item of each PROM and to accurately record their responses.

Data Collection & Analysis

The graduate student researcher conducted the interviews. The PI observed all interviews. Both the graduate student researcher and PI took field notes during the interviews. Immediately following the interviews, the PI and graduate student researcher debriefed to "discuss what they viewed as salient information from the interview as well as how to best describe or characterize this information," and to compare field notes for accuracy and coherence of information (Burns, Baylor, et al., 2015, p. 344). Interviews were audio-recorded and videotaped for accurate transcription of verbal and nonverbal responses (e.g., gestures, facial expressions, etc.) that are often used by people with aphasia to supplement their impaired spoken or written language. Interviews were transcribed verbatim. Nonverbal communication was noted in the transcripts in parentheses. Any written or typed responses was also recorded in the

transcripts. Once transcribed, the data was uploaded into NVivo (qualitative software) and organized for analysis. The graduate student researcher and two additional researchers (the PI and Dr. Baylor from the University of Washington) coded within and across the transcripts. A codebook was collaboratively developed during initial reviews of the transcripts. Once coded, a phenomenological method was applied to develop themes. Final stages of coding are currently in progress. PROMs were scored according to each measure's administration manual. PROM data will be entered, organized, and stored in Excel and analyzed for statistical significance using SPSS when appropriate. Additional procedures for relating the PROM data to the qualitative interview data will be conducted in collaboration with Dr. Baylor.

INITIAL/PRELIMINARY RESULTS

Data was collected during the summer 2018 ICAP. Eight stroke survivors with aphasia completed all PROMs. Five stroke survivors with aphasia participated in interviews. All interviews have been transcribed and checked for reliability across reviewers. The codebook has been developed and all interviews have been coded by the graduate student researcher and PI. Reliability has been checked with Dr. Baylor as the third coder. Initial themes that are emerging include: (1) experience with the ICAP and each of its components is generally positive, (2) participants noticed the impact of the ICAP on communication skills, and (3) relationships with people in the ICAP are important to stroke survivors with aphasia. Coding and description of themes will be completed by the end of October 2019. Mixed methods analyses will be used to relate the themes of the interviews to the data extracted from the PROMs.

DISSEMINATION OF FINDINGS

Anya Leyhe, graduate student researcher, will be presenting the qualitative findings in November 2019 in Orlando, Florida at the American Speech, Language, Hearing Association's National Convention. Her proposal was accepted as an oral seminar format. Dr. Baylor will be presenting with Anya. A portion of this project was submitted as Anya's master's thesis. The PI, Anya Leyhe, and Dr. Carolyn Baylor are currently finalizing analyses and interpretations and will be submitting the manuscript for publication in early 2020.