Working Together to Learn New Oral Hygiene Techniques: Pilot of a Carepartner-assisted Intervention for Persons with Cognitive Impairment

Ruth A. Anderson, RN, PhD, FAAN,

University of North Carolina Chapel Hill School of Nursing, 2007 Carrington Hall CB#7460, Chapel Hill, NC 27599, rutha@email.unc.edu

Jing Wang,

Duke University School of Nursing, jing.wang@duke.edu

Brenda L. Plassman, PhD,

Duke University School of Medicine, Department of Psychiatry, brenda.plassman@duke.edu

Kathleen Nye,

Duke University School of Medicine, Kathleen.nye@duke.edu

Melanie Bunn,

Duke University School of Nursing, Melanie.bunn@yahoo.com

Patricia A. Poole,

University of North Carolina Chapel Hill, School of Dentistry, Patricia_Poole@unc.edu

Connor Drake,

University of North Carolina Chapel Hill, Gillings School of Global Public Health, Department of Health Policy and Management, cddrake@live.unc.edu

Hanzhang Xu,

Duke University School of Nursing, hanzhang.xu@duke.edu

Zhao Ni, and

Duke University School of Nursing, Zhao.ni@duke.edu

Bei Wu, PhD

New York University Rory Meyers College of Nursing and NYU Aging Incubator, Bei.wu@nyu.edu

Abstract

We pilot tested a carepartner-assisted intervention to improve oral hygiene in persons with cognitive impairment (participants) and help carepartners become leaders who can adapt approaches that foster participants' ability to develop new skills for oral hygiene care. Following

Correspondence to: Ruth A. Anderson.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

the intervention, we conducted interviews with participants and carepartners to understand their challenges in working together to learn new oral hygiene skills. Participants reported challenges such as frustration using the electric toothbrush correctly, lack of desire to change, uncertainty about correctness of technique, and difficulty sustaining two minutes of toothbrushing. Carepartners reported challenges such as learning a new way of toothbrushing, learning new communication techniques, switching from instructing to working together, learning to balance leading with being too bossy, and being mindful of word choices. Findings suggested that despite challenges, participants were able to learn adaptive strategies to support new oral hygiene behaviors with support of the carepartner as the adaptive leader.

Keywords

Oral Hygiene; Community dwellers; toothbrushing; caregivers; cognitive impairment

Introduction

Oral health is a critical part of older adults' general health and a contributing factor to their adequate nutrition, but often it is overlooked. Oral health problems accumulate throughout the life span, but they occur more frequently in later life.^{1,2} Individuals with cognitive impairment are one subgroup of the older population that is at particularly high risk of poor oral health, including those with mild cognitive impairment and mild dementia.^{3,4} Evidence shows that individuals with cognitive impairment have more oral plaque, more severe periodontal disease, more caries, and fewer teeth than cognitively intact older adults.^{2,5-7} Research shows that inadequate oral hygiene practices primarily contribute to poor oral health for individuals with cognitive impairment.^{5,8} Thus, interventions are needed to help people with cognitive impairment improve oral hygiene. Studies conducted in nursing homes, although few, have shown that standard routine oral hygiene practices, supported by dental staff, are effective.⁹

Most of the individuals with early stage cognitive impairment (i.e., mild dementia and mild cognitive impairment) live in the community and they might lack supportive care to engage in adequate oral hygiene. Family members who provide care (i.e. carepartners) to individuals living at home with cognitive impairment, provide supervision or assistance with other daily activities, but often neglect oral hygiene.¹⁰ Our research has shown that only 44% of community-dwelling individuals with mild to moderate dementia brush their teeth at least twice per day compared to 72% of those with normal cognition.^{2,5} Moreover, cognitive changes make it more challenging for individuals with cognitive impairment to follow standard instructions to improve their oral hygiene care.¹¹ Individuals with early stage cognitive impairment are an ideal target population for oral hygiene intervention because they are still able to perform oral hygiene tasks with minimal assistance from an informal carepartner. Engaging them in adequate oral hygiene practices at an earlier stage of their cognitive impairment might make it possible for them to maintain these practices as their cognition declines. A recent literature review, specific to oral hygiene, found that effective interventions for activities of daily living included threat reduction techniques, such as gesturing or cueing,¹² which Jablonski and colleagues coined "threat reduction" techniques.¹³

A literature review not specific to oral hygiene found prompting to be effective in many studies.¹⁴ Two recent oral hygiene specific literature reviews concluded that existing nursing home educational interventions for staff and in some case, residents, reported minimal benefit, possibly due to low-quality evidence.^{15,16} Furthermore no studies were conducted with elders and care partners living in the community.⁹

Informal carepartners play a major role in caring and promoting health self-management for individuals with cognitive impairment living in the community. For example, 75% of the approximately 1.5 million individuals with mild dementia in the U.S. receive assistance, reminders, or supervision for daily activities from carepartners such as spouses or adult children.¹⁷ Carepartners play a critical role in supervising and caring for persons with cognitive impairment,¹⁸ but oral hygiene tasks have not often been a part of this assistance. Including the carepartner as part of skill-learning interventions has distinct benefits for the persons with cognitive impairment from the perspectives of social interaction, observational learning, and social reinforcement.¹⁹⁻²¹ Reviews of the literature of interventions for carepartners of individuals with cognitive impairment to improve activities of daily living provide evidence that interventions should be multicomponent, including dementia education, behavior management strategies, communication skills, psychological skills such as cognitive reframing, reflective learning facilitation, skills practice, and threat reduction techniques,¹³ such as gesturing or cueing,¹² and prompting from another.¹⁴

The Theory Based Intervention

We developed an intervention to create a partnership between the individual with cognitive impairment and the carepartner. Based on the literature, we included evidence-based approaches. The intervention is designed specifically to address short term memory deficits in teaching carepartners to use communication strategies that are tailored for the individual with cognitive impairment and to use memory prompts gesturing and verbal and visual cues. The dyad creates SMART goals to break multistep processes into manageable steps. The interventionist for the carepartner coaching intervention was a nurse. A dental hygienist did the measures of oral outcomes and tailored the oral care instructions for the dyad. The intervention was multidimensional with 1) an oral hygiene component that included basic oral hygiene education, personalized oral hygiene instruction from a dental hygienist, and practice with return demonstration with an electric toothbrush; 2) both the participant and his/her carepartner received a study electric toothbrush; 3) a carepartner component that included 4 interactive sessions (in person and by phone) between the interventionist and carepartner; learning threat reduction techniques,¹³ such as gesturing, cueing, and prompting,¹² communication skills tailored for individuals with cognitive impairment,^{22,23} and coaching that included self-reflection to build second-order learning, which is learning that moves carepartner thinking from facts to understanding such as how and why behaviors might occur in the individual with cognitive impairment.²⁴ Fiest and colleagues²⁵ synthesized the literature on caregiver mediated interventions and described our type of intervention as inform-activate-collaborate and concluded that such interventions lead to the best outcomes for patients and caregivers. Shown in Table 1, the first session took place at visit 1; The second session was a phone call 4 weeks after visit 1; The third session was a phone call 8 weeks after visit 1 and the last session took place at visit 2 (12 weeks after visit 1). Each

session took approximately 30 minutes. 4) joint care planning component in which the dyad were guided in developing SMART (Specific, Measurable, Action-oriented, Reasonable, and Timely) goals.²⁶ Below are the scripts from our carepartner module where the participant and carepartner set SMART goals with the interventionist:

Specific: You need to state exactly what you want to change; **Measurable:** How will you know you are doing what you say you want to do? **Action oriented:** The goal needs to be what you are going to do to make the change. **Reasonable:** This means the change you can reasonably expect to do successfully. It might not be “perfect” but it will be better!

Timely: Using time to measure your goal. How often and how long?

Specifically, our carepartner-assisted intervention aimed to improve oral hygiene and oral hygiene behaviors in persons with cognitive impairment and to help the carepartners become leaders who are able to adapt approaches to match behaviors of the participant, fostering the individual’s ability to engage in work to maintain or change behaviors, and develop new skills to independently carry out oral hygiene care. One example of the new skills required for the intervention is that several participants had not previously used an electric toothbrush. Even for those who had used an electric toothbrush, the skills required for effective tooth brushing, when used as prescribed by the dental hygienist, were deceptively difficult. We employed the Adaptive Leadership Framework Applied to Chronic Illness²⁷ to guide the carepartner-assisted intervention. This framework supports the idea that individuals with cognitive impairment work collaboratively with their carepartner to achieve optimal health outcomes and daily function.

There are five key concepts in the framework²⁸: technical challenges, technical work, adaptive challenges, adaptive work, and adaptive leadership (assessing adaptive challenges and guiding collaborative work). Technical challenges are situations in which both the problems and the potential solutions can be clearly defined by the right expert,²⁹ although this does not mean these problems always are easy to resolve. In this research, an example is that the dental hygienist might find a gum condition (technical challenge) that suggests reducing pressure during brushing (technical work). Adaptive challenges occur in situations in which problems require the person with the problem to do the work of learning, adapting, and changing values and /or behaviors. These types of problems are sometimes difficult to identify and are easy to deny. Typical examples of adaptive challenges for the participant (and/or the carepartners) would include changing attitudes toward oral hygiene, learning good hygiene techniques (e.g., tooth brushing and flossing), which increase self-efficacy.

The framework suggests that most situations have a combination of technical and adaptive challenges. However, because of cognitive changes in persons with cognitive impairment, standard instruction might be insufficient to improve oral hygiene care and thus most challenges will involve aspects that are adaptive, such as requiring changing attitudes towards oral hygiene, developing new skills of using the electronic toothbrush, and increasing self-efficacy. These situations require collaborative work of the persons with cognitive impairment and their carepartners. Ideally, the carepartner, as an adaptive leader, will assess challenges by encouraging the care recipient to share information so that together

they develop a shared understanding of the particular challenges that the dyad faces, using tested communication intervention approaches.³⁰ The Adaptive Leadership Framework provides useful lens through which to focus not only on how to assess adaptive challenges that the persons with cognitive impairment and their carepartners experienced and to anticipate new adaptive challenges related to oral hygiene, but also to prepare carepartners with a variety of adaptive approaches to reduce or eliminate the challenges and maintain a higher quality of life.

After subjects completed the intervention, we conducted semi-structured interviews separately with the study participants and their carepartners to understand their experience with the challenges of learning new oral hygiene skills together. We aimed to describe the adaptive challenges and adaptive work of the study participants and carepartners and how they were able or not able to engage in collaborative work in learning the new behaviors and skills.

Methods

Ethical Approval

Institutional Review Board (IRB) approval was obtained from [blinded for review]. Signed informed consent was obtained from each participant and his/her carepartners after explaining risks and benefits, confidentiality, and options for withdrawal at the time of the first in-home evaluation.

Design

This qualitative pilot study used semi-structured open-ended interviews³¹ to explore participants' and their carepartners' experiences in the study, regarding their learning about and carrying out oral care, working with each other, communicating with each other and so forth. We then used directed coding, applying the framework of Adaptive Leadership for Chronic Illness to the analysis of the interviews to identify challenges facing participants and their carepartners as they learned about and carried out oral care and collaborative work. The current study design allowed informants the freedom to express their views in their own terms but also provided a clear set of instructions for interviewers to ensure reliable, comparable qualitative data, adding to the in-depth understanding of their experience and perceptions. We wanted to collect as much data as possible on the feasibility of the intervention. Thus, given the limited funding for this feasibility pilot study, we decided to limit the number in the control group to be able have as many in the intervention (treatment) group as possible. All the data collection and measures were the same in both groups and thus did not need to be tested in a control group. We included all 22 intervention participants and carepartners which is an adequate sample to reach data saturation as described in similar qualitative studies.³² Furthermore, we did not evaluation saturation separately for participants and carepartner because of our focus on interaction and relationship. We did not include the two dyads (n=4) in the control group because we were interested in learning about challenges encountered during the carepartner intervention and how the dyad learned together.

Setting and Sample

Subject Recruitment and Compensation: Using a purposive sampling strategy, we recruited participants from the [blinded for review] Memory Disorders Clinic through flyers distributed by providers and direct referral from providers. We also recruited participants from caregiver support groups. After potential participants had been identified, patients were sent a letter from their [blinded for review] provider introducing the study, explaining that a study coordinator would be contacting them by phone to see if they were interested in participating in the study and to answer any questions. We included carepartners and persons with either mild cognitive impairment or mild dementia. Although these are two different types of cognitive impairment, the challenges face in learning new oral hygiene skills might be similar, such as challenges of brushing and flossing, forgetfulness, and sustaining attention span.

The study coordinator then completed a preliminary telephone screening to determine eligibility for participation in the study. Potential participants were 60 years of age or older with mild cognitive impairment or mild dementia. In the study, we refer to the persons with cognitive impairment as “participant.” Participants were eligible if they: 1) had a diagnosis of mild cognitive impairment or mild dementia within the past year; 2) had at least 4 natural teeth; 3) lived with an informal, unpaid, carepartner who was willing to participate; 4) were community-dwelling; and 5) were physically able to brush their own teeth. Participants were excluded if they had: 1) edentulism; 2) were unable to have an oral health evaluation done; 3) had sensory or physical problems that prevent participation in the intervention; or 4) had terminal illness or behavioral or psychiatric disorder that would interfere with participation in the intervention. In addition, individuals at increased risk of bleeding due to hemophilia or due to anti-platelet therapy were also excluded.

The study coordinator obtained verbal willingness to participate from the participants and their carepartner for the study team to visit them in their home. Written informed consent was then obtained separately from the participant and the carepartner at the first in-home evaluation. The staff member who obtained consent assessed the cognitively impaired individual’s understanding of the purpose of the study and the procedures involved in the study. This was based on in-person discussion with the participant and his/her care partner. Because of the level of involvement in the intervention that we wanted from the individual with dementia, we enrolled only those where were able to provide consent for themselves. To characterize level of cognitive impairment, the Montreal Cognitive Assessment scores (MoCA) was administered by trained research staff at each of the 3 home visits (See Table 1). Given the typically slow, gradual decline of most progressive neurodegenerative diseases such as Alzheimer’s disease, it is likely that most participants remained at their baseline cognitive status level (i.e. MCI or mild dementia) for the duration of the 6-month study. However, the distinctions are very fine between MCI and mild dementia, and between mild and early-moderate dementia, and the study protocol was appropriate even if participants’ cognitive decline had progressed sufficiently to meet criteria for the more advanced level of impairment.

Data Collection

Study staff collected data between November 2015 and April, 2017. During 6 months of contact, the dyads were in an active intervention for 3 months with 3 months of maintenance and a final data collection at 6 months (Table 1). Study staff made three home visits and 2 additional phone contacts. After completing the second visit, which marked the end of the active intervention phase, the coordinator conducted the post-intervention interviews with the participants and carepartners to gather feedback about their experience in the study. The participants and their carepartners were interviewed separately in a quiet room. Because the intervention was based on developing a partnership in oral hygiene, separate interviews provided the opportunity for openness and to reveal potentially sensitive topics³³ Both participants and their carepartners were interviewed using the same semi-structured interview guide, beginning with an open-ended question: “What has it been like for you and your partner/spouse to be in this study?” followed by probes that encouraged participants to reflect on their feelings and experiences, such as “What did you learn about your strength and weakness for your oral hygiene care?” and “Did anything about your experience in the study surprise you?”. The coordinator then asked participants three key questions: 1) “How did you and your partner/spouse work together to carry out what you learned about oral care?” 2) “Is there anything more you would like to tell me about what it is like to communicate or work with your study partner/spouse on oral hygiene?” and 3) “Tell me about your relationship with your study partner/spouse.” We drew on the Adaptive Leadership Framework for Chronic Illness to develop these questions and prompts.

The interviews lasted about 30 minutes. All interviews were digitally recorded. Recordings were transcribed verbatim and the study coordinator verified accuracy. Transcripts were then de-identified to assure their privacy. All the transcripts were uploaded into QSR NVivo 10.0 for qualitative data management, organizing, and analysis.

Data Analysis

The coding team (RAA, JW, and KN) conducted data analyses using directed content analysis.³⁴ We adopted this method because it allowed interpretation of data within the context of the theoretical framework Adaptive Leadership Framework for Chronic Illness.²⁷ We used a two-cycle coding approach.³⁵ In the first-cycle coding, we developed a priori codes and a codebook using concepts in the framework (Table 2). The team then expanded the codes to reflect experiences, adaptive challenges/work and collaborative work specific to the participants and their carepartners in this study based on the narratives. New codes were discussed among the coding team members before being added to the codebook during the data analysis. Three coders in the coding team independently coded the transcripts. They met to discuss and compare the coding decisions and any disagreements were resolved in the larger research team (RAA, BW, BP, JW, and KN). In the second-cycle coding, the coded text was arranged into categories and subcategories based on how they were related.³⁴ During analysis, we used memos to clarify coding decisions.³⁶ We reread the original quotations whenever more context was needed. Eventually, patterns of participants’ and their carepartners’ adaptive challenge, adaptive work and collaborative work were synthesized and differences between participant and carepartner responses were identified.

To further insure rigor, we held frequent meetings of the coding team to discuss the coding, our use of codes, and refined definitions needed. RA, as an experienced qualitative researcher, guided the other coders, a PhD student and the Project Coordinator, in the coding process. Using features in NVivo, we compared our coding patterns and discussed to ensure that the interpretations and hypotheses made from the analysis were sound. Periodically, we engaged the full team so that non-coders could review and challenge our interpretations with discussion until disagreements were resolved and or new interpretations were added.

Results

Sample characteristics

We interviewed participants and their carepartners (n=22). Saturation was reached within the first 12 participants and carepartners in keeping with similar qualitative literature,³² We met criteria for data saturation including data replication and redundancy that additional interviews failed to uncover new thematic ideas in relation to the study purpose. Among all study participants, eight were diagnosed with mild dementia and three were diagnosed with mild cognitive impairment (MCI). We present the sample characteristics in Table 3. The mean age of study participants was 73.3. The majority of the participants were male, non-Hispanic white, had post college education, and reported fairly good functional status. More than half of the participants had health insurance that covers dental expenses. Nine out of eleven the carepartners were spouses and the rest two were adult children. Most carepartners were female, non-Hispanic white, and received some college education. Table 2 also included descriptives for dental insurance and the participants' average MoCA scores.³⁷

Below, we organized the presentation of finding by describing the adaptive challenges and adaptive work and finally collaborative work. We presented the perspectives of the participant and carepartners separately for adaptive challenges and adaptive work. We presented the perspectives of participants and carepartners jointly on findings about collaborative work.

Adaptive Challenges and Adaptive Work

We asked participants and their carepartners to describe adaptive challenges they faced improving oral hygiene during the intervention. We defined adaptive challenges as disparity between a person's capabilities of familiar methods, habits or values and the demands of the present circumstances, which required the individual with cognitive impairment and/or their carepartners to adjust to a new situation and to do the adaptive work of adapting, learning, and changing behavior. Our goal in the intervention was to help the participant and carepartner address their adaptive challenges by facilitating the carepartner to lead the participant using communication and memory aide strategies. In this section, we present the findings about adaptive challenges and adaptive work described by participants, followed by the findings for the carepartners.

Challenges and Work Described by Individuals with Cognitive Impairment (Participants)

Quite a few participants described their adaptive challenges during the intervention as "adjusting to something new" with which they were "unfamiliar" or making them "feel

frustrated” or something that required them to learn and change their attitudes and behaviors. Participants tended to feel more challenged when they had to confront or accept their weaknesses and vulnerability.

Participants described that they believed they were already using the proper oral care techniques but learned otherwise in the intervention; most changed their attitude about their knowledge level during the intervention. One participant stated, “I didn’t realize I wasn’t brushing my teeth with proper technique. I think that is the biggest help of this [intervention] and having a really good toothbrush to work with.” Another stated, “it certainly does make us think about taking oral hygiene more seriously.” Supporting the value of the adaptive approach for addressing the participants’ adaptive challenges, several described that initially they did not want to use the new toothbrush or techniques but were eventually able to make the transition with the support of the carepartner. For example, a participant stated, “At first I was afraid of the [toothbrush]. ... I knew that [husband] doesn’t have any problems with it and I guess that encouraged me... When I did adapt to it, I liked it and it makes your mouth feel fresh and everything.”

A few participants related their challenges to their lack of knowledge about the mechanism of tooth brushing. One participant shared his understanding with us that this intervention is not just about using a new brush (electric toothbrush) but about learning a new muscle movement. He believed that he did not do well with the brushing because he was not sure if he was making the right moves. He stated,

“Cause at first I wasn’t so great... each week I really couldn’t get the knack of it, so that was about the worst thing if you will. I looked for ways to get to that point where I knew that I was doing... but it took quite a while for me to apply it.... Now still not a superstar and but I’m getting better.”

In order to adjust to something new, participants and their carepartners worked out ways to narrow disparity between their capabilities and demands of the new oral hygiene recommendations by changing their attitudes and behaviors. For example, the recommended length of two minutes for tooth brushing was difficult for many participants. One participant stated, “I would say a minute and a half is enough.” He went on to say he thought brushing longer is not going to matter. Another participant described “...experiencing the two minutes of brushing every time you brush was a little of a challenge initially. When you think about the time spent doing that—two minutes is a long time. So that’s the hardest thing actually.” However, he learned strategies during the intervention that helped, as he indicated later in the intervention,

Well, after [interventionist’s] last visit I slowed down my brushing motion and I used my grandson’s names to help slow down. And, if I can, I look out the window at the work going on next door.... It doesn’t seem that long any more. But it was quite an adjustment early on.

Challenges and Work Described by Carepartners

Carepartners also described adaptive challenges and adaptive work as they led their participant in improving oral hygiene. One basic challenge often was that the carepartner

also was learning a new way of tooth brushing. As one carepartner commented, “Basically in the beginning I, myself, was learning to use the toothbrush and I coached her some. And we, we got along fine interacting together to learn how to use the electronic brush and everything.”

For carepartners in our study, some were carepartners were not yet comfortable in their caregiving role or in leading the person with mild cognitive impairment or mild dementia in their activities. For example, one carepartner told us that her mother believed that she knew what she was doing with tooth brushing although in fact the carepartner identified problems with the mother’s techniques such as the speed of brushing:

“For me, to tell her that she was doing it wrong created definitely some challenging moments ... My mom’s someone who’s very proud of herself and she is like I can do anything, I can learn anything. You can say ‘OK, go slowly’ but she was still doing it fast...having me involved was a little tricky.”

This daughter engaged in adaptive work to overcome the challenges in helping her mother. “It was tricky at times. So that’s usually when I just take a step back and let her do what she wants to.” By showing respect and protecting her mother’s pride, the carepartner learned not to “just tell her [mother] that she was doing it wrong or asking her to slow down.” Instead she brushed her own teeth with her mother, so her mother could see and compare “the speed at which she goes and then the speed that was recommended to us [by the dental hygienist].”

Carepartners described learning about themselves in terms their ability to work with their family member. One daughter stated, “Yes the study is about oral hygiene...but from my perspective as [a] daughter and carepartner, it gave me an opportunity to see my strengths and weaknesses of working with my mom and the challenges that come up.”

Another carepartner shared with us that she was aware of being too aggressive and bossy, which became a barrier to effective communication with her father, the participant. She also realized that it is her personality and it is never easy to work on things related to one’s personality. She told us that:

“I’m bossy [laughs] with most people...I am too watchful when people are doing things. I am checking it too much. I have always been an in-charge, take-control type of person. It made me more aware that that is my personality—not that I am going to change it but there are things I need to work on.”

Thus, finding the balance from being too directive versus making things fun was a learning experience for many of the carepartners. One carepartner reported,

“So it was suggested to me that in giving feedback, in particular to mom, in particular around instructions, to do so in a way that is not seen as challenging.... Just finding more humor in it. I think light heartedness and humor is probably better than the style that I was doing with more instructions.”

Similarly, another carepartner learned to stop “telling” the participant what to do.

We always learn to work together. There may be problems on his part first, because, I told him, reminding him to brush his teeth.... After talking with (nurse

interventionist), she made suggestions on how for me of how to say it, and after I started doing that, he didn't seem to balk at it, and it hasn't seemed to bother him at all.

Overcoming old ways of communicating was a key issue for carepartners who learned in the intervention how to engage in focused communication with the participant. One carepartner summarized this learning,

I guess my technique for communication might could stand a little improvement. Just, you know, how to approach checking in, the way I word questions. To maybe be a little more mindful of how I word it so it doesn't seem like I'm nagging him about it. So, just trying to learn those techniques that were given in the packet. I just have to try to put those into practice, so I'm trying to improve in those areas.

Collaborative Work

In the intervention training with the participant and carepartner, we helped them learn to use collaborative work which is a strategy used by the carepartner as the adaptive leader who monitors behavioral responses that might interfere with oral hygiene, such as forgetting or concentration to complete the task. The carepartner learned to work with the participant to foster independence in accomplishing oral hygiene to the extent possible. Strategies provided in the intervention coaching with carepartners included threat reduction techniques, cueing techniques and communication techniques which supplemented tailored instruction in oral hygiene.

Brushing together was the most commonly used cueing technique reported by the carepartners. For example, one carepartner stated, "we started by practicing in the bathroom when we were getting ready in the morning, and we both kind of brush our teeth at the same time." A participant indicated, "He always would just wait for me to do the act. He'd demonstrate it... It was helpful." Furthermore, the participants sometimes did the reminding. For example. One participant stated, "I did want to cooperate so... One or the other is going to say, "You've got to brush". We get reminded." This participant went on to describe how they used the reminding strategy for other tasks such as making the grocery list.

The participant and carepartner set SMART goals with the interventionist and one cueing strategy would be to write the goals on the bathroom mirror to remind about brushing, technique, or flossing. One participant reported, "[Writing on the mirror] helped me to maintain [brushing] up and down, up and down." A participant noted the benefit of the automatic stop on the electric toothbrush indicating that he could stop brushing after two minutes. Another visual reminder was described as successful by a carepartner, "I haven't had to tell him and he hasn't missed a day. We put [floss sticks] in the little jar (visual reminder) up by the toothbrush."

Creating a routine that included tooth brushing was described by several carepartners as being helpful and to keep from being too overwhelmed. One carepartner described how in the past they shared the tasks but now it all falls to her to remember. She stated,

[We] just really didn't follow a good regimen with our teeth, cause I know that my mouth is now a whole a lot better...I have a long list of things now. [In the past] I would do certain things, he would do certain things before we go to bed at night. Now I have to think about all of them. I just have my list, and I will go down that list and I have gotten so used to it now, it is just automatic, but before I go and get to the bed I will say "oh, no, I got to get my teeth brushed before I do that." And that has been helpful to me tremendously. It is getting to be a good routine. I think everybody needs to do that. I will recommend everybody to do that, because it has helped both of us, even he is getting to the point that I don't have to remind him every night to brush his teeth.

Discussion

In this study, we explored adaptive challenges, adaptive work, and collaborative work described by the participants (persons with cognitive impairment) and their carepartners, following an intervention in which as they learned to engage in new oral care behaviors. In keeping with prior meta-analysis findings,³⁸ the intervention engaged both the participant and his/her carepartner and was tailored to the needs of each. The dyads participated in an intervention designed to help the participant and carepartner work together to 1) learn basic oral hygiene knowledge, 2) engage in personalized oral hygiene recommendations from a dental hygienist using a standard electric toothbrush provided by the study and 3) improve oral hygiene by adopting techniques to overcome both adaptive and technical challenges.. A carepartner component facilitated learning of threat-reduction techniques, such as gesturing, cueing, and prompting,¹² communication skills tailored for individuals with dementia,²² and coaching behaviors that include self-reflection to build second-order learning, which is learning that moves carepartner thinking from facts to understanding such as how and why behaviors might occur in the individual with dementia.³⁹ In a joint care planning component the dyad was guided in setting SMART goals.²⁶

Individuals with cognitive impairment reported challenges in learning new oral self-care such as unfamiliarity, frustration with manipulating the electric toothbrush correctly, lack of desire to change their way of doing oral self-care, fear of the electric toothbrush, uncertainty about whether the technique was correct, and feeling that it was difficult to brush for two minutes. Challenges reported by the carepartners included learning a new way of toothbrushing, being uncomfortable in the caregiver role which for these participants was relatively new and this intervention was often the first time they began to think about the impact of the diagnosis on behavior and activities of daily living. Carepartners described the challenges of learning new ways of communicating, switching from telling to working together, learning to balance leading with being too bossy, and being mindful of word choices and sentence structure.

The findings suggested that although it was challenging, the participants with cognitive impairment were able to learn adaptive strategies to support new ways of conducting oral hygiene with the support of the carepartner as the adaptive leader. It was critical for the carepartner to allow the participant to move at his or her own pace and to set reasonable expectations which in this case were supported by jointly developed SMART goals.^{40,41}

This study results support prior work which suggests the mechanisms of action for SMART goals; they 1) improve communication between the carepartner and the participant by setting direction for behavior⁴¹ and 2) improve performance of tasks by including specific manageable steps.⁴² Furthermore, participants described coming up with some strategies on their own, for example one used distraction—saying his grandson’s names or looking out at the neighbors’—to pass the two minutes of brushing time.

Carepartners and participants alike frequently mentioned that working together was key to adapting to new oral self-care routines. Frequently, they mentioned standing together to brush their teeth in front of the mirror. Both our intervention and some caregiver-guides⁴³ encourage the strategy of doing daily hygiene activities together. Carepartners used “contextual cueing” by placing the toothbrush and flossers where the participants would see them. Research indicates that visual cueing can be a stronger memory trigger than words because of how familiar objects stimulate the brain.⁴⁴ Objects can trigger a form of implicit memory that “allows for these representations to facilitate behavior even while conscious recognition or recollection is not supported.”^{45, p. 30} Establishing a routine for the joint tooth brushing was described by both the participant and carepartners as a useful strategy as reported by caregivers in prior studies.^{40,46}

Carepartners described that communication techniques^{22,47} learned in the intervention, such as giving one instruction at a time and using short, simple sentences, required practice but were helpful in gaining cooperation and facilitating a partnership. Prior case study research suggested that these communication techniques work by reducing the number of communication breakdowns, increasing use of “techniques to signal and repair” when there has been a communication problem, and decreasing “negative emotional response to challenging behaviors” of individuals with dementia.^{48, pg. 11-12} Our goals for developing the carepartner as an adaptive leader is similar to Bourgeois,⁴⁹ Clark,⁵⁰ and Ripich²³ who advocate that caregivers adopt the role of facilitator for which effective communication techniques are essential.

Limitations

The sample was small but allowed for the long engagement of the research team with the dyads which established rapport to facilitate trust during interviews and a willingness to be forthright, thus strengthening credibility of the findings. We included only individuals in the early stage of cognitive impairment and thus the findings may not apply to person with moderate to severe stages of cognitive impairment. Generalizability of the findings of qualitative study is usually not an expected attribute. The focus of this study was to pilot the intervention with dyads living in community dwellings and thus findings cannot be interpreted beyond this setting. However, we did establish transferability by providing readers with sufficient contextual information and allow them to have a proper understanding of the findings, thus enabling them to compare it with what is emerging in other situations, such as institutional settings. Thus the adaptive challenges and adaptive work described in this context might have implications for caregivers in other of care contexts.

Conclusion

Although this study focused on oral hygiene, the approaches learned by participants in the pilot of this intervention can be used by them to tackle many other challenges that persons with cognitive impairment and their carepartners face. Thus, the intervention shows promise for positive results if improved oral hygiene outcomes, such as plaque and gingivitis reduction also occur. A larger clinical trial is warranted.

Acknowledgements

Funding: This work was supported in part by the National Institutes of Health [R34 DE023881-01]; the Duke University School of Nursing; Duke University School of Medicine, Department of Psychiatry; Duke/Duke-NUS collaborative research pilot project funds; and the University of North Carolina at Chapel Hill, School of Nursing.

References

1. Chalmers JM, Carter KD, Spencer AJ. Caries incidence and increments in community-living older adults with and without dementia. *Gerodontology*. 2002;19(2):80–94. [PubMed: 12542217]
2. Wu B, Fillenbaum GG, Plassman BL, Guo L. Association Between Oral Health and Cognitive Status: A Systematic Review. *Journal of the American Geriatrics Society*. 2016;64(4):739–751. [PubMed: 27037761]
3. Li J, Xu H, Pan W, Wu B. Association between tooth loss and cognitive decline: A 13-year longitudinal study of Chinese older adults. *PLOS ONE*. 2017;12(2):e0171404. [PubMed: 28158261]
4. Iwasaki M, Kimura Y, Ogawa H, et al. Periodontitis, periodontal inflammation, and mild cognitive impairment: A 5-year cohort study. *Journal of Periodontal Research*. 0(0).
5. Lee KH, Plassman BL, Pan W, Wu B. Mediation Effect of Oral Hygiene on the Relationship Between Cognitive Function and Oral Health in Older Adults. *Journal of gerontological nursing*. 2016;42(5):30–37. [PubMed: 26716459]
6. Delwel S, Binnekade TT, Perez RSGM, Hertogh CMPM, Scherder EJA, Lobbezoo F. Oral hygiene and oral health in older people with dementia: a comprehensive review with focus on oral soft tissues. *Clinical oral investigations*. 2018;22(1):93–108. [PubMed: 29143189]
7. Maldonado A, Laugisch O, Bürgin W, Sculean A, Eick S. Clinical periodontal variables in patients with and without dementia—a systematic review and meta-analysis. *Clinical oral investigations*. 2018.
8. Zhang W, Wu YY, Wu B. Does Oral Health Predict Functional Status in Late Life? Findings From a National Sample. *Journal of Aging and Health*. 2018;30(6):924–944. [PubMed: 28553812]
9. Sjögren P, Wårdh I, Zimmerman M, Almståhl A, Wikström M. Oral Care and Mortality in Older Adults with Pneumonia in Hospitals or Nursing Homes: Systematic Review and Meta-Analysis. *Journal of the American Geriatrics Society*. 2016;64(10):2109–2115. [PubMed: 27590446]
10. Syrjala AM, Ylostalo P, Ruoppi P, et al. Dementia and oral health among subjects aged 75 years or older. *Gerodontology*. 2012;29(1):36–42. [PubMed: 20604811]
11. Wu B, Plassman BL, Crout RJ, Liang J. Cognitive function and oral health among community-dwelling older adults. *The journals of gerontology Series A, Biological sciences and medical sciences*. 2008;63(5):495–500.
12. Siegel E, Cations M, Wright C, et al. Interventions to Improve the Oral Health of People with Dementia or Cognitive Impairment: A Review of the Literature. *The journal of nutrition, health & aging*. 2017;21(8):874–886.
13. Jablonski RA, Therrien B, Mahoney EK, Kolanowski A, Gabello M, Brock A. An intervention to reduce care-resistant behavior in persons with dementia during oral hygiene: a pilot study. *Special care in dentistry : official publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry*. 2011;31(3):77–87.

14. Smallfield S, Heckenlaible C. Effectiveness of Occupational Therapy Interventions to Enhance Occupational Performance for Adults With Alzheimer's Disease and Related Major Neurocognitive Disorders: A Systematic Review. *The American journal of occupational therapy* : official publication of the American Occupational Therapy Association. 2017;71(5): 7105180010p7105180011–7105180010p7105180019.
15. Albrecht M, Kupfer R, Reissmann DR, Mühlhauser I, Köpke S. Oral health educational interventions for nursing home staff and residents. *Cochrane Database of Systematic Reviews*. 2016(9).
16. Siegel E, Cations M, Wright C, et al. Interventions to improve the oral health of people with dementia or cognitive impairment: A review of the literature. *The journal of nutrition, health & aging*. 2017;21(8):874–886.
17. Gitlin LN, Corcoran M, Winter L, Boyce A, Hauck WW. A randomized, controlled trial of a home environmental intervention: effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist*. 2001;41(1):4–14. [PubMed: 11220813]
18. Egan KJ, Pinto-Bruno AC, Bighelli I, et al. Online Training and Support Programs Designed to Improve Mental Health and Reduce Burden Among Caregivers of People With Dementia: A Systematic Review. *Journal of the American Medical Directors Association*. 2018;19(3):200–206.e201. [PubMed: 29306605]
19. Bourgeois J, Laye M, Lemaire J, et al. Relearning of Activities of Daily Living: A Comparison of the Effectiveness of Three Learning Methods in Patients with Dementia of the Alzheimer Type. *J Nutr Health Aging*. 2016;20(1):48–55. [PubMed: 26728933]
20. Clarkson JE, Young L, Ramsay CR, Bonner BC, Bonetti D. How to Influence Patient Oral Hygiene Behavior Effectively. *Journal of Dental Research*. 2009;88(10):933–937. [PubMed: 19783802]
21. Woodbridge R, Sullivan M, Harding E, et al. Use of the physical environment to support everyday activities for people with dementia: A systematic review. *Dementia*. 2016;0(0): 1471301216648670.
22. Ripich DN, Wykle M, Niles S. Alzheimer's disease caregivers: The FOCUSED program: A communication skills training program helps nursing assistants to give better care to patients with Alzheimer's disease. *Geriatric Nursing*. 1995;16(1):15–19. [PubMed: 7859996]
23. Ripich DN. Functional communication with AD patients: a caregiver training program. *Alzheimer disease and associated disorders*. 1994;8 Suppl 3:95–109. [PubMed: 7999352]
24. Siller M, Hotez E, Swanson M, Delavenne A, Hutman T, Sigman M. Parent coaching increases the parents' capacity for reflection and self-evaluation: results from a clinical trial in autism. *Attachment & Human Development*. 2018;20(3):287–308. [PubMed: 29513132]
25. Fiest KM, McIntosh CJ, Demianschuk D, Leigh JP, Stelfox HT. Translating evidence to patient care through caregivers: a systematic review of caregiver-mediated interventions. *BMC Medicine*. 2018;16(1):105. [PubMed: 29996850]
26. Page J, Roos K, Banziger A, et al. Formulating goals in occupational therapy: State of the art in Switzerland. *Scand J Occup Ther*. 2015;22(6):403–415. [PubMed: 26087696]
27. Anderson RA, Bailey DE Jr., Wu B, et al. Adaptive leadership framework for chronic illness: framing a research agenda for transforming care delivery. *ANS Advances in nursing science*. 2015;38(2):83–95. [PubMed: 25647829]
28. Anderson RA, Bailey DEJ, Wu B, et al. Adaptive Leadership Framework for Chronic Illness: Framing a Research Agenda for Transforming Care Delivery. *Advances in Nursing Science*. 2015;38(2):83–95. [PubMed: 25647829]
29. Bailey DE Jr., Docherty SL, Adams JA, et al. Studying the clinical encounter with the Adaptive Leadership framework. *Journal of healthcare leadership*. 2012;2012(4).
30. Haberstroh J, Neumeyer K, Krause K, Franzmann J, Pantel J. TANDEM: Communication training for informal caregivers of people with dementia. *Aging Ment Health*. 2011;15(3):405–413. [PubMed: 21491226]
31. Ashton S Researcher or nurse? Difficulties of undertaking semi-structured interviews on sensitive topics. *Nurse researcher*. 2014;22(1):27–31. [PubMed: 25251817]
32. Guest G, Bunce A, Johnson L. How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field Methods*. 2006;18(1):59–82.

33. Eisikovits Z, Koren C. Approaches to and outcomes of dyadic interview analysis. *Qual Health Res.* 2010;20(12):1642–1655. [PubMed: 20663940]
34. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15(9):1277–1288. [PubMed: 16204405]
35. Saldaña J *The coding manual for qualitative researchers.* Los Angeles: SAGE Publications; 2013.
36. Sandelowski M *Qualitative analysis: What it is and how to begin.* Research in Nursing & Health. 1995;18(4):371–375. [PubMed: 7624531]
37. Nasreddine ZS, Phillips NA, Bedirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society.* 2005;53(4):695–699. [PubMed: 15817019]
38. Henry B, Alisa G, Annette K. Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia. *Journal of the American Geriatrics Society.* 2003;51(5):657–664. [PubMed: 12752841]
39. van Woerkom M *The Concept of Critical Reflection and Its Implications for Human Resource Development.* *Advances in Developing Human Resources.* 2004;6(2):178–192.
40. Rodakowski J, Reynolds CF, Lopez OL, Butters MA, Dew MA, Skidmore ER. Developing a Non-Pharmacological Intervention for Individuals With Mild Cognitive Impairment. *Journal of Applied Gerontology.* 2018;37(5):665–676. [PubMed: 27106884]
41. Page J, Roos K, Bänziger A, et al. Formulating goals in occupational therapy: State of the art in Switzerland. *Scandinavian Journal of Occupational Therapy.* 2015;22(6):403–415. [PubMed: 26087696]
42. Levack WM, Taylor K, Siegert RJ, Dean SG, McPherson KM, Weatherall M. Is goal planning in rehabilitation effective? A systematic review. *Clinical Rehabilitation.* 2006;20(9):739–755. [PubMed: 17005499]
43. Alzheimer's Association. Dental Care. 2018; <https://www.alz.org/help-support/caregiving/daily-care/dental-care>. Accessed July 20, 2018, 2018.
44. Kirk M, Berntsen D. A short cut to the past: Cueing via concrete objects improves autobiographical memory retrieval in Alzheimer's disease patients. *Neuropsychologia.* 2018;110:113–122. [PubMed: 28676268]
45. Chun MM, Jiang Y. Contextual Cueing: Implicit Learning and Memory of Visual Context Guides Spatial Attention. *Cognitive Psychology.* 1998;36(1):28–71. [PubMed: 9679076]
46. Polenick CA, Struble LM, Stanislawski B, et al. “I’ve learned to just go with the flow”: Family caregivers’ strategies for managing behavioral and psychological symptoms of dementia. *Dementia.* 2018;0(0):1471301218780768.
47. Small JA, Gutman G, Makela S, Hillhouse B. Effectiveness of Communication Strategies Used by Caregivers of Persons With Alzheimer's Disease During Activities of Daily Living. *Journal of Speech, Language, and Hearing Research.* 2003;46(2):353–367.
48. Orange JB, Colton-Hudson A. Enhancing Communication in Dementia of the Alzheimer's Type. *Topics in Geriatric Rehabilitation.* 1998;14(2):56–75.
49. Bourgeois MS. Communication treatment for adults with dementia. *Journal of speech and hearing research.* 1991;34(4):831–844. [PubMed: 1956191]
50. Clark LW. Interventions for persons with Alzheimer's disease: Strategies for maintaining and enhancing communicative success. *Topics in Language Disorders.* 1995;15(2):47–65.

Table 1.

Time Points of Home Visits

Weeks from Baseline Visit	Event
0	Baseline Visit/ Home Visit 1
4 weeks	Coaching Module 2 (via telephone)
8 weeks	Coaching Module 3 (via telephone)
12 weeks	Home Visit 2
12-16 weeks	Post Intervention Interview (via telephone)
24 weeks	Home Visit 3 for follow up measures.

Table 2.**A priori Codes in Used in Directed Content Analysis**

<i>A priori</i> Codes	Definitions
Adaptive Challenge	The disparity between a person's capabilities of familiar methods, habits or values and the demands of the present circumstances. Adaptive challenges require the Individual with Mild Dementia (IMD) (or family member) to adjust to a new situation and to do the work of adapting, learning, and behavior change.
Adaptive Work	Engaging in activities to facilitate specific changes (e.g. values/attitudes, skills, learning and behaviors) that the IMD or caregiver needs to make to achieve the clinical, lifestyle, or system outcomes they desire.
Collaborative Work	The process of engaging others (IMD or carepartner) in developing shared understanding of symptoms, IMDs' responses to the symptoms, associated challenges, and sense-making for shared meaning. These are the basis for jointly developing care plans to address technical and adaptive challenges.

Table 3.

Participant and Carepartner Demographics

Characteristic	Participant	Carepartner
Age, Mean (SD)	73.3 (6.4)	65.7 (13.9)
Relationship to study partner (%)	--	
Spouse		81.8
Child		18.2
Male (%)	63.6	36.4
Race/Ethnicity (%)		
Non-Hispanic White	72.7	72.7
Non-Hispanic Black	18.2	9.1
Hispanic		9.1
Asian	9.1	9.1
Educational Level (%)		
High School	9.1	18.2
Some College	27.3	63.6
College		9.1
Post college	63.6	9.1
Health insurance status (%)		
Having health insurance with dental coverage	54.5	54.5
Having health insurance without dental coverage	36.4	36.4
No health insurance	9.1	9.1
Mild Dementia (%)	72.7	--
MCI (%)	27.3	--
Montreal Cognitive Assessment, Mean (SD)	18.1 (4.2)	--