Title: "Like a Bird in a Cage": Construction and Negotiation of Identity in Institutionalized IWA

Abstract:

Individuals with aphasia (IWA) are a group of people that experience unique hardships when interacting in the social world. When considering IWA in nursing homes, communication appears to be even more complex and arduous. As a result of the culture inherent in nursing homes, IWA find themselves in a context that is not traditionally interactive in its own right and often become at risk for further exclusion from society. IWA in healthcare facilities have few opportunities for conversing about subjects that fall outside of the boundaries of institutionalized-type talk (e.g., Hersh, Godecke, Armstrong, Ciccone, & Bernhardt, 2014; Gordon, Ellis-Hill, & Ashburn, 2008). As a result, many defining characteristics of IWA have the potential to be forgotten or never fully realized (i.e., the person that he/she was prior to aphasia, opinions and values, desires for the future).

Little is known about how IWA perceive their role in institutionalized culture or how identity is constructed during day-to-day interactions in nursing homes. This presentation provides data on the patterns of behaviors of both IWA and their interactive partners during authentic routine interactions in nursing homes.

Four IWA were included in this study that were long-term residents of four different nursing homes in the southern United States (U.S.). These data were part of a more extensive qualitative study undertaken to discover the effects of aphasia on social access and inclusion in nursing homes. Several data collection procedures frequently used in qualitative research were employed in this investigation including participant observation, ethnographic interviews, and artifact analysis. Data analysis was performed in a cyclical manner so that initial patterns of behaviors that emerged from the data acted as foci of interest for future data gathering. During the data analysis process, interpretations made by the researcher were data driven and followed the general process of analysis and interpretation that is well established in all forms of qualitative inquiry (Creswell, 2007). Verification techniques including triangulation and lamination were employed to ensure authenticity of findings.

Data analysis revealed that all IWA experienced a profound loss of individuality in their daily lives that was a combined result of institutionalization and aphasia. Identity was constructed on both a foundational level and on an interpersonal level. There was an overarching infrastructural identity that the nursing home perpetuated and, within those constraints, IWA maintained an effort to construct and negotiate his/her own personal identity. Nursing homes often placed increased emphasis on group identity with little focus on the distinctive needs and desires of the IWA. Personal histories were often lost and staff members rarely knew anything about the IWA besides the most basic information. Residents that interacted with IWA exhibited patterns of behaviors that also contributed to dissociation and marginalization. IWA responses in these situations evidenced a loss of control, surrendering of voice, decreased confidence, and various

affective manifestations. A greater explanation of patterns of behaviors that contributed to identity negotiation will be described in detail with specific examples provided from the data. Various clinical and theoretical implications will be provided.

References:

Creswell, J. W. (2007). *Qualitative enquiry and research design: Choosing among five approaches (2nd ed.).* Thousand Oaks, CA: Sage.

Gordon, C., Ellis‐Hill, C., & Ashburn, A. (2009). The use of conversational analysis: nurse–patient interaction in communication disability after stroke. *Journal of advanced nursing, 65*(3), 544-553.

Hersh, D., Godecke, E., Armstrong, E., Ciccone, N., & Bernhardt, J. (2014). "Ward talk": Nurses' interaction with people with and without aphasia in the very early period poststroke. *Aphasiology,* 1-20. doi:10.1080/02687038.2014.933520