

Scientific Research Publishing

ISSN Online: 2169-0502 ISSN Print: 2169-0499

VoiceMyChoice™: Facilitating Understanding of Preferences of Residents with Dementia

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How to cite this paper: Bourgeois, M.S., Camp, C.J., Antenucci, V. and Fox, K. (2016) VoiceMyChoice™: Facilitating Understanding of Preferences of Residents with Dementia. Advances in Aging Research, 5, 131-141

http://dx.doi.org/10.4236/aar.2016.56013

Received: September 16, 2016 Accepted: October 8, 2016 Published: October 11, 2016

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Abstract

The purpose of this study was to develop and evaluate the effects of visual materials (labeled pictures and a preference sorting template) on the ability to increase the convergence (agreement) of responses by persons with dementia and their nursing assistants on a Preference Assessment Questionnaire that contained 25 items related to Quality of Life (QoL). A total of 33 nursing assistants participated; 54% were native English speakers and 46% were non-native English speakers. Thirty-seven residents with dementia were randomly assigned to either the treatment condition, a 10-min preference card sorting task (VoiceMyChoice™; VMC) which reflected the items and content of the Preference Assessment Questionnaire, or a control condition consisting of a 10-min card matching activity using the materials from VMC. Before and after the treatment or the control session, residents and their assigned NA were administered the Preference Assessment Questionnaire; one week later, these procedures were repeated to assess consistency in responding and improved convergence between dyad members' responses over time. Results revealed that convergence scores between members of NA-Resident dyads increased significantly after the use of VMC for both the English and non-native English dyads, but not in the control condition. VMC has the potential to enable persons with dementia to communicate personal choices and for their caregivers of various linguistic and/or cultural backgrounds to understand them better.

Keywords

Dementia, Quality of Life, Long-Term Care, Visual Stimuli, Choice, Nursing Homes

1. Introduction

Communication impairments that worsen with advancing dementia create challenges

DOI: 10.4236/aar.2016.56013 October 11, 2016

for caregivers to meet the needs of persons with dementia. The hallmark symptom of dementia, memory deficit, limits the retrieval of vocabulary for the expression of wants, needs, preferences and choices to professional and family caregivers [1]. This is especially true for persons with more advanced dementia, such as those seen in long-term care communities. The concept of person-centered care (PCC), driving much of the efforts for quality improvement in dementia care, is predicated on the ability of persons providing care to know and understand the desires of persons with dementia [2]-[4]. A challenge exists for PCC in situations in which the person with dementia is unable to express verbally their preferences or choices. This, in turn, can have a critical and detrimental impact on the Quality of Life (QoL) of the person with dementia [5].

In addition, many primary care providers for persons with dementia in long-term care residential settings are not native English speakers. As a result, this poses an additional barrier to the ability of persons with dementia to express wants, needs, preferences and choices that will be understood well by caregivers for whom English is not their native language [6]. Finding the means to remedy this situation, therefore, is an important and immediately pressing issue for PCC to be realized for persons with dementia.

Bourgeois *et al.* [7] explored a variety of techniques for improving the understanding of verbal interactions between NAs and residents with dementia. They found that after a single 10-minute conversation about quality of life topics supported by written cue cards (augmented verbal procedure), residents' and nurse aides' ratings demonstrated greater agreement on quality of life indicators as measured by the Dementia Quality of Life scale (DQoL) [8] compared to their pre-test ratings. In a follow-up study, Bourgeois, Camp, & Zeisel [6] [9] tested two procedures delivered by nursing staff for eliciting opinions about quality of life indicators from long-term care residents with dementia. These involved: 1) a verbal enhanced condition consisting of giving printed questions to NAs to guide verbal discussion of QoL topics; and 2) a category sorting activity in which visual cues (labeled photos and a preference template indicating amount of preference for items/topics represented in the photos) were used to elicit discussion between NA-resident with dementia dyads.

During coding of the experimental sessions' videotapes, it was observed that some residents did not appear to understand the instructions and questions posed to them by their NA during their interactions. Upon further review of the sessions it became apparent that some interactions reflected repetitions of instructions, repeated questioning by the resident, and very little actual information transfer. The NAs in these sessions were observed to speak in heavily accented dialects, mostly other languages (e.g., Swahili, Haitian Creole). A total of 19 of 60 NAs were determined to be non-native English speakers. Data then were analyzed using the additional factor of language matched (NA and resident were native English speakers) and language mismatched (NA was a non-native English speaker and resident was a native English speaker).

Residents with dementia were able to discuss more topics on average in the category sorting condition than in the verbal enhanced condition both with language matched NAs (25 topics vs. 12, respectively) and with language mismatched NAs (16 topics vs.

11, respectively). This finding suggests that visual materials have the potential to improve the interactions between residents with dementia and language mismatched nursing aides, particularly with regard to discussing quality of life topics and food and activity preferences, and possibly emotions, pain ratings, advance directives, and end of life choices. There were no significant effects, however, on the congruence of resident and NA DQoL ratings for either experimental condition or language condition. This finding suggests that the DQoL may be too distal a measure to capture the potential effects of improved communication between resident and NA.

The purpose of the current study was to further explore the effects of visually based category-sorting materials on the interactions of NAs and residents with dementia on preference and choice determination. The visual materials were expanded to create VoiceMyChoice™ (VMC). VMC materials involved a category-sorting task similar to that used in the previous study, except that the number of items designed to elicit preferences increased and a set of items designed to elicit presence or absence of pain in different parts of the body was added. It was predicted that the observation of the behavior of residents during category sorting would enable NAs to better understand their residents' preferences and feelings. This would be measured by comparing NAs' proxy ratings of residents' responses with actual responses of residents on a Preference Assessment Questionnaire and determining the degree of convergence (or agreement) between their scores. This questionnaire would be developed to assess quality of life indicators that were more proximal to the items used in the experimental conditions than the DQoL indicators.

We further predicted that this approach would be useful in assisting NAs who were not native English speakers to better understand the preferences and feelings of English speaking residents in their care. The convergence scores of nonnative English speaking NAs and their residents in the VMC condition were expected to improve after one exposure to the VMC condition, and to show further improvements after the second administration of the VMC condition, in comparison to the control dyads whose convergence scores were not expected to change as a function of spending time together playing a card game.

Finally, the procedures were repeated one week later to determine the consistency of residents' responses over time. It is important to document that residents with dementia have reliable and consistent opinions about their preferences, in spite of their known expressive language deficits and as their dementia progresses.

2. Methods

2.1. Participants

Participants were recruited from two long-term care facilities in the Greater Cleveland, Ohio area and one long-term care facility in Columbus, Ohio. The sample consisted of both assisted living and skilled nursing care residents. The research team met with the facility administration to outline the study inclusion criteria and then sent a targeted mailing to the families of residents that explained the study in detail. Resident enrollment criteria included: documented dementia diagnosis, between the ages of 65 - 85,

and passing scores on functional vision, hearing, communication, and reading screenings. Exclusion criteria include: documented neurological or psychiatric condition that would impede communication (e.g., aphasia, psychosis, tardive dyskinesia), blind, deaf, does not speak English, or scores higher than 24 on the Mini-Mental Status Exam (MMSE; Folstein, Folstein, & McHugh, 1975)). When the research team received a signed consent form from the family or guardian, the resident was screened using the instrumentation described below. Residents who passed the screening were then randomly assigned to either the VMC or the Control condition. A nursing assistant regularly assigned to the resident was identified and research staff met with him/her to explain the study and obtain consent to participate. At all but one of the facilities the nurse assistants participated in the VMC activity during regular working hours. One facility insisted that the nurse assistants complete the activity on their own time. These nurse assistants worked with the residents either before or after their shift and were compensated for their time.

2.2. Residents

A total of 37 residents with dementia were recruited for the study and completed all four assessments, (along with their NA dyad members). Their mean MMSE score was 15 (range = 7 - 24); 78% were female, 97% were Caucasian, and 3% were African American; their mean age was 86 years (range = 67 - 96). All were native English speakers and passed the screening procedures.

2.3. Nursing Assistants (NAs)

A total of 33 nursing assistants took part in the study (a small number of NAs worked with two resident participants). Their mean age was 42 years (range 23 - 65); 97% were female and had worked as a nursing assistant for an average of 13 years (range 1 - 30) and at the facility for an average of 8 years (range 1 - 27). Native English speaking aides accounted for 54% (N = 20) of the sample and the non-native English speaking aides (N = 17) listed the following as their native languages: Jamaican, Ghanaian, Spanish, Philippine, Ukrainian, Tagalog, Visaya, Twi, Italian, French, Yoruba, and Haitian.

2.4. Screening Procedures

Resident screening measures consisted of a vision screen, hearing screen, communication screen [10] to determine functional abilities sufficient for participating in the subsequent interview procedures. This was followed by the MMSE [11] and the WRAT 4 [12] to screen for reading ability at the word level.

There were no screening measures developed for the nurse assistants; a willingness to participate and a signed informed consent document were the only requirements, along with the ability to read and speak English.

2.5. Materials

The VMC materials were developed by having five project members select 10 iconic

pictures from an array of pictures on Google Images for each of five categories representing areas that residents might possibly have choices offered to them from an array of pictures on Google™ Images. Categories included food, activities, daily living, socializing/communication, and pain. An analysis of the five researchers' selections was then compiled and the five most frequently chosen pictures in each category across the five researchers were selected for the measure. The research team decided to limit the number of items on the measure to 25 to minimize fatigue related to answering the questions. The size of the cards (3 × 5 inches) and the text (42-point type size) on the cards was chosen based on previous experience with residents' reading similar materials in other studies. The sorting template included three 3 × 5 inch boxes that were labeled "Always," "Sometimes," and "Never" for activity preferences and for presence or absence of pain.

The Card Sorting Activity for the Control condition consisted of two copies of each of the VMC™ cards; to begin, 12 cards (6 sets of matching cards) were placed face down on the table in front of the resident. NAs engaged the resident in a matching game, taking turns to uncover two cards at a time until all cards had been matched. At that point, 12 new cards were used from the VMC cards. This continued until 10 minutes had elapsed.

2.6. Dependent Measure

A Preference Assessment Questionnaire (PAQ) was created for use as the primary outcome measure. As shown in **Appendix 1**, this measure contained five domains (food, activities, daily living, socializing, and pain). Within each of the five domains there were five items listed, and each item was associated with three possible response choices, which were scored as: Always (2), Sometimes (1), and Never (0). This measure reflected the items and content of VMC.

The PAQ was administered separately by researchers, and concurrently, to each member of resident-NA dyads on four occasions. For the NAs on each of these occasions, they were handed a form with the 25 items printed in English along with the rating choices (Always; Sometimes; Never) for each item. For residents on each of these occasions, a printed version (42-point type size) of the rating choices was placed in front of the residents and each item was read verbally to the residents, who then indicated which rating reflected their opinion of the item.

For each occasion, a Convergence Score was created by taking the absolute value of the difference between the resident's and NA's responses on each item of the Preference Assessment Questionnaire, and then adding these values to create a Convergence Score. For example, if a resident responded that Bingo was never liked (a score of 0) and the resident's NA thought that the resident always liked Bingo (a score of 2) then the Convergence Score for this NA-resident dyad would be 2 (absolute value of [0 - 2]) for this item. This total Convergence Score thus could range from 0 to 50. Lower total Convergence Scores reflect greater overall convergence between members of a dyad.

2.7. Procedures

When residents passed the screening procedures and their NA consented to participate, research staff administered the Preference Assessment Questionnaire (Pretest 1) to both members of the dyad as described previously. Research staff asked residents to verbally indicate how often they enjoyed or experienced each of the 5 items in the 5 categories; NAs were asked to indicate how often they thought their resident enjoyed or experienced each of the same 25 items. Next, the experimental group NAs prompted their resident to sort labeled VMC™ picture cue cards into rating categories for up to 10 minutes; Control group NAs engaged their resident in the card matching activity for 10 minutes. The Preference Assessment Questionnaire was then re-administered to dyad members separately (Posttest 1). Thus, data were gathered for Pretest 1 and Posttest 1 immediately before and after either the NAs presented VMC or control procedures to their residents.

Each dyad repeated these same procedures after 7 days to examine the consistency of expressed preferences in each condition, and whether convergence between NAs and residents in dyads increased over time in the VMC condition (Pretest 2 and Posttest 2).

2.8. Design

A within-subjects design, with two between-subject factors of Treatment (VMC vs. Control) and Language (English vs. Non-English as native language), was used across four assessment occasions to assess resident preferences on the Preference Assessment Questionnaire. Thus, there was a 2-level Time factor, involving Pretest vs. Posttest (measures taken before and after the administration of either the VMC or control conditions) and a 2-level Week factor (data gathered in Week 1 or in Week 2). Twenty NA-Resident dyads involved NAs whose native language was English, and 17 dyads involved NAs who were non-native English speakers. For the 20 native English-speaking dyads, 10 were in the VMC treatment condition and 10 in the control condition. For the 17 non-native English-speaking dyads, 10 were in the VMC treatment condition and 7 in the control condition.

2.9. Treatment Fidelity Measures

Conversations between nurse assistants and residents were audio recorded during the application of VoiceMyChoice™ to ensure that all of the items of were provided appropriately during treatment sessions. Similarly, conversations were recorded between dyads during the control condition to ensure that the NAs were all following the protocol procedures. Both the nurse assistants and residents were given the opportunity to opt out and not have the session recorded. While only three residents declined to have their sessions recorded, 16 of the 33 nurse assistants would not allow us to record their sessions. To further insure that the protocol was being followed research staff observed from a distance all sessions and made corrective recommendations if the NA was not following the protocol.

3. Results

3.1. Convergence between NA-Resident Dyads on the PAQ

Means and standard deviations of total convergence scores, as described earlier, are shown in **Table 1**. Results of the 2 (Treatment: VMC vs Control) × 2 (NA Native Language: English vs non-English) × 2 (Time: Pretest vs Posttest) × 2 (Week: Week 1 vs Week 2) Analysis of Variance (ANOVA) revealed significant effects for Treatment, $[\underline{F}(1,33)=6.34,\, p<0.02]$, as well as Treatment × Time $[\underline{F}(1,33)=6.53,\, p<0.02]$, and Treatment × Week $[F(1,33)=12.54,\, p<0.001]$. No significant effects were detected for NA Native Language. Significant within-subjects effects included those for Week $[\underline{F}(1,33)=25.81,\, p<0.001]$; and Week × Time $[\underline{F}(1,33)=4.86,\, p<0.03]$.

These results, combined with an examination of the means associated with these outcomes, lead to the following explanations. Overall, NAs using VMC generated scores that were more convergent with those of their resident dyad members than NAs in the control condition. Convergence levels in the control condition remained stable over time. Convergence levels in the VMC condition improved from Pretest to Posttest in both Week 1 and in Week 2, though the largest improvement occurred after the first use of VMC. Effects of VMC were similar for both native English speaking NAs and non-native English speaking NAs.

3.2. Consistency in Residents' PAQ Scores

For conclusions regarding convergence between resident-NA dyads to be valid regarding PAQ scores, it was necessary to demonstrate that residents' PAQ scores were consistent and reliable. We approached this issue in a number of ways. First, we examined residents' overall PAQ scores for all four occasions of testing, broken down by NAs' native language and experimental condition. This resulted in an analysis using the 2-level between-groups factors of NAs' Native Language (English vs non-English) and Experimental Condition (VMC vs Control), along with a 4-level within-subjects factor of Time of Testing (Pretest 1, Posttest 1, Prerest 2, and Posttest 2). A Multivariate Analysis of Variance approach to repeated measures was used to compare these four times of measurement based on linearly independent pairwise comparisons (using Greenhouse-Geisser adjustment to degrees of freedom) among the estimated marginal means along with a test of the main effects of Experimental Condition, of NA's Native Language, and the interactions among these factors. None of these factors were significant. We then combined all residents into a single group, and the resulting analysis also resulted in a nonsignificant Time of Testing effect, F(3,34) = 1.79, p > 0.15, and no Bonferroni pairwise comparisons between means were significant. Thus, overall PAQ scores of residents remained stable over time, and were not significantly different in either NA language group nor in the experimental conditions. These means are shown in Table 2 (N = 37). In addition, correlations at Week 1 and Week 2 between pretest and posttest scores across all 37 residents were strong and significant, $\underline{r} = 0.8$, p < 0.001, and $\underline{r} = 0.8$, p < 0.001, respectively. Thus, residents' overall PAQ scores were consistent and reliable.

Table 1. Mean (and S.D.) convergence scores by treatment, NA native language, and time of test on the preference assessment questionnaire*.

Treatment	NA Native Language	Week 1		Week 2		
		Pretest 1	Posttest 1	Pretest 2	Posttest 2	
VIMC	English	17.3 (5.4)	9.1 (3.0)	12.4 (4.7)	10.4 (3.5)	
VMC	Non-English	17.7 (3.0)	13.6 (3.9)	13.9 (3.8)	10.2 (3.2)	
0 1	English	15.8 (3.5)	14.1 (4.1)	16.5 (5.3)	15.7 (3.8)	
Control	Non-English	15.7 (4.2)	14.9 (3.3)	15.0 (3.8)	15.1 (2.5)	

^{*}Lower scores = better convergence between dyad members.

Table 2. Mean (and S.D.) Preference assessment questionnaire scores for residents.

	Pretest 1	Posttest 2	Pretest 1	Posttest 2
Total	26.2 (5.4)	27.1 (5.3)	28.4 (5.9)	28.3 (5.6)

We also examined whether, for residents, consistency in PAQ responses was stable across individual PAQ items and across time, and whether consistency in PAQ scores was related to mental status. To assess this, for each item of the PAQ, we took the difference between the response to the item at pretest and at posttest, then took the absolute value of that difference, and summed all of these absolute values across the 25 items of the PAQ. We did this separately for Week 1 and for Week 2 scores. These summed scores represented total overall consistency in responding by each resident for the PAQ. The means (and standard deviations) for these residents' consistency scores were M = 8.5 (3.6) for Week 1 and M = 8.1 (3.1) for Week 2. A paired t-test comparison of these scores was not significant. These consistency scores then were correlated with MMSE scores for Week 1 and again for Week 2. No significant correlations were obtained, signifying that residents' responses were consistent across items and across time, and that mental status was not related to residents' consistency in responding to PAQ items.

4. Discussion

These results demonstrated that the use of VMC could significantly improve NAs' understanding of preferences of long-term care residents with dementia for both English speaking and non-native English speaking NAs. To the extent that concepts such as PCC emphasize the need to honor the individual's preferences, VMC appears to be a quick and easy tool for enabling residents to communicate personal choices. It especially may be useful in situations where caregivers come from different linguistic and/or cultural backgrounds than the persons with dementia they work within their daily routines.

These results are consistent with Bourgeois *et al.* [7], who showed improved congruence between NAs and residents on the DQoL after an enhanced verbal condition, and with Bourgeois, Camp, and Zeisel [9], who demonstrated improved conversational interactions when using visual stimuli, but not with enhanced verbal stimuli, for both na-

tive and nonnative English speaking NAs. However, results of the current study are different than those of Bourgeois, Camp, & Zeisel [9], who did not show greater congruence on the DQoL after either verbal or visual treatment conditions; in this study the VMC treatment condition did lead to greater convergence on the PAQ than the control condition. This suggests that the choice of a QoL measure that is better aligned with the treatment condition has greater potential to measure the effects of treatment. This study also showed that improvements in convergence are possible with additional exposure to the VMC treatment condition, suggesting that facilities that want to address the PCC needs of their residents with dementia should plan time for NAs and residents to converse about QoL topics using visual supports.

While the pattern of improved convergence from initial pretest to final posttest appeared somewhat different for the native English speaking NAs versus the non-native English speaking NAs, and the pattern of improvement for non-native English speakers matched those that we hypothesized, these results did not reach statistical significance. What is interesting is that in the VMC treatment condition, initial levels of convergence at initial pretest and the improved levels of convergence at the final posttest were relatively equivalent for both groups of NAs. Thus, VMC seems to be beneficial in producing understanding on resident's preferences and situations for a wide variety of NA's regarding their native languages. Perhaps most importantly, these results were achieved with a small amount of time commitment by NAs and were achieved very quickly.

There are interesting implications for further development of this approach, such as expanding the options for where pain might be occurring, types of discomfort other than pain (e.g., afraid - not afraid; nervous - not nervous; boring - not boring;), other types of preferences (e.g., now - not now; want - do not want); and other types of areas for communicating preferences, such as end of life wishes. In addition, other populations besides those with dementia might benefit from the use of this tool, such as those with expressive aphasia, traumatic brain injury, those recovering from a CVA, etc.

Ultimately, of course, to be useful, a tool such as VMC must be incorporated into job routines, supported by supervisory staff and administrators, and the preferences of residents must be both included in plans of care and honored. Most persons with experience in geriatrics and gerontology have seen living wills and other requests of older adults being disregarded, even when documented and placed in plans of care or medical charts. Thus, use of tools such as VMC must be accompanied by a commitment to implement the values of PCC [2]-[4] to ensure that individuals' wishes and preferences are not ignored. This is especially relevant when the individuals have dementia.

Acknowledgements

Thanks to Veronica Rose, Emily Reifsteck, Caitlin Stewart, Diana Chang, Jeanette Benigas, and Evan Shelton for data collection and data management.

Conflict of Interest

VoiceMyChoice™ was developed through an SBIR grant to the Center for Applied Re-

search in Dementia. The purpose of an SBIR grant is to create evidence-based interventions and products that will be taken to market.

Funding

This work was supported by the National Institute of Aging [R43AG043188-01 to C.C (PI).].

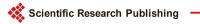
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Appendix 1: Preference Assessment Questionnaire Form

VoiceMyChoice™ Preference Assessment Form

Name:	Date: _		·	PRE	POST
		Please C	Circle One		
1. Food:					
a. Roasted chicken		always	sometime	s r	never
b. Pancakes		always	sometime	s r	never
c. Apple pie		always	sometime	s r	never
d. Soup and crackers		always	sometime	s r	never
e. Bananas		always	sometime	s r	never
2. Activities:					
a. Bingo		always	sometime	s r	never
b. Reading		always	sometime	s r	never
c. Gardening		always	sometime	s r	never
d. Keeping pets		always	sometime	s r	never
e. Word games		always	sometime	s r	never
3. Daily Living:					
a. Taking a shower		always	sometime	s r	never
b. Exercising		always	sometime	s r	never
c. Napping		always	sometime	s r	never
d. Eating meals		always	sometime	s r	never
e. Going for walks		always	sometime	s r	never
4. Socializing/Communicati	on:				
a. Talking on the phone		always	sometime	s r	never
b. Talking with residents		always	sometime	s r	never
c. Family visits		always	sometime	s r	never
d. Holding hands		always	sometime	s r	never
e. Going to church/religious		always	sometime	s r	never
5. Pain:					
a. Headache		always	sometime	s r	never
b. Arthritis/ joint pain		always	sometime	s r	never
c. Stomach ache		always	sometime	s r	never
d. Toothache		always	sometime	s r	never
e. Chest pain		always	sometime	s r	never



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