

IMPROVING COMMUNICATION FOR PERSONS WITH DEMENTIA

Sara K. Mamo^{1,2}, Samantha J. Mayhew⁴, Matthew McNabney¹, Esther S. Oh¹, and Frank R. Lin^{1,2,3}

¹Johns Hopkins School of Medicine, ²Johns Hopkins Center on Aging and Health,

³Johns Hopkins Bloomberg School of Public Health, ⁴University of Cincinnati College of Medicine

1 Introduction

Older adults with hearing loss and dementia may be particularly at risk for further cognitive and functional decline due to the combined effects of hearing loss and dementia on communication and social engagement. Further, the presence of hearing loss can exacerbate dementia symptoms, making the disease stage appear more severe than the person's true cognitive function. Importantly, there is evidence that treating hearing loss can reduce dementia-related problem behaviors [1, 2].

The purpose of this project is to provide basic hearing intervention services in a group care environment to improve access to hearing loss treatment for older adults with dementia and their families. By integrating services into an interdisciplinary, comprehensive health program, this project aims to improve communication for at risk adults attending a Day Health Center (DHC) for social engagement opportunities.

During Phase I of developing an affordable and accessible group care hearing intervention, a series of observations and focus groups were undertaken to assess the social environment at the DHC. Using exploratory qualitative methods, findings from Phase I will inform the development of staff training and small group therapy sessions to support communication for individuals with age-related hearing loss and dementia.

2 Methods

2.1 Participants

The participants in this research project include employees at the Johns Hopkins ElderPlus Program of All-inclusive Care for the Elderly (PACE; n=13) and PACE participants (n=5) who were selected in partnership with the PACE recreation and rehabilitation therapists as well as members of the medical team.

2.2 Direct observation

Group activity

Over a two-week period, activities in the DHC were observed and field notes were recorded by two researchers (SKM and SJM). Observations were completed in 2-hr blocks and sampled throughout the entire day of services.

smamo1@jhmi.edu

mayhewsj@mail.uc.edu; mmenabne@jhmi.edu

coh9@jhmi.edu; flin1@jhmi.edu

The researchers collected field notes together for the first two sessions in order to compare field notes and develop a similar system, including rich description of communication interactions. Through an iterative process, a codebook was developed for coding the field notes. The coded field notes were then analyzed for themes, with a particular interest in communication between staff and participants as well as between participants.

Individual activity

Behavioral coding was undertaken with five target individuals at the DHC. The individual participants were invited to participate based on having hearing loss and cognitive impairment. The invited individuals were chosen due to having low activity levels at the DHC per reports by the recreation therapy staff.

Based on pilot observations, a coding system was developed through an iterative process to capture frequency counts of communication-related behaviors. All coding sessions were completed by at least two researchers and compared after each session to improve the fidelity of the coding system.

2.3 Staff focus groups

Three focus groups (n=13) were held as an opportunity to learn about the staff's perception of hearing loss and communication challenges with PACE participants. Topics in the focus group guide included communication challenges and repair strategies, training interests, and amplification devices. The audio recordings were transcribed and a research team read and discussed the text in order to develop codes. The coded passages in the transcripts were compared and discussed to improve the reliability of the coded passages.

3 Results

3.1 Communication environment

Overall impressions of communication in the DHC included that it was a friendly and interactive environment that was, at times, too loud for clear communication. Through analysis of the coded transcripts, a pattern emerged such that the staff-participant interactions fell into categories that mapped onto common communication strategies. A brief sample of categories are shown in Table 1.

Table 1: Observations at the DHC were coded and grouped into examples of communication strategies.

| Strategy | Successful Example | Unsuccessful Example |
|---------------------------|---|---|
| Get Face-to-Face | <i>[Participant] is calling out about things she needs. Two staff members talk to her right next to her ear...</i> | <i>The noise level began to increase ...Participants & staff were trying to talk...across the room. A lot of 'huhs' were heard.</i> |
| Use Nonverbal Cues | <i>A staff member tells 3 participants to close their eyes...The staff member then repeats herself, closes her own eyes...points to her eyes.</i> | <i>A staff member pushes the wheel chair directly behind the participant and tells him to sit down...He pulls the participant into his wheel chair from behind by the hips.</i> |

3.3 Behavioral characteristics of individual participants

Between individual participants, the levels of behavioral responses varied, but within subjects, steady behavioral responses were seen across 2-weeks of baseline recording. An example of responses for one individual is shown in Figure 1. This figure shows the frequency count of the 'look' behavior, which was operationally defined as orienting to a person in the environment in a purposeful way (e.g., a person walking past, saying hello, giving instructions).

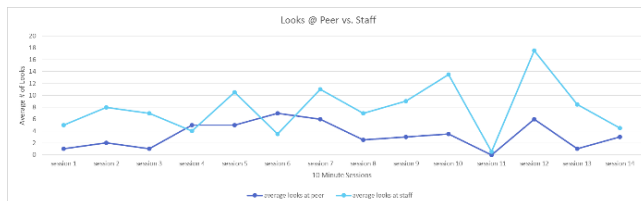


Figure 1: 'Look' responses for one individual at 13 observation blocks. Shown are number of 'looks' at peers (blue) and staff (teal). Each observation block is a 10 minute observation episode collected across multiple days and activity opportunities. Response range = 0-18.

3.2 Staff perceptions and communication strategies

Analysis of the coded transcripts from the staff focus groups revealed several specific training and communication support opportunities. Common compensatory strategies (e.g., getting closer to the person or taking the person to a quiet place) that the staff developed through experience were discussed across the groups as well as a desire to improve knowledge regarding signs of hearing loss, degrees

of hearing loss and its impact on communication, and how to use over-the-counter amplification to improve hearing, especially during medical appointments.

4 Discussion and conclusion

The purpose of this exploratory data set is to build an effective multicomponent intervention that supports communication in a group care environment for individuals with hearing loss and dementia. Direct observation at the DHC revealed opportunities to incorporate real-life scenarios into a staff training focused on communication strategies. Moreover, the observational coding of individual participants provides the groundwork for using behavior in the activity hall as the primary outcome of a future intervention investigation. Finally, the focus groups provided insight into the barriers experienced by staff in terms of communicating with some participants and identified topics that would be welcomed with regards to training.

Nearly all persons with dementia experience distressing problem behaviors at some point in the disease progression [3, 4]. Such behavioral symptoms are often treated with psychotropic medications that can have negative side effects. Developing and implementing an affordable and accessible intervention that improves the listening environment, staff awareness, and use of amplification devices among individuals with dementia in group care settings provides a low-risk, low-cost, non-pharmacological treatment that may improve social engagement and reduce dementia-related behavioral symptoms.

Acknowledgments

This work was supported by AAA (SKM), AFAR and JHSOM Div of Geriatrics and Gerontology (SJM), NIH/NIDCD K23DC011279 (FRL), NIH/NIA K23AG043504 (ESO), the Roberts Fund (ESO), and the Eleanor Schwartz Charitable Foundation (FRL).

References

- [1] Allen, N.H., et al., *The effects of improving hearing in dementia*. Age Ageing, 2003. **32**(2): p. 189-193.
- [2] Palmer, C.V., et al., *Reduction in caregiver-identified problem behaviors in patients with Alzheimer disease post-hearing-aid fitting*. J.Speech Lang Hear.Res., 1999. **42**(2): p. 312-328.
- [3] Lyketsos, C.G., et al., *Neuropsychiatric symptoms in Alzheimer's disease*. Alzheimers Dement, 2011. **7**(5): p. 532-9.
- [4] Kales, H.C., L.N. Gitlin, and C.G. Lyketsos, *Assessment and management of behavioral and psychological symptoms of dementia*. BMJ, 2015. **350**: p. h369.