CANADIAN JOURNAL OF SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY

CJSLPA | RCOA

REVUE CANADIENNE D’ORTHOPHONIE ET D’AUDIOLOGIE

Winter ➤ hiver, 2012/2013
Volume 36, No. 4

CASLPA | ACOA

COGNITIVE-COMMUNICATION AND DEMENTIA: SPECIAL CONSIDERATIONS

SPECIAL ISSUE

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CANADIAN JOURNAL OF SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY

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The Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) is the only national body that supports and represents the professional needs of speech-language pathologists, audiologists and supportive personnel inclusively within one organization. Through this support, CASLPA champions the needs of people with communications disorders. The association was founded in 1964 and incorporated under federal charter in 1975. CASLPA's periodical publications program began in 1973.

The purpose of the Canadian Journal of Speech-Language Pathology and Audiology (CJSLPA) is to disseminate contemporary knowledge pertaining to normal human communication and related disorders of communication that influence speech, language, and hearing processes. The scope of the Journal is broadly defined so as to provide the most inclusive venue for work in human communication and its disorders. CJSLPA publishes both applied and basic research, reports of clinical and laboratory inquiry, as well as educational articles related to normal and disordered speech, language, and hearing in all age groups. Classes of manuscripts suitable for publication consideration in CJSLPA include tutorials; traditional research or review articles; clinical, field, and brief reports; research notes; and letters to the editor (see Information to Contributors). CJSLPA seeks to publish articles that reflect the broad range of interests in speech-language pathology and audiology, speech sciences, hearing science, and that of related professions. The Journal also publishes book reviews, as well as independent reviews of commercially available clinical materials and resources.

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CASLPA Vision and Mission

Vision

The Canadian Association of Speech-Language Pathologists and Audiologists ...the national voice and recognized resource for speech-language pathology and audiology.

Mission

The Canadian Association of Speech-Language Pathologists and Audiologists ...supporting and empowering our members to maximize the communication and hearing potential of the people of Canada.

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REVUE CANADIENNE D'ORTHOPHONIE ET D'AUDIOLOGIE

Objet et Portée

L'Association canadienne des orthophonistes et audiologistes (ACOA) est l'association professionnelle nationale reconnue des orthophonistes et des audiologistes du Canada. L'Association a été fondée en 1964 et incorporée en vertu de la charte fédérale en 1975. L'Association s'engage à favoriser la meilleure qualité de services aux personnes atteintes de troubles de la communication et à leurs familles. Dans ce but, l'Association entend, entre autres, contribuer au corpus de connaissances dans le domaine des communications humaines et des troubles qui s'y rapportent. L'Association a mis sur pied son programme de publications en 1973.

L'objet de la Revue canadienne d'orthophonie et d'audiologie (RCOA) est de diffuser des connaissances relatives à la communication humaine et aux troubles de la communication qui influencent la parole, le langage et l'audition. La portée de la Revue est plutôt générale de manière à offrir un véhicule des plus compréhensifs pour la recherche effectuée sur la communication humaine et les troubles qui s'y rapportent. La RCOA publie à la fois les ouvrages de recherche appliquée et fondamentale, les comptes rendus de recherche clinique et en laboratoire, ainsi que des articles éducatifs portant sur la parole, le langage et l'audition normaux ou désordonnés pour tous les groupes d'âge. Les catégories de manuscrits susceptibles d'être publiés dans la RCOA comprennent les tutoriels, les articles de recherche conventionnelle ou de synthèse, les comptes rendus cliniques, pratiques et sommaires, les notes de recherche, et les courriers des lecteurs (voir Renseignements à l'intention des collaborateurs). La RCOA cherche à publier des articles qui reflètent une vaste gamme d'intérêts en orthophonie et en audiologie, en sciences de la parole, en science de l'audition et en diverses professions connexes. La Revue publie également des critiques de livres ainsi que des critiques indépendantes de matériel et de ressources cliniques offerts commercialement.

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ACOA : Vision et Mission

Vision

L'Association canadienne des orthophonistes et audiologistes : porte-parole national et ressource reconnue dans le domaine de l'orthophonie et de l'audiologie.

Mission

L'Association canadienne des orthophonistes et audiologistes appuie et habilite ses membres en vue de maximiser le potentiel en communication et en audition de la population canadienne.

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From the guest editor

WINTER ISSUE

The papers in this special issue came about as a result of collaborations among several of the authors who presented their leading-edge research at a dementia-themed workshop held at the CASLPA Conference in 2009. The collection of conceptually linked articles on the topics of communication, discourse, hearing, caregivers, interventions, and Alzheimer's disease and related dementias is timely and relevant for audiologists and speech-language pathologists. Writers of recent published reports, such as those from the Alzheimer Society of Canada (2010), the World Health Organization (2012) and Alzheimer Disease International (2012) (World Alzheimer Reports, 2009, 2010, 2011, & 2012), present startling facts about the rising prevalence of dementia and its social, emotional and economic impacts. Current estimates indicate that there are over 500,000 people in Canada with Alzheimer's disease and related dementias, and over 37 million people worldwide with dementia. Estimated costs in 2010 were over $604 billion (US dollars) to care for all individuals with dementia and their caregivers. Audiologists and speech-language pathologists now face, and will continue to take on in their practices and caseloads over the next three to four decades, increasing numbers of clients with Alzheimer's disease and related dementias. The scholarly articles in this special issue offer theoretically sound and clinically useful material that will advance our understanding of the consequences of dementia on communication, language, hearing and caregiving. Moreover, the information in the papers will help us optimize the evidence-based professional care we provide for clients and their caregivers who are in desperate need of our professional input and guidance.

The opening paper by Mrs. June McKay sets the tone for the other articles in this special issue. Mrs. McKay was a spousal caregiver for nearly two decades as she looked after her husband who had Alzheimer's disease. McKay describes the inexorable changes in her husband, in herself and in their relationship during the onset and course of his dementia. She captures eloquently their partnered-journey, and how family caregivers, particularly spouses, can best come to understand the disease and to reconcile its devastating effects on their lives. In the second paper, Watson and co-authors outline the breadth and depth of the relationships among communication, caregiver burden and stress related to Alzheimer's disease and related dementias. Their contribution adds voice to McKay's personal story on the impact of and outcomes from dementia on communication and caregivers, thus broadening the traditional practice of audiologists and speech-language pathologists. The article by Purves and Phinney provides an elegant and scholarly data-driven interpretation using a family systems approach to understand the varying dynamics of conversations among family caregivers of individuals with dementia and the conversations they hold with their relatives with dementia. The data from the two families whose multiple members participated in Purves' original study show that members within the same family have widely divergent communication needs, perceptions and patterns of conversation with their relative. As a consequence, the authors note that clinicians must be cognizant of these myriad disparities among family members and suggest practitioners offer family-member-centered conversation enhancement considerations unique to each family member.

The three remaining articles in this special issue address intervention-based topics related to hearing loss and dementia, communication strategies for activities of daily care (e.g., handwashing), and communication enhancement education and training for caregivers. Hopper and Hinton provide clinically relevant material on hearing loss and dementia. What is of greatest importance, so write the authors, is a compelling need for clinicians to minimize multiple barriers to hearing among individuals with dementia. The authors propose convincingly that approaches to minimize barriers include, but are not limited to, recognizing that persons with dementia can suffer profound hearing loss, eliminating the stigma that nothing productive can be done to minimize the effects of hearing loss among persons with dementia, adapting hearing assessment protocols to reveal real hearing profiles, and implementing holistic, client-centered hearing interventions. Wilson and colleagues in the fifth paper in this series offer a comprehensive discussion of findings from their study on formal caregivers' perceptions of effective communication strategies related to handwashing by persons with dementia. Data were obtained from focus-group interviews from ten formal caregiving staff at two long-term care facilities in Ontario Canada. Analyses based on a multidimensional observation-coding scheme yielded thirty-three strategies while theme analyses of the interview data produced twelve strategies. The authors concluded that staff perceived person-centered strategies to be effective in optimizing communication during activities of daily living. The final paper in this special issue, contributed by Small and Perry, addresses TARGET - Training in Communication Enhancement for Dementia, a program developed by the authors for family caregivers of individuals with Alzheimer's disease. The discussion of TARGET by Small and Perry is clear, cogent and compelling because of its comprehensiveness, relevance and empirically based clinical value. The two principles that underscore the communication enhancement strategies of the TARGET program, (1) compensating for the cognitive and communication limitations of the person with AD and (2) connecting with the person on a relational level, provide scientifically sound, data-driven and real-world options for enhancing communication for family caregivers of relatives with Alzheimer's disease.

On behalf of the contributing authors, I extend our thanks to former CJSLPA Editor Tim Bressman and to his assistant, Suzie Dumitrescu, who were instrumental in initiating this Special Issue and who helped us through the first phases of its inception. I also offer our deep gratitude and thanks to current CJSLPA Editor Elizabeth Fitzpatrick and to her assistant Sarah Healy, who worked tirelessly providing and shepherding the scholarly peer-reviewed feedback on our manuscripts. They managed adroitly a timely review process and led us through to the final publication. Finally, I acknowledge the tremendous efforts of the many external reviewers who provided useful critical feedback on our manuscripts.

J.B. Orange, Ph.D.
Special Issue Editor
jborange@uwo.ca

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Préface au numéro spécial

NUMÉRO D'HIVER

Les communications composant ce numéro spécial ont vu le jour grâce à la collaboration entre plusieurs auteurs qui présentaient leur recherche de pointe à un atelier placé sous le thème de la démence dans le cadre de la Conférence de l'ACOA en 2009. Cette collection d'articles conceptuellement reliés, sur la communication, le discours, l'audition, les soignants, les interventions et la maladie d'Alzheimer et les démences associées, arrive à point nommé et avec pertinence pour les orthophonistes et les audiologistes. Des auteurs de rapports publiés récemment, comme la Société Alzheimer Canada (2010), l'Organisation mondiale de la santé (2012) et Alzheimer Disease International (2012) (World Alzheimer Reports, 2009, 2010, 2011, & 2012), présentent des faits surprenants concernant la prévalence croissante de la démence et ses impacts sociaux, émotifs et économiques. Les estimations actuelles indiquent qu'il y a plus de 500 000 personnes au Canada qui sont atteintes de la maladie d'Alzheimer et de démences associées, et plus de 37 millions de personnes dans le monde qui sont aux prises avec la démence. Les coûts estimatifs, en 2010, pour prendre soin de toutes les personnes atteintes de démence et de leurs soignants, étaient de plus de 604 milliards de dollars (US). Les audiologistes et les orthophonistes font maintenant face à des nombres de plus en plus importants de clients atteints de la maladie d'Alzheimer et des démences associées et vont continuer à accepter ces personnes dans leurs pratiques et leurs charges de cas pendant les trois ou quatre prochaines décennies. Les articles scientifiques qui composent ce numéro spécial offrent du matériel théoriquement solide et cliniquement utile qui fera avancer notre compréhension des conséquences de la démence sur les communications, le langage, l'audition et les soins. De plus, l'information contenue dans les communications vont nous aider à optimiser les soins professionnels à base de preuves que nous dispensons à nos clients et à leurs soignants, qui ont désespérément besoin de notre apport et de nos conseils professionnels.

La communication d'ouverture, par Mme June McKay, donne le ton aux autres articles de ce numéro spécial. Mme McKay a été épouse soignante pendant presque vingt ans alors qu'elle s'est occupée de son mari atteint de la maladie d'Alzheimer. Elle décrit les inexorables changements survenus chez son mari, en elle-même et dans leurs relations pendant l'installation et le cours de sa démence. Elle capture avec éloquence leur périple de couple et nous montre comment les soignants familiaux, particulièrement les époux et épouses, peuvent le mieux comprendre la maladie et se réconcilier avec ses effets dévastateurs sur leurs vies. Dans la deuxième communication, Watson et ses co-auteurs décrivent la largeur et la profondeur des relations entre la communication, le fardeau des soignants et le stress relié à la maladie d'Alzheimer et aux démences associées. Leur contribution ajoute un voix à l'histoire personnelle de McKay sur l'impact et les résultats de la démence sur la communication et les soignants, élargissant ainsi la pratique traditionnelle des audiologistes et des orthophonistes. Les articles de Purves et Phinney donnent une interprétation élégante et scientifiquement fondée sur des données en utilisant une approche systémique familiale pour comprendre les dynamiques variantes des conversations entre les soignants familiaux de personnes atteintes de démence et les conversations qu'ils tiennent avec ces parents. Conséquemment, les auteurs notent que les cliniciens doivent être au courant de ces myriades de disparités entre les membres d'une famille et suggèrent aux praticiens d'offrir des considérations d'amélioration de la conversation centrée sur le parent qui soient propres à chaque membre de la famille.

Les trois derniers articles de ce numéro spécial traitent de sujets reliés à l'intervention ayant trait à la perte auditive et à la démence, aux stratégies de communication pour les activités de soins quotidiens (par ex., le lavage des mains), et l'éducation et la formation visant à améliorer la communication à l'intention des soignants. Hopper et Hinton offrent du matériel cliniquement pertinent sur la perte auditive et la démence. Ce qui est le plus important, écrivent les auteurs, c'est un besoin incontournable, pour les cliniciens, de minimiser les multiples obstacles à l'audition chez les individus atteints de démence. Les auteurs proposent, de façon convaincante, que des approches visant à minimiser les obstacles comprennent, mais sans s'y limiter, la capacité de reconnaître que les personnes atteintes de démence peuvent subir une perte auditive profonde, d'éliminer le stigmatisme que rien de productif ne peut être fait pour minimiser les effets de la perte auditive chez les personnes atteintes de démence, d'adapter les protocoles d'évaluation de l'ouïe pour révéler les véritables profils d'audition et de mettre en œuvre des interventions auditives holistiques axées sur le client. Wilson et ses collègues, dans la cinquième communication de cette série, offrent une discussion complète des constatations découlant de leur étude sur les perceptions des soignants formels de stratégies de communication efficaces en rapport avec le lavement des mains par des personnes atteintes de démence. Les données ont été obtenues au moyen d'entrevues de groupes de discussion auprès de dix personnes soignantes formelles travaillant à deux installations de soins à long terme de l'Ontario (Canada). Des analyses basées sur une structure d'observation-codage a produit trente-trois stratégies tandis que des analyses thématiques des données d'entrevues en a produit douze. Les auteurs concluent que le personnel a perçu les stratégies centrées sur la personne comme efficaces dans l'optimisation de la communication pendant les activités de la vie quotidienne. La dernière communication de ce numéro spécial, une contribution de Small et Perry, traite de TARGET – Training in Communication Enhancement for Dementia, un programme élaboré par les auteurs à l'intention des soignants familiaux de personnes atteintes de la maladie d'Alzheimer. La discussion de TARGET par Small et Perry est claire, convaincante et attirante à cause de son aspect complet, de sa pertinence et de sa valeur clinique à base empirique. Les deux principes qui soulignent les stratégies d'amélioration de la communication du programme TARGET, -- (1) compenser pour les limites de cognition et de communication de la personne atteinte de l'Alzheimer et (2) établir une connexion avec la personne sur un niveau relationnel, -- offrent des options scientifiquement solides, basées sur des données et ancrées dans le monde réel pour améliorer la communication pour les soignants familiaux de parents atteints de la maladie d'Alzheimer.

Au nom des auteurs collaborateurs, j'offre nos remerciements à l'ancien rédacteur de l'ACOA Tim Bressman, à son adjointe, Suzie Dumitrescu, qui ont joué un rôle capital dans la préparation de ce numéro spécial et qui nous ont aidés à passer à travers les premières étapes de son démarrage. J'offre également notre gratitude la plus profonde et nos remerciements à la rédactrice actuelle de l'ACOA, Elizabeth Fitzpatrick, et à son adjointe Sarah Healy, qui ont travaillé sans relâche à dispenser et à gérer la circulation des commentaires de pairs scientifiques sur nos manuscrits. Elles ont mené avec adresse un processus de révision bien synchronisé et nous ont mené à travers ce processus jusqu'à la publication finale. Enfin, je reconnais les efforts formidables des nombreux réviseurs externes qui ont offert des commentaires critiques utiles sur nos manuscrits.

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Organisation mondiale de la santé. (2012). *Dementia: A public health priority.* Geneva. Switzerland: WHO Press.

J.B. Orange, PhD
Rédacteur du numéro spécial
jborange@uwo.ca

Communication and Dementia: Perspectives from a Spouse

La communication et la démence : les points de vue d'une épouse

June McKay

Caregivers of relatives with dementia face a multitude of changes including loss and adjustments to relationships and lifestyle. It takes courage, flexibility and willingness to change and to grow to be an effective caregiver for a family member who has dementia.

I was first a caregiver for my three children, then sometimes for my Mom who lived to almost 103 years of age and who once said when she was 92, "I'm not going into one of those homes. Everyone there is either old or crazy!" The next time I was a caregiver was for my husband, Jack McKay, who had Alzheimer's disease for about 20 years. He was in long-term care for almost seven years.

Caring for my husband Jack is very close to my heart, so I write this contribution from the heart. Caregiving is a very emotional experience. Disraeli once said, "Never apologize for showing feelings. When you do so, you apologize for truth."

My caregiving for Jack followed a long, rocky and unexpected road; certainly not an easy journey. I write this paper to share some of the frustrations of our journey as well as to recount some of the brighter times we shared. My purpose is to not minimize the immensity of the task that caregiver's face regardless of their profession (e.g., those who work in a nursing home, audiologists, speech-language pathologists, personal care workers, registered practical nurses etc.) or the clients for whom they provide care (e.g., those with cancer, stroke, hearing loss, multiple sclerosis Alzheimer's disease, etc.). My intention is to be of help to other caregivers and to professionals providing care to persons with dementia.

Here is our story. My husband Jack was born and raised on a farm near Kintore Ontario, a farm that had been established by his great-grandfather who emigrated from Scotland in 1830. The farm has been in the McKay family for four generations. From that farm, two of my husband's great-uncles and four of his uncles left to enter the Christian ministry. It was the hope of Jack's parents that he would be the seventh McKay to enter the work of the church, but he became sick and tired of hearing about their goals for him. When he was 13 years of age, just entering Grade 9, he stomped out of school one day saying to his teacher, "If they think they are going to make a minister out of me, they're wrong!"

Jack went to work on the farm with his Dad, which is what he really wanted to do. He loved the farm, which eventually he was to inherit. However, after seven years of farm work it became very clear to Jack that serving the church was his real calling. After not reading a book for seven years, he returned to complete five years of high school in just three short years. He once told me how he cried himself to sleep because at age 20 he could not do Grade 9 memory work. After completing his high school diploma in record time, despite the learning hurdles, he completed a three-year B.A. degree and then his master's degree at Emmanuel College in Toronto. I share this history with you so that you can understand the depth of his commitment and determination to follow that dream. Jack was ordained into the United Church in 1957. He served the church for over 37 years. During that time he served on many national and local committees as President and Chairperson.

Jack was a born speaker and motivator, a genuine sparkplug whose innovative and creative nature re-kindled the fire which was needed frequently to re-energize many congregations. Church memberships increased and participation of congregational members on church-based projects soared wherever he went. He had great compassion for people, welcoming newcomers to our community, visiting hundreds of homes and hospital rooms and officiating at myriad weddings, baptisms and funerals.

Jack spent a great deal of time reading and writing. He was always ready to listen. He also made extra special efforts to help others. Interestingly, he was a naturally gifted handyman, able to take apart and to repair machinery. He even took a course in plumbing at Fanshawe College but that did not mean that we never called a plumber to fix the leaky faucets!

In the late 1980s, at about age 58, Jack began having trouble remembering appointments. I tried to be gentle with my reminders so that he would not feel threatened. It became more difficult for him to concentrate on what he was reading. He began getting uncomfortable in large gatherings where there were several conversations going on at one time. Prior to these emerging difficulties in large-group conversations, he had always been front and center of every conversation. However, after being in a group for a short while, he would say, "Well Junie, I think we should be on our way". He experienced trouble putting back together items he had dismantled when trying to fix them. His sense of judgment changed. He became easily frustrated. Sometimes, he made comments that seemed inappropriate.

These emerging features were so unlike the Jack with whom I had shared my life for many years. He took retirement three years earlier than planned, at age 62, because he had trouble coping with the fast pace and the stress with which members of the clergy have to deal. I tried to convince myself that the confusion and frustration were a result of decades of work overload. Then came periods of depression. He slept a great deal. He would say, "I can't do things anymore. I guess things are going to be over for me". When he said words like these, I would suggest a walk or supper at a local restaurant for fish and chips to divert his attention from his sorrowful moments.

We sought professional guidance and were told initially that he appeared to be suffering from short-term memory loss. He was given medication to help with the depression. Eventually, we went through numerous tests; the EEGs, the mini-mental tests, the questioning, the counseling, all of which led to the dreaded but not unexpected, and I might write very bluntly, verdict: "You have Alzheimer's disease. There is no cure". This was a horrible blow. We knew that the outlook with this irreversible, relentless disease was pretty bleak. It was a darn shame! Although not unforeseen, I was not really aware of the depth of anxiety that it would cause him and me. Little did I realize just how much our lives would change.

Aricept was prescribed as a medication for Jack to slow the progression of the disease. The next blow to Jack was losing his driver's license — another bitter pill to swallow. We attended the 10-week Family Information Sessions at the Alzheimer's Outreach Service at McCormick Home in London Ontario run by social workers Magdalen Carter and Helen Jevnikar. I found the sessions very helpful. I learned a great deal about Alzheimer's disease but Jack did not want to go after the first three sessions. I could not force him to attend.

Jack's depression continued. He would go for long walks preferring to go alone, although we used to walk together almost every day. I often found him crying. He would say, "Maybe I'll just go down to the river", presumably to drown himself. This was scary! This was NOT what retirement was supposed to be like!

Then came the realization that I would have to find a facility for Jack where he would be safe, where there would be activities that he could become involved to help fill his days. I am tremendously grateful that we had completed our Powers of Attorney for personal care and finances a few years before the onset of Jack's Alzheimer's disease.

I first chose a retirement residence for Jack in 2002. I will never forget the day that I had to tell him that there was a room waiting for him. I am haunted still by the memory of leaving him, knowing that he would never be home again, never share the travelling that we loved so much, never walk the beach together, never stuff the Christmas turkey together, never again share the same bed. His move to a retirement residence led to a huge shift in my life and my roles. We once were a team! Now I held responsibilities for our finances, insurance, property upkeep, and family.

Jack's medications gave him hallucinations. Twice when I went to visit I found him hiding in his closet. He told me that he saw strange things flying around his room. He began wearing two and three shirts at a time, and shoes without socks. He gave away his belongings and tried to slip out of the main door of the residence. I tried my best to be with him each day, help him dress properly and to help shower and shave. He called me on the phone several times each day with the same wistful, "When are you coming?" Many times when I went I found him crying.

The success of this placement was mediocre. I longed to bring him home. However, I knew that I could not look after him at home. In less than a year it became apparent that he would have to be placed in a secure locked unit in another facility. I made application to our local Community Care Access Centre and visited several long-term care facilities. The first site we were offered included a semi-private room. The bathroom was located inside the doorway on the left, and Jacks' roommate's bed was next to the bathroom. Jack's bed was by the window. He had to walk past the other bed to use the bathroom. The physical layout was most confusing to him. He could not cope well with this room design.

Jack then moved to a private room in the same facility with a shared bathroom. This arrangement was frustrating for Jack because he could not figure out why someone else would be in the bathroom when he opened the door. After another year or more I was told that he would be moved to the special Alzheimer's floor. I admit that I resisted this move for a while. Surely MY husband was not going be one of "them". The choice was not mine, however, as he was wandering in and out of other people's rooms. But it was time for the move. I had no other options. On the Alzheimer's floor, the wandering was accepted. It was not uncommon to find someone coming into his room, either walking or in a wheelchair, or even sleeping on his bed. Sometimes I would find Jack sleeping in someone else's room. We had to make sure that everything that belonged to Jack was labeled with his name because items would go missing. Fortunately Jack had his own teeth because I had heard of residents trying to wear someone else's false teeth!

Various medications and combinations were given to him, some helpful and some with negative results, making him quite groggy and unresponsive some days. Despite the multiple medications, Jack still knew me. He would give me smiles that warmed my heart. My daily routine was to visit him at about 3 o'clock and take him walking around the halls. He just wanted to keep on going. Sometimes we went into the garden when the weather allowed. I fed him his evening meal.

As the disease progressed he rarely spoke, maybe a "No" or a "Yep". He had no memory of the churches in which he served, of his family or of our homes. He gradually lost his ability to feed and to dress himself. He needed total care for his daily activities. Then came the wheelchair because he was unsteady. It was used most of the time unless I, a family member, volunteer, or staff took the time to walk with him. The more he was in the chair, of course, the more his muscles deteriorated. Another miserable change was the onset of incontinence. It is embarrassing, sickening and not pleasant by any means. "Somebody, please say it isn't so!"

Thankfully there were bright spots and even funny events that helped us through the day. Once after Jack had not spoken for quite some time, on a day when he was particularly alert and listening to me, I said, "Let's get married". He looked at me and then said "Oh, my Gosh!" After a moment he smiled and said, "Sure sounds good to me!"

Jack also had trouble swallowing. He would just keep on chewing the same bite and not swallow. We changed to a pureed diet that he tolerated for a while but certainly did not enjoy.

I assisted the staff in getting Jack ready for bed. He was more comfortable when I was there. I massaged his legs and feet with lotion. As I tucked him in there was always that familiar smile, that loving face that held all those cherished memories. Sometimes he got pushy and resistant when strangers came in to undress him. It must have been frightening. I am sure that those suffering from dementia must feel exposed and uncomfortable. No wonder they can become difficult. Any one of us probably would.

I admit that I got impatient when I could not find staff to give me a hand in the evening. Often times there were just three personal care staff to care for 36 residents, to see that they were fed, and washed and ready for bed. Their load is just too heavy, but that is just how it is. One day I read in the local London newspaper that a member of parliament, Carolyn Bennet, said that the future for senior care looked even more grim! So I said to myself, "June, get used to it!"

I want to note some feelings that I experienced during this time. I do so after much thought and soul-searching, hoping that my comments are constructive. Imagine, for a moment if you can, being in some state of dementia or confusion. Someone comes and wheels you into a room and begins taking off your shirt, trousers or slacks. You are frightened and strike out with your arm or foot because this just does not feel right. Your actions must be reported as an incident. As a consequence, your medication is increased which makes you even more dopey and bewildered. Similarly, imagine being attended to by two staff who are raising you in one of those big lifts to get you into bed who do not talk to you at all, or who talk around you and over your head about when they will have their break, what they are going to do with the kids on the weekend, or a shopping spree they are planning.

On the other hand, think about this scenario. Someone says to you "Hi there! It's time to get ready for bed. Let's go into your room. Let's start with the shirt. Can you bend your arm for me? Now we need to put on your pyjama pants. Now, let's get those teeth brushed". I thank God for those angels who start their workday, saying "Today. I am going to make someone's day a little bit brighter." I met some of these wonderful people and have not forgotten their care, their gentle way with Jack and their heartfelt, sincere chats with me.

Like every other caregiver, I wanted my spouse to have the best of care. That is not always what our current health system provides. Sometimes it was 8 or 9 o'clock when I got home from caring for Jack. It was a tough 'part-time' job. Some nights when I got home I filled up the Jacuzzi tub, turned on the jets and sat for a long time. Some evenings my tears could almost have filled the tub. We all have those times. What happened to Jack was a darn shame, but I felt wrapped in the concern and compassion of those marvelous caregivers.

I knew that as long as Jack knew me I would be there …. long after that! Someone said, "He will know your touch long after he has lost his ability to speak," and I believe that this is true. Until the day he passed away Jack would look at me and his eyes would open wide and he would make some sort of sound as if trying to speak.

Not being able to swallow for months and just choking and choking, he went from 190 pounds to 139 pounds during the last eight months, and passed away in January 2009.

During my caregiving my family was gracious enough not to load me with their concerns. I know that this whole experience has affected them deeply. Their fears for their own future health are real, and rightly so.

There were times when I was asked, "How can you keep on doing this and still smile? Where do you get the strength? " Well, I cried lots! One of the outcomes of my caregiving for Jack was that I developed a life apart from looking after him. I saw and still see caregivers who do nothing else but look after a partner, a parent or a child. I could not survive that way. I tried to realize my own limitations. I needed change, and sometimes took breaks so that I could be refreshed when I was with Jack. My greatest strength comes from my faith. I believe that faith is there for everyone whether it is the Christian faith, Jewish, Muslim or Buddhist. We can all find faith in different places. Maybe strength will come from within your family unit or your neighborhood group. Mine is a faith I grew up with. It is there, miraculously, each new day, and because of it I can face the challenges. I have never been alone.

I have a favourite quote, held on my refrigerator by four little ladybug magnets right beside a photo of Jack, which I read every day:

Take Heart. Even though the person you have loved may appear different and behave in ways alien to their past, rest assured that within this disturbed physical body rests the unblemished spirit of the person you love. Treasure that person, even as he or she may be slipping from your hands into the hands of a loving God. And rest assured that, in God, all memories are preserved.

Links Among Communication, Dementia and Caregiver Burden

Liens entre la communication, la démence et la charge des soignants

Barbara Watson
Lisa Dawn Aizawa
Marie Y. Savundranayagam
J.B. Orange

KEY WORDS
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Barbara Watson, MN, RN, Ph.D. student,
Health and Rehabilitation Sciences Program, Faculty of Health Sciences, Western University
London, ON
Canada

Lisa Dawn Aizawa, MClSc, S-LP(C), Reg. CASLPO,
Toronto, ON
Canada

Marie Y. Savundranayagam, Ph.D.
Assistant Professor, School of Health Studies, Faculty of Health Sciences, Western University
London, ON
Canada

J.B. Orange, Ph.D., S-LP(C), Reg. CASLPO
Professor and Director, School of Communication Sciences and Disorders, Faculty of Health Sciences, Western University and Associate Scientist, Lawson Health Research Institute
London, ON
Canada

Abstract

Dementia is a degenerative syndrome that affects multiple mental functions including cognition and behaviour. Family caregivers of individuals with dementia also experience the devastating effects of the syndrome because of their relatives' memory, language and communication problems. Currently, Canadian family caregivers provide more than fifty percent of the care for an estimated 500,000 people with dementia. Audiologists and speech-language pathologists need to be cognizant of the expanding communication, hearing and language needs of individuals with dementia and their family caregivers. This paper addresses the complex relationships among communication problems in dementia, the burdens suffered by family caregivers, and the effects of communication education and training programs designed to enhance communication and to minimize caregiver burden. The literature shows clearly that clinicians must include both family caregivers and their relatives with dementia in comprehensive communication care interventions in order to achieve optimal outcomes. Moreover, clinicians must provide education and training to caregivers concerning the use of evidence-derived effective communication, hearing, language and speech strategies to help reduce caregiver burden.

Abrégé

La démence est un syndrome dégénératif qui affecte de multiples fonctions mentales, dont la cognition et le comportement. Les personnes atteintes de démence éprouvent des problèmes de mémoire, de langage et de communication. Ces problèmes ont également des effets dévastateurs chez les proches des personnes atteintes de ce syndrome. Présentement, les soignants familiaux canadiens dispensent plus de cinquante pour cent des soins à des personnes atteintes de démence, dont on évalue le nombre à 500 000. Les audiologistes et les orthophonistes se doivent d'être au courant des besoins croissants au plan de la communication, de l'audition et du langage des personnes atteintes de démence et de leurs soignants familiaux. Cet article traite des relations complexes entre les problèmes de communication reliés à la démence, la charge imposée aux soignants familiaux et les effets des programmes d'éducation et de formation en communication conçus pour améliorer la communication et minimiser la charge des soignants. La littérature montre clairement que les cliniciens doivent inclure autant les soignants familiaux que leurs personnes atteintes de démence dans leurs interventions visant la communication globale afin d'atteindre des résultats optimaux. De plus, les cliniciens doivent renseigner et former les soignants concernant l'utilisation de stratégies efficaces dérivée de preuves dans les domaines de la communication, de l'audiologie et de l'orthophonie pour aider ceux-ci à réduire la charge infligée aux soignants.

Introduction

The practices and caseloads of audiologists and speech-language pathologists in Canada now include increasing numbers of clients who have dementia. These same clinicians will be confronted with rising numbers of individuals with dementia over the coming three decades. Estimates suggest that currently there are over 500,000 people with dementia in Canada, with predictions that there will be close to 750,000 individuals with dementia in Canada by 2031 (Canadian Study of Health and Aging Working Group, 1994).

Authors of the report titled "Rising tide: The impact of dementia on Canadian society" (Alzheimer Society of Canada, 2010) state emphatically that medical, health and social practitioners need to be educated fully and trained carefully to meet the changing multi-faceted needs of those with dementia. The authors advocate for the provision of unwavering support to informal caregivers of persons with dementia including family members, relatives, neighbours, and to professional/formal caregivers such as health care aids, nurses, occupational and physical therapists, recreation therapists, and social workers, among others. New role-emerging elements within the scopes of practice of audiologists and speech-language pathologists mean that clinicians who embrace evidence-based practice patterns must adopt a holistic and empirically-based perspective of communication care that, at its minimum, considers the dyad consisting of the person with dementia and her/his caregiver. Audiologists and speech-language pathologists are well positioned to take on the mantle of new emerging roles of practice for persons with dementia and their caregivers. The purpose of this paper is to discuss the conceptual links among dementia, communication problems, and informal caregivers, with special emphasis on the emotional, social and physical burdens experienced by family caregivers of individuals with dementia. The implications of these links are discussed within the context of communication enhancement education and training programs for family caregivers that can be implemented by audiologists and speech-language pathologists.

Communication and Dementia

Communication provides people with mechanisms to connect, to interact with others and their environments, and to establish, to maintain and to change relationships. It provides a means to interpret one another's needs through the exchanges of information (Bourgeois, 2002). Cognitive-communication refers to the relationships among language, speech, cognition and brain functions. These relationships become evident when an individual suffers language impairments and associated disruptions to cognitive systems and processes. Diseases affecting cognition, such as dementia, reveal the important links among episodic memory problems (i.e., the long-term declarative memory component responsible for temporal-based events such as one's birthdate), semantic memory impairments (i.e., long-term declarative memory component for concept and fact-based knowledge, word meaning) and language disturbances that result in a cognitive-communication impairment.

Dementia is a progressive, degenerative neurological and psychiatric syndrome that stems from changes to neuronal and neurochemical activities that control behaviours and mental abilities including language, communication, and cognitive skills (McKhann, et al., 2011). There are multiple types of dementia with the common unifying feature being declines in cognition, language, behaviour and social skills that manifest over three clinical stages (i.e., early/mild, middle/moderate, late/severe) (Lubinski & Orange, 2000; Macoir & Turgeon, 2006).

Language changes associated with dementia range from difficulties finding words in the early/mild clinical stage to little or no verbalizations in the late/severe clinical stage (Azuma & Bayles, 1997; Bayles & Tomoeda, 2007). During the early/mild clinical stage cognitive abilities decline more rapidly than do verbal abilities but word finding problems are the hallmark feature (Macoir & Turgeon, 2006; Richter, Roberto & Bottenberg, 1995; Tang-Wai & Graham, 2008). Language problems become more noticeable in the middle/moderate clinical stage where spoken and written statements are vague due to semantic emptiness. In the late/severe clinical stage there is less eye contact, significantly impaired listening and reading comprehension of semantically common words, plus substantially reduced access to and retrieval from semantic memory (Beach & Kramer, 1999; Causino-Lamar, Obler, Knoefel, & Albert, 1994; Roberto, Richter, Bottenberg, & Campbell, 1998). Communication becomes increasingly difficult as language impairment progresses during the course of dementia.

Speech accommodation theory posits that speakers modify the way they speak to older adults (Coupland, Coupland, Giles, & Henwood, 1988). The intent of the speakers is to adapt their speech and language to meet the perceived needs of the older adults (Kemper, 1994). However, speakers risk over-accommodating their speech and language patterns due to negative stereotypes of older adults that can result in patronizing, condescending communication (Coupland et al., 1988). Lagace, Medouar, Loock, & Davign (2011) examined the relationship between communication and caregiving among 26 caregivers in a long-term care facility. They found evidence of less communication and more instances of patronizing communication, sometimes referred to as elderspeak (Kemper, 1994). Examples of elderspeak include high pitch when speaking, exaggerated intonation, terms of endearment (e.g., Honey, Sweetie, Dearie, etc.), and simplified grammar and syntax, among other features (Kemper, 1994). Staff-resident conversations were limited to topics such as diseases, medications and topics pertaining to the residents' immediate health. The professional caregivers admitted they completed sentences for seniors, and used patronizing gestures and communication. Staff cited time restraints as a cause for their elderspeak style of communication.

The Communication Predicament of Aging model describes what older individuals face when there is overaccommodated or elderspeak communication (Hummert, Garstka, Ryan, & Bonnesen, 2004). Encounters based on negative stereotypical cues of older adults that result in elderspeak often include the use of inappropriate speech and language modifications and nonverbal behaviours, especially when the person has dementia (Ryan, Meredith, Maclean, & Orange, 1995). The use of elderspeak is hypothesized to lead to inadequate care and to the loss of self-esteem for the individual with dementia (Kemper, Anagnopoulos, Lyons, & Heberlein, 1994; Orange, Ryan, Meredith, & MacLean, 1995). Professional and family caregivers need to understand the impact of elderspeak and to resist the use of this derogatory style of communication that undermines dignity and leads to a degenerating cycle of frustration and withdrawal. Family caregivers in particular who use elderspeak, especially those who are much younger than their older relatives (i.e., intergenerational dyads), run the risk of disenfranchising older relatives from the family unit and marginalizing their own role as a supportive member of the health care team.

Caregivers who adopt the basic tenets of the Communication Enhancement model are thought to counteract the decline in communication associated with dementia (Ryan et al., 1995). The primary concept of the model is that speakers adjust communication on real and individualized communication needs rather than stereotyped, ageist expectations of older adults. When caregivers see individuals with dementia as independent rather than dependent they are more likely to attribute the independence as unique to that individual and not rely on their own negative expectations (Polk, 2009). Family caregivers who learn and use supportive and enhancing methods of communication for relatives with dementia may very well be able to optimize personhood (Kitwood, 1997), and to improve the health and communication related quality of life for their relatives and for themselves. The recent development of valid and reliable communication assessment and observation scales for persons with dementia will help clinicians establish individualized communication strategies for family caregiver that also may help reduce the use of elderspeak (Orange et al., 2008; Williams & Parker, 2012).

Communication, Dementia, and Caregiver Burden

Family caregivers of persons with dementia have poorer mental health outcomes compared to caregivers of other illnesses such as cancer (Hooker, Monahan, Bowman, Frazier, & Shifren, 1998) which implies that the distinct qualities of dementia are what make caregiving burdensome. Communication problems are one of the distinct features of dementia, as noted above, and are perceived as stressful by family caregivers (Murray, Schneider, Banerjee, & Mann, 1999; Small, Geldart, & Gutman, 2000). Self-reports by family caregivers indicate that communication breakdown between the caregiver and person with dementia often leads to a decline in the quality of their interaction and relationship (Orange, 1991). Rabins, Mace, and Lucas (1982) stated that over two-thirds of family caregivers in their study reported their relatives with dementia had communication difficulties; of those caregivers, 74% reported that communication difficulties were problematic.

Caregivers often are unprepared for the declines in communication and its associated challenges (Orange et al., 1995; Williams, 2011). Family caregivers describe the loneliness, anger, and frustration related to the communication problems they experience with their relative with dementia (Murray et al., 1999; Small et al., 2000). Moreover, family caregivers mourn the loss of conversations and relationships with their spouses and parents (Millar, 2010; Orange, 1991; Parsons, 1997). Even persons with dementia have written about their own frustration with difficulty finding words, problems maintaining the topic of conversations and not being understood by caregivers (Taylor, 2007).

The relationship between communication problems and caregiver burden has been unclear because previous studies examined burden in terms of a group of stressors, only one of which included communication difficulties (Kinney & Stephens, 1989; Vitaliano, Young, & Russo, 1991). For example, Morycz (1985) included communication problems as part of a global measure on a vigilance-disruptiveness scale. Communication problems contributed to caregiver strain but other variables masked their potentially stronger effect on caregivers. Some communication difficulties have been grouped with problem behaviours. In particular, repetitive verbalizations (or repetitive questions) have been a source of stress to caregivers and have been the subject of behavioural interventions (Bourgeois, Burgio, Schulz, Beach, & Palmer, 1997; Pruchno, Kleban, Michaels, & Dempsey, 1990). However, the importance of communication difficulties in relation to caregiver burden is hidden when they are grouped with problem behaviours because problem behaviours do not address fully the range of communication issues associated with dementia.

Other studies suggest that communication problems may trigger problem behaviours (Burgio, Allen-Burge, Stevens, Davis, & Marson, 2000; Rau, 1993; Vitaliano, Young, Russo, Romano, & Magana-Amoto, 1993). Persons with dementia may respond with problem behaviours, such as yelling or agitation, when they experience communication breakdowns or misunderstandings in their conversations with their family caregivers (Murray et al., 1999). Indeed problem behaviours may be the result of difficulties retrieving words to explain the need to engage in activities (Volicer & Bloom-Charette, 1999), problems understanding verbal directions, or challenges finding words to express feelings/intent (Bourgeois, 2002). In an effort to disentangle the relationship between communication problems and caregiver burden, and prominent stressors such as problem behaviours, Savundranayagam, Hummert, and Montgomery (2005) found that problem behaviours mediated the relationship between communication problems and behaviors. Specifically, the more frequent the communication problems, the more frequent the problem behaviors. Problem behaviours were directly related to caregiver burden, reflecting findings from previous studies that behaviours, such as wandering, restlessness, fear and agitation, were one of the top contributors to caregiver burden (Richter et al., 1995; Ripich, 1994; Schulzet al., 2002).

Most of the research to date has focused on the role of communication patterns and impairments of the person with dementia and examined the relationship to caregiver burden. However, communication is interactive. Family caregivers may cope with disruptive behaviours using communication. For instance, Richter and colleagues (1995) found that caregivers used communication strategies such as providing reassuring words and gestures to manage problematic behaviours exhibited by their family members with Alzheimer's disease. Family caregivers' use of effective communication strategies may yield positive outcomes. Roberto and colleagues (1998) examined the communication patterns of audio-recorded conversation between 14 individuals with Alzheimer's disease and their spousal caregivers. They found that caregivers with higher communication adequacy scores possessed better communication patterns, fewer behavioural problems, and lower levels of caregiver stress and burden. Although the aforementioned studies examined the various ways in which family caregivers cope effectively with difficult behaviours, these coping mechanisms may also contribute to communication breakdown by their use of ineffective communication strategies. Savundranayagam and Orange (2011) recently investigated the relationship between caregiver communication strategies and caregiver burden, after controlling for potentially confounding factors such as kinship status in addition to cognitive level and problem behaviours of the family member with Alzheimer's disease. They specifically examined the relationship between burden and caregivers' appraisals of the effectiveness of communication strategies used to repair misunderstandings. The findings revealed that when caregivers correctly appraised effective strategies, they experienced lower levels of anxiety in their relationship and perceived their relative with Alzheimer's disease as less demanding or unreasonable. In other words, interpersonal relationships are strengthened when caregivers correctly appraise and use strategies that have been shown to be effective. These findings can inform future communication enhancement interventions designed to help family caregivers (see contributions in this special issue by Small and Perry and by Wilson and colleagues). Specifically, they highlight the importance of assessing caregivers' perceptions of the effectiveness of communication strategies. If caregivers do not think a strategy is effective, they might be less likely to use it. Conversely, if caregivers think a strategy is helpful when the evidence suggests otherwise, they may be more likely to use strategies that exacerbate communication breakdowns, possibly leading to further problems. For this reason, Savundranayagam and Orange (2011) recommended that assessing such perceptions is an initial component of communication interventions aimed at family caregivers.

Communication Intervention and Family Caregiver Burden Studies

A literature search was conducted to identify communication skills and education training interventions for family caregivers of persons with dementia that included caregiver burden as an outcome measure. Results of this literature search yielded a total of seven studies published from 1995 to 2011. Authors of two studies found that family caregiver burden decreased following education and training. Authors of one study indicated that burden increased marginally whereas authors of three papers indicated no change.

Authors of one paper found inconclusive evidence of change in caregiver burden.

Gentry (2010) evaluated an idiographic, individualized approach to communication education and training using indirect repair responses with four family caregiver/care-recipient dementia dyads, For example, saying, "Let me see if I understand…", allows the listener to paraphrase for the person with dementia instead of highlighting errors or providing correction. Individualized education and training was provided in the caregiver's home over two sessions. Caregivers received general information about typically occurring speech, memory, communication and behavior difficulties over the progression of dementia, with a special focus on communication problems. This was followed by a discussion of specific communication problems occurring on audio-recorded conversations between the caregiver and the person with dementia. Caregivers were shown how their verbal behaviors contributed to incomplete communication interactions and then received training in "indirect repair" responses. Two of the four dyads showed modest improvements in burden pre- to post-intervention, with further decreases in burden at a three-month follow-up. Roque, Ortiz, Arajuo, and Bertolucci (2009) examined interactions between seven caregivers and patients with dementia using analyses of a questionnaire and videotaped interactions between individuals with dementia and their caregivers to determine which communication strategies caregivers used before and after receiving communication skills training from a speech-language pathologist. Questionnaire and communication data were collected 7 to 21 days post-training. While no specific outcome tool was used to measure burden, the authors of this study subjectively noted that caregivers reported that this training had a "positive impact on them"; however, no specific caregiver statements were provided.

The case study by Orange and Colton-Hudson (1998) included videotaped mealtime conversational data between a wife caregiver and her husband who had Alzheimer's dementia. Communication breakdown and repair strategies based on the video recorded meals provided the basis for an individualized caregiver communication enhancement education and training program. The Zarit Burden Interview (Zarit, Orr, & Zarit, 1985) scores showed a marginal increase of six percent in burden post education and training, despite the spouse reporting subjectively the usefulness and helpfulness of the education and training on care provision to her husband.

Done and Thomas (2001) conducted a randomized clinical trial to determine the effectiveness of an information booklet versus a short training workshop for teaching communication techniques targeted for family caregivers of individuals with dementia. Thirty family caregivers attended two group-training sessions of an hour, each separated by a week, while 15 caregivers only received the booklet. Data indicated that there was an equal reduction in emotional stress in both groups of caregivers. Weinrich, Jensen, and Hughes (2006) provided group communication counseling through two, ninety-minute communication counseling sessions, based on modules five and six of the FOCUSED program (Ripich, 1994; Ripich, Wykle, & Niles, 1995). Findings for the six family caregivers showed no significant changes pre- to post-program on their level of burden but did show that caregivers' awareness of strategies had increased. Ripich, Ziol, and Lee (1998) compared 19 caregivers who participated in the FOCUSED communication education and training program (Ripich, 1994; Ripich et al., 1995) to a control group of 18 individuals pre- and post-intervention(6-months post and 1-year post). Results showed a significant decrease in communication problems over time but no change in general levels of burden (i.e., hassles) for the group who participated in the FOCUSED program relative to the control group.

Haberstroh, Neumeyer, Krause, Franzmann, and Pantel (2011) developed and evaluated TANDEM - a psychosocial communication intervention designed to increase caregivers' use of effective strategies and to decrease caregiver burden. Nine participants received TANDEM intervention and were compared to a control group of 13 individuals. Findings showed that the highly structured weekly education and training of 2.5 hour sessions over 5 weeks resulted in significantly enhanced quality of life for the individuals with dementia. Caregivers reported an increased frequency of communication with persons with dementia and noted that their moods were significantly better on training days. However, a reduction of burden pre- and post-intervention could not be verified because the outcome measure, the Häusliche-Pflege-Skala (Gräßel, E. 2001) was not sufficiently sensitive to detect changes in caregiver burden.

Collectively, the findings from these small sample studies are equivocal with respect to showing improvements in caregiver burden through individualized education and training that targets specific communication enhancement strategies. It is also possible that observing reductions in caregiver burden is more likely with studies of a longer duration, as in the case of the study by Gentry (2010). The more important message from these and related studies is that family caregiver burden is a major problem that is only expected to grow in years to come as the large cohort of Canadian baby-boomers age and society continues the shift towards community-based healthcare.

Providing education and training to caregivers of individuals with dementia is an accepted practice. However, what remains unknown are the effects of any intervention as it relates to improved care for persons with dementia and the effects of communication skills education and training on family caregivers' burden. To date, only six published studies with objective measures of burden related to communication interventions were identified. Caregiver burden was conceptualized in these and related studies based on inconsistent terminology (e.g., burden, depression, stress, hassles). Furthermore, it is difficult to make sound comparisons across studies given the different study methods, sample sizes, and outcome measures of burden and communication success. Despite these methodological challenges, the aforementioned studies as a group possess scientific and clinical merit in that they show the potential to decrease caregiver burden via individualized communication skills education and training. As such, they lay the foundation for future theoretically sound and methodologically rigorous communication enhancement education and training programs for family caregivers of individuals with dementia and a novel way of conceptualizing family caregiver support.

Conclusion

As the number of individuals with dementia increases in the coming decades, the need for effective, readily available, and cost-efficient communication enhancement education and training programs to improve care for individuals with dementia and their families is vital. Audiologists and speech-language pathologists are key members of the healthcare team to advocate for the importance of early intervention in the provision of communication education and training to family caregivers of individuals with dementia. Their roles are particularly crucial given the decline in language abilities and the emergence of challenging behaviours as dementia progresses, and that individualized communication skills education and training has the potential to decrease caregiver burden. Research suggests that educating and training caregivers in communication strategies that increase successful interactions can result in reductions in caregiver burden (Zientzet al., 2007).

It is crucial that future communication education and training programs for family caregivers be effective from a health care cost standpoint, and a quality of life standpoint for both the individual with dementia and her/his caregiver (i.e., decrease in burden and health related burden associated conditions) (Bourgeois, Schulz, Burgio, & Beach, 2002). The work described by Small and Perry (2013) in this special issue provides an excellent and comprehensive outline of a communication education and training program for caregivers. Moreover, the paper by Purves and Phinney (2013) in this special issue on the need to individualize communication education and training to suit the needs of each family member-based dementia illustrates the need for clinicians and researchers to continue research on the complexities of family caregiver education and training interventions.

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Authors' Note

Correspondence concerning this article should be addressed to Barbara Watson, Health and Rehabilitation Sciences Program, Faculty of Health Sciences, 1201 Western Road, Elborn College, Western University, London, ON N6G 1H1. Email: bwatson3@uwo.ca

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Family Voices: A Family Systems Approach to Understanding Communication in Dementia

Les voix familiales : une approche familiale systémique à la compréhension de la communication dans les cas de démence

KEY WORDS
DEMENTIA
FAMILY SYSTEMS
COMMUNICATION
ETHNOGRAPHIC APPROACHES

Barbara A. Purves
Alison Phinney

Abstract

The impact of communication impairment in dementia on families is widely recognized in both the clinical and research literature, as is the relevance of family-centred practice. However, the way in which "family" is defined in these domains varies widely, and most often it refers to single individual family members who represent the family as a whole. In contrast, a family systems approach defines "family" as a social unit comprising all members in an interconnected, dynamic system. This paper illustrates how a family systems approach taken to explore the impact of communication impairment on two families, each including one member with dementia, can bring new insights to understanding that impact. We focus on findings from one data set (semi-structured interviews with members in each family) in a qualitative research study to describe, first, how individuals within each family experienced changes in conversation associated with communication impairment in dementia and, second, how each family as a unit accommodated to those changes. Results highlight ways that individuals within each family developed to adapt to the changing conversational abilities of their affected kin, but they also reveal how family members experienced a deep sense of loss when they could no longer maintain familiar conversational patterns with the person with dementia. Overall, findings illustrate how a family systems approach can offer new insights into the impact of acquired communication impairment on families. These insights are discussed with a specific focus on the implications for clinical practice.

Abrégé

L'impact sur les familles des troubles de communication dans les cas de démence est largement reconnu dans la littérature clinique et de recherche, tout comme la pertinence d'une pratique axée sur la famille. Mais la façon dont la « famille » est définie dans ces domaines varie largement, et, le plus souvent, le mot renvoie aux membres d'une seule famille individuelle qui représentent la famille dans son ensemble. Par contre, une approche familiale systémique définit la « famille » comme une unité sociale composée de tous les membres d'un système dynamique interconnecté. Cet article illustre comment une approche familiale systémique adoptée pour explorer l'impact des troubles de communication sur deux familles, chacune comprenant un membre atteint de démence, peut apporter de nouvelles connaissances visant à comprendre cet impact. Nous nous concentrons sur les constatations d'un ensemble de données (des entrevues semi-structurées auprès de membres de chaque famille) dans une étude de recherche qualitative qui avait pour but de décrire, dans un premier temps, comment les individus au sein de chaque famille ressentent les changements dans les conversations associées aux troubles de communication dans un cas de démence et, en deuxième lieu, comment chaque famille, en tant qu'unité, s'est accommodée à ces changements. Les résultats monrent que des individus au sein de chaque famille ont développé des façons de s'adapter aux capacités changeantes en situation de conversation de leur parent affecté, mais ils révèlent également comment les membres des familles ont éprouvé un profond sens de perte quand ils n'ont plus été en mesure de maintenir des comportements familiers de conversation avec la personne atteinte de démence. Dans l'ensemble, les constatations illustrent comment une approche familiale systémique peut offrir de nouvelles connaissances concernant l'impact sur les familles des troubles de communication acquis. Ces connaissances sont discutées en attirant particulièrement l'attention sur les implications qu'elles ont pour la pratique clinique.

Barbara A. Purves, Ph.D., S-LP(C),
School of Audiology & Speech Sciences, University of British Columbia,
Vancouver, BC
Canada

Alison Phinney, Ph.D., RN,
School of Nursing, University of British Columbia,
Vancouver, BC
Canada.

The impact of dementia on communication affects not only persons with the disorder but also those in their social networks, most notably, their families (Brewer, 2005; Orange, 1991; Savundranayagam, Hummert, & Montgomery, 2005; Small, Geldart, & Gutman, 2000). Given this, there is a need for family-centred practice in interventions with people with dementia, including counselling with respect to communication issues. Such counselling could help families to develop more effective communication while also supporting them in coming to terms with losses associated with communication impairments (Burns, 1996; Holland, 2007). Although there are reports in the research literature of interventions to support communication developed specifically for family members (e.g., McCallion, Toseland, & Freeman, 1999; Orange & Colton-Hudson, 1998; Spilkin & Bethlehem, 2003), there is little evidence regarding the extent to which such approaches are routinely implemented in speech-language pathology practice. While over 80% of 101 speech-language pathologists in Canada, who responded to a survey question concerning intervention for individuals with dementia, indicated that they often or always provided education to caregivers about strategies to improve communication for people with dementia, the question did not differentiate between family and professional caregivers (Hopper, Cleary, Oddson, Donnelly, & Elgar, 2007), reflecting a trend encountered elsewhere in the speech-language pathology literature (see, for example, Egan, Bérubé, Racine, Leonard, & Rochon, 2010). Yet, particular attention to family is surely warranted. The World Health Organization International Classification of Functioning, Disability, and Health (ICF: World Health Organization, 2001), which is widely accepted as a framework for speech-language pathology service delivery, emphasizes the importance of taking into consideration the unique contextual factors specific to individuals, including their families. Experiences of people with dementia, exemplified in the words of Carey Henderson in a coauthored memoir, also draw attention to the needs of family in the context of dementia:

> *"One of the things about this — it's in the family, and the family has not only me and my wife, but we have our children and our children have their spouses…In other words, this thing about Alzheimer's is not just about two people. It's about a whole mess of people"* (Henderson & Andrews, 1998, p. 65).

Henderson's words suggest that a family-centred approach to intervention invites involvement of a whole family, but they also raise an important question: who is family? Burns (1996), in describing intervention for people with dementia, acknowledges that the clinical setting may constrain who can be included as family, but where such constraints are not in place "family" can include a much broader range of people, including extended as well as immediate family (and in some cases, others in the person's social network).

In contrast to this broad designation of who may be considered family, "family" in much of the research literature regarding dementia, as well as in clinical practice, has come to be represented by a single individual often described as a family or primary caregiver, a term that can mask the complex and sometimes subtle differences between caregiving and family caring (Keady & Harris, 2009; Hicks & Lam, 1999). Keady and Harris note that "people with dementia have become separated from their family systems within research, practice and policy attention with the weight of these resources being targeted at individual or dyad based methods of support/understanding" (2009, p. 6). This has important implications that are relevant for speech-language pathologists working with families because conversation is not confined to caregiving relationships, nor is it the primary responsibility of any particular individual in the family; it is an integral part of every relationship within the family. This is exemplified in Brewer's (2005) description of family conversations that included her mother-in-law, who had Alzheimer disease. Brewer associated features of her mother-in-law's talk with her adult children, including her use of comments, questions and topic shifts, with changes in roles, sometimes speaking with the authoritative voice of a parent, at others times in the dependent voice of a child. Brewer's description, captured in a metaphor of "carousel conversations" (p. 87), not only offers a unique and valuable analysis of family conversation from the perspective of participants themselves; it also highlights the importance of understanding conversation in the context of family members' roles and relationships.

To date, in the research literature examining the impact on families of communication impairment in dementia, there has been very little attention given to specific relationships between participants with dementia and their family members; often, these latter participants are simply designated as family caregivers. In some (but not all) studies, inclusion criteria specified only spousal caregivers because family relationship was identified as a potentially confounding factor (e.g., Small & Perry, 2005). In single case studies, information about relationships has been included, for example, as spouse or daughter, but without exploring the implications of that relationship further (e.g., Orange & Colton-Hudson, 1998; Spilkin & Bethlehem, 2003).

In contrast to the research literature focused on communication in dementia, research concerning the experience of family caring in dementia more broadly has addressed the issue of type of family relationship quite extensively. Studies have explored the experiences of wives caring for husbands (Brown & Alligood, 2004; Perry & O'Connor, 2002), husbands caring for wives (Kirsi, Hervonen, & Jylhä, 2004; Parsons, 1997; Russell, 2001), daughters caring for mothers (Perry, 2004; Ward-Griffin, Oudshoorn, Clark, & Bol, 2007) and daughters-in-law and sons-in law caring for their spouses' parents (Globerman, 1996). Others have compared family caring across these different types of family relationships (Chesla, Martinson, & Muwaswes, 1994; MacRae, 2002). Findings from these studies shed light on how caring for a person with dementia may be experienced differently within the context of different family relationships, suggesting the possibility that family relationship may also affect the experience of coping with acquired communication impairment. This possibility points to the importance of studies that explore the impact of acquired communication impairment as experienced within different family relationships (e.g., Hallé, Duhamel, & LeDorze, 2011).

In addition to studies of more diversified family relationships, research regarding family caring for persons with dementia has also acknowledged "family" as including more than a single individual. Several studies have included multiple family members, contributing to our understanding of tensions and negotiations within families caring for relatives with dementia, but their findings were discussed across families, obscuring visibility of each family as an independent unit (Garwick, Detzner, & Boss, 1994; Globerman 1994, 1996). One study (Perry & Olshansky, 1996) incorporated a family systems approach to explore the interactions among members of one family in coming to terms with dementia (although the study did not include the person with dementia as a study participant). Their findings highlight the importance of approaching the family as a system in order to understand the challenges that they face collectively in coming to terms with dementia. More recently, there have been studies that have addressed the concept of family analytically as a unit, but have focused methodologically on one subsystem within the unit, i.e., the person with dementia and his or her spouse (Davies, 2011; Hellström, Nolan, & Lundh, 2005; Phinney, 2006) or the person with dementia and a daughter (Forbat, 2003; see Harlow & Murray, 2001 for an example in aphasia).

For speech-language pathologists offering communication counselling (Holland, 2007) for individuals with dementia and their families, a family-centred approach to practice offers a way to understand the multiple, overlapping needs and resources within the family, even in circumstances where intervention focuses most on a particular dyad. The importance of family-centred approaches in early intervention for children has been acknowledged for at least 30 years as evidenced in the implementation of Individualized Family Service Plans (Mahoney et al., 1999), but their value has also been acknowledged in recommendations for similarly collaborative approaches with adults with acquired communication disorders (dePompei & Williams, 1994; McLaughlin & Ross, 2006). Such a trend invites a closer look at concepts of family, drawing on family theories to develop models that can be incorporated into clinical practice. Family systems theories, developed in the fields of social work and family therapy, have provided much of the impetus for family-centred philosophies of service delivery (Hammer, 1998). While Hammer's review of family systems theories is oriented to early language intervention, it is just as applicable to service delivery for older adults. She draws on the work of Beevar and Beevar to identify four assumptions of family systems theory that: 1) the individual is part of a family system in which all members are interdependent; 2) patterns of behaviour are circular, not linear, with behaviours of all members influencing and being influenced by those of others; 3) change and development are ongoing and inherent in family systems and 4) failing to communicate or to act is as much a form of communication as choosing to communicate or act. She adds that different individuals will give different meanings to these communications and actions (or lack thereof), but each of these meanings holds true only for the person who ascribes it (Hammer, 1998, p. 6). Given these assumptions, a family is characterized by multiple perspectives, with different members giving different meanings to the same situation. It is these overlapping and sometimes conflicting perspectives that, in a family systems approach, form the starting point for intervention.

Family-centred approaches to clinical practice emphasize the importance of working from the perspectives of the family. Hammer (1998) suggests that a family systems approach that incorporates strategies from ethnography can help clinicians to identify those perspectives more clearly, using them as a starting point for intervention. However, acknowledging that the actual application of such strategies is time intensive and not necessarily within the scope of one's clinical training, Hammer suggests that speech-language pathologists "employ the sensibilities of ethnographers" (p. 9) in approaching intervention with families (see Simmons-Mackie & Damico, 2001, for a description of clinical application in aphasia). To date, however, there are few examples in the clinical or research literature to illustrate how this might be accomplished for families with dementia. Hammer's suggestion to use an ethnographic family systems approach applies equally well to research, where such an approach can inform our understanding of how changes in communication associated with dementia are experienced within a family. Such studies can provide a starting point for highlighting issues that might warrant further investigation in research while also suggesting possible questions for clinicians to address in their interventions for particular families.

The goal of this paper is to illustrate how an ethnographic family systems approach can inform our understanding of family members' experiences of communication changes in dementia. We also seek to illustrate how highlighting the perspectives of family members can bring new insights into the problems that they face and the resources that they bring individually and collectively to addressing those problems. In order to do this, we draw on selected findings from a qualitative study of two families conducted by the first author (Purves, 2006) that incorporated participant observation, interviewing and analysis of recorded conversations among family members — including the person with dementia. In this paper, we focus primarily on the interview data as a way to emphasize how exploring the interplay of different perspectives within each family can be relevant for speech-language pathology interventions such as communication counselling.

Overview and Methodology

The original study on which this paper is based sought to explore changes in family conversation associated with a diagnosis of dementia, the meanings that family members gave to those changes, and the implications of those meanings for the family as a unit. The study included two families (described below) and, as noted above, incorporated three sources of data, including: first, semi-structured interviews with each family member; second, everyday conversations among one or more family members (always including the person with dementia); and, third, fieldnotes from participant observation. Detailed descriptions of qualitative methodology, including the conceptual framework that grounded the study, specific procedures for data collection and analysis integrating and interpreting findings from all data sources, and steps to ensure methodological rigour, have been provided in previous publications (see Purves, 2009, 2011) and so will not be repeated here. Instead, we provide a brief description of the procedures as context for our presentation and discussion of the interview findings.

Participants

Two families were recruited, in accordance with a research protocol approved by a University of British Columbia behavioural ethics board, through a multidisciplinary facility specializing in the diagnosis of Alzheimer disease and related dementias. All participants are identified by pseudonyms. The Tanaka family included Rose, a woman with a diagnosis of probable Alzheimer disease, her husband Tom, and their three adult children, Linda, Maria, and Colin. The Thompson family included Margaret, a woman diagnosed with primary progressive aphasia[1], her husband John, and their four adult children, Angela, Christine, Stephen, and David. A detailed description of each family is given as part of the findings.

Procedures

There were three sources of data for the study, collected and analyzed separately for each family. The first was audio-recorded and transcribed semi-structured interviews (Kvale, 1996) of up to one and a half hours with each individual in each family, exploring the participant's understandings of the diagnosis of dementia, the impact of dementia on everyday family life and, finally, the impact of dementia on everyday conversations (see Appendix A for the interview questions). The second data source was everyday conversations among one or more family members (always including the person with dementia), selected and either audio- or video-recorded by family members themselves over a period of several months. For each family, one of these recorded conversations included the researcher (first author) and the husband/wife dyad, getting together for lunch or coffee. Overall, there were six recorded everyday conversations totalling approximately five hours for the Tanaka family, and five conversations totalling approximately three and a half hours for the Thompson family. The third data source was field notes from participant observation conducted by the researcher (first author) with each family over a period of several months in order to gain a richer understanding of their everyday lives. Every meeting with family members provided opportunities for participant observations including initial visits regarding the study, interviews, dropping off or picking up recording equipment and visiting for recorded conversations. Additional occasional visits that were not audio- or video-recorded took place at the invitation of the parents in each family.

Data sets for each family were analyzed at two levels, focusing first on the individual and then on the family as a unit. Interviews were analyzed thematically using constant comparative analysis to identify patterns and themes (Luborsky, 1994) in the three topic areas of diagnosis, family life and conversation within and then across individual interviews for each family. Conversations were then analyzed using principles from interactional sociolinguistics (Schiffrin, 1994) and conversation analysis (Heritage, 1984) to explore how features emerging from the interview data were reflected in each family's everyday talk. The final step of analysis involved integration of findings from interviews and from conversations to gain insight into how each family as a whole accommodated to the changes associated with dementia in one of their kin.

Findings

Each of the two families is presented here as a separate case. For each family, a description based on all of the above data sources and analyses is provided as context for the subsequent presentation of interview findings regarding changes in patterns of conversation and the meanings those changes hold for individual family members. A report linking those findings to patterns observed in conversational data has been published previously for the Thompson family (Purves, 2009) and for the Tanaka family is in preparation.

The Tanaka Family

The Tanaka family included Rose, a 74-year-old woman who was diagnosed with Alzheimer disease some months prior to the study, her husband Tom (also in his mid-seventies), and their three adult children, Linda, Maria and Colin. The family is Japanese-Canadian with both Rose and Tom having been born in Canada. Both Rose and Tom had lived all their lives in the city in which this study was conducted, with the exception of a period of internment during the Second World War. The Tanaka adult children were all between the ages of 30 and 40, with Linda the eldest and Colin the youngest. All three lived in their own homes with their partners; only Colin had children, one of whom was aged 6 years and the other 1.5 years. All three of the Tanaka adult children had a university education, as did Tom. The family was very close, both geographically and socially, all living within a few kilometres of each other and spending time together regularly, often over family meals. In addition, family members, including Rose, had worked together over the years in a variety of different businesses. Rose had also provided childcare for Colin's children. In their retirement, Rose and Tom enjoyed travelling together, as well as being quite active in their social community.

Rose's diagnosis of probable Alzheimer disease (AD), made about four months prior to her family volunteering for the study, was the result of a multidisciplinary assessment over the preceding several months. Results from that assessment indicated that she had cognitive impairment consistent with mild AD, which progressed to moderate AD by the end of the study. Her family had all been aware of changes in her behaviour over two or three years that eventually led to the assessment and all, including Rose, were aware of her diagnosis. Although family members described differences in when and how they each became aware of Rose's increasing difficulties, both in conversation (e.g., repeating herself) and in everyday functioning (e.g., forgetting to pay bills), the three adult children became collectively sufficiently concerned to push their father to seek medical assessment for their mother, a move that he initially resisted. During the months that followed the assessment, Rose's abilities continued to decline, and, although her family worked to keep her as involved as possible in their everyday activities (see Purves, 2011, for a description of how this was reflected through their talk), she was no longer able to look after her grandchildren, nor to perform independently such household tasks as cooking, formerly an area of real accomplishment for her. Finally, while she and Tom continued to take short trips together, sometimes with friends, they were no longer able to travel together as they once had done.

These changes in Rose's abilities caused realignments within the family as a whole in several ways. First, all three adult children were aware of the need to support not only their mother but also their father, who Maria described as "being more of a caregiver," while also acknowledging the impact on him: "I mean it's obvious — he has to carry the burden" as well as the result of that burden: "he's stressed, he has to do this all the time, so when he lashes out it's because of his frustration." Second, all three adult children commented that while they had always been close, their mother's Alzheimer's[2] had brought them even closer (although one questioned whether "this is just the new focus?"). They made efforts to coordinate their time with their parents to maximize their support, as Linda reported: "Maria, Colin and I now purposely schedule times where we're spending – so that we don't overlap our times." At the same time, changes in patterns of everyday activity meant that individual family members sometimes had to make more effort to schedule time together when their mother was not with them, as one sister described: "So my sister will call me up and say 'tell me when Rose is not around, and then we can go to lunch together just the two of us' because we like to do that."

Changes in conversation: Interview findings.

For the Tanaka family, the impact of Rose's dementia on her ability to maintain her role and responsibilities in everyday family life was a more dominant theme than its impact on their conversations together. Nevertheless, that impact was evident throughout the interviews. In talking about changes in conversation associated with Alzheimer's, Rose's family members all described similar patterns in her contributions. All talked about her telling the same stories and asking the same questions repeatedly. All described her as participating much less, if at all, in conversations with larger groups, although they also described her as enjoying talking with others in a variety of settings. Tom, in talking about taking Rose with him to different social events, commented that "she does enjoy chatting with people." However, in contrast to these signs of preserved social skills, Linda also described her mother as making negative comments to or about others that she would not have made before, in addition to chatting socially with people in circumstances when previously she would not have considered it appropriate to do so. Family members too noticed changes in topics of conversation, with ever fewer dominating: stories of the past, her grandchildren, her daughters' cats. Rose herself showed some awareness of the effect on others of her conversation, though there is no evidence that she linked it to Alzheimer's.

While family members were consistent in their accounts of changes in Rose's conversation, their responses to those changes were remarkably individual despite points of similarity, particularly along gendered lines. This individuality stands in strong contrast to the dominance of a unified family voice that emerged in the context of all other topics. The following section describes the response of each individual family member to changes in conversation.

Tom: "There's no point."

For Tom, the first comment about changes in his conversations with Rose was that they had become "very very limited." He attributed her enjoyment of social outings in part to their own current lack of conversation, saying "it's partly because I don't - we don't talk that much, no we don't - you know, sit down and talk." He described himself as "probably one to blame for that because I would just as soon sit at my computer." At the same time, he pointed out that "if you've been married for a long long time, you don't spend a lot of time talking. You know, body language quite often suffices, you know?" However, when asked if he thought that their long marriage, more than Alzheimer's, contributed to their lack of conversation, he responded: "more so because of Alzheimer's I think. Because really there's no point in my saying what – or discussing what we should do. I've got everything planned out for her." While he attributed this in part to Rose's memory problems, he also expressed some uncertainty about whether she was actually listening to him in conversation: "maybe she listens to conversations with me, I don't know." From this and similar comments, several of which included the phrase "there's no point", it appeared that for Tom, who clearly enjoyed travelling and looked forward to social events, a significant loss in conversation was the loss of sharing the planning for upcoming events. He contrasted the conversations that he could still have with Rose ("so all I can do is talk about a long time ago, period, you know? And that's okay on a casual basis for acquaintances") with what was now, from his perspective, lacking ("there's hardly any real discussion"). In Tom's view, Rose's conversational needs were best met in casual social conversations with others.

Colin: "Filling up the conversation time."

Colin, like his father, described a decline in conversations with his mother, and, like his father, acknowledged his part in that: "I would have to say, I don't speak to her as much." He too alluded to her tendency to repeat the same stories but for him, unlike his father, these became the focus of their current conversations:

> "I guess we probably talk, maybe about the same, but it's my response is – instead of asking more questions about a story since I already know the ending, I may just nod my head or – you know, say yes or no, or 'is that so' type of thing."

On further reflection, Colin suggested that overall "there's probably a lot less talking altogether," again alluding to his own behaviour: "it's sort of sad to say but I almost feel that if I tell her something, she's not going to remember the story, so it's almost a waste of breath, other than filling up the conversation time." Colin, like his father, saw information that was not retained as information that was wasted; unlike his father, however, he appeared to be more willing to take part in conversations about the past, if only to acknowledge through backchannelling his role as listener.

Linda: "We don't have conversations anymore."

In Linda's discussion of changes in conversation with her mother, she focused more on the difference in quality of talk than on quantity. In doing so, she differentiated between conversation and other kinds of talk, saying: "I don't think we have conversations anymore – they're just comments." Linda gave several examples of ritual exchanges: "she remarks on the price of gas, every morning when I pick her up, you know, it's gone down, or up." She went on to explain how at first she tried to extend those exchanges into conversation by asking questions that linked them to Rose's past, but tired eventually of hearing the same stories in reply.

Another ritual exchange was Rose's daily question about Linda's cats. Like Colin, Linda believed that her mother, even when asking for information, would not remember it, commenting: "when I have to say one day, that the cats have passed away - she'll still ask me though."

In addition to exchanges routinely initiated by Rose, Linda described exchanges that she herself routinely initiated. These included questions to which Linda knew at least part of the answer, (e.g., "so what did you do yesterday") in which she could use her foreknowledge to prompt Rose if needed. But these, too, for Linda did not constitute conversation: "they're just reports." For her, there is an explicit connection between conversation and relationship. In reflecting on her and Rose's communications (a word that she used instead of conversation), she commented: "It's very one-sided, and you know relationship is really two-sided? You've gotta give, and take. That's – so the part that she asks me? It's just my cats." Her comments draw attention to the one-sidedness inherent too in Colin's descriptions of Rose's conversations but, unlike him, Linda tried consciously to identify ways to keep interactions going: "I remember thinking that – I have to ask her about something the next time I pick her up." At the same time, she was aware of making "small talk," something which she described as difficult to do with Rose, adding that she was similar to her father in that regard. Linda, together with the rest of her family, also avoided telling Rose in advance about significant events, not because Rose forgot them, but because of the consequences of her partial forgetting, namely, her repeated questions and anxiety about them; this too, however, contributed to one-sidedness in their conversations. Overall, these accommodations to Rose's changing abilities contributed to a sense of loss of relationship with her mother. Linda related telling a friend, who was talking about missing his mother, "You know what? I miss my mom too."

Maria: "You find ways."

Maria identified herself as the one among her siblings "who actually talks to her one on one." Her emphasis on "talks" gave it a special status in her account, which became evident in her description of that talk. In discussing changes in her mother's conversation, Maria's first comment drew attention to changes in her own behaviours: "you do change, you find ways." These included ways to mitigate the effects of behaviours associated with Alzheimer disease, some of which she learned "from a pamphlet." She gave examples of these, including avoiding challenging her mother, describing this as "'don't you remember that? – you don't?' – so many times we would say that, we changed to not saying that." Other examples involved giving her mother clues, describing saying "'oh I heard that Nathan and Nancy came over on the weekend' and then she would have the option of remembering it or not." However, Maria also described changes in her expectations and goals of conversations with Rose. For Maria, the act of talking with her mother appeared to be a meaningful end in itself, with content a secondary consideration. She alluded to "safe stuff" including grandchildren, the past, her mother's repeated questions about her business or about her cat; both could draw on these topics to maintain conversation. Maria clearly recognized that while these offered a way of sustaining conversation with her mother, they sometimes led to more: "But as time goes on and we're just sitting there, she will have older memories that she knows and that she feels confident about, and sometimes there'll be some new stories that I'm totally excited about." Nonetheless, Maria too acknowledged that, despite finding ways to keep conversations going, she experienced a sense of frustration and loss: "Other times it's a little – it's tough. I think sometimes she can see sometimes the frustration in other people, and even myself, that we can't have the same conversation that we used to." Finally, Maria reported finding ways to encourage her mother's participation in group conversations, "going one on one with her" to ensure that she was involved.

Rose: "I don't even think of it."

When asked about whether she had noticed any changes in her conversations with people that she associated with having Alzheimer's, Rose answered: "I don't realize it. I don't even think of it." She went on to explain that she felt "like anybody else," although she appeared to be aware that she sometimes experienced difficulty in conversation. For example, in an unrecorded conversation with the first author, she asked to be told if she was not "talking properly," because sometimes she said things that were not quite right. Similarly during her interview in describing speaking with other wives when she and Tom visited his friends she commented: "when I start talking too much about my children, you know? She'll think, 'oh my god,' you know." Her primary concern seemed to be the effect of her conversation on others, as she also commented "...but as long as I don't annoy anybody, if I come out with something foolish, well... that's me."

Summary of interview findings.

Overall, a key finding for the Tanaka family was that conversation was only one of several aspects of family life affected by Rose's Alzheimer's; others included her inability to maintain activities associated with long-standing roles in the family (cooking, child-minding, etc.). In this context of significant changes across several domains of family life, interview findings revealed that members of the Tanaka family all experienced changes in conversational patterns with Rose as a loss of relationship, albeit in different ways. This sense of loss was present even though family members also acknowledged ways they found for including Rose in their talk and for keeping conversations going with her.

The Thompson Family

The Thompson family included Margaret, a 63-year-old woman diagnosed with primary progressive aphasia several months prior to the onset of the study. John, also in his early 60s, retired at the time of the study, and their four children Angela, Christine, Stephen and David, all in their thirties. Of the four, only Angela was married with two children aged nine and three. Christine and Angela lived in a different city to the others, having moved to the city where their parents were raised and their maternal grandmother still lived. Both daughters maintained regular contact by telephone and email, with visits from and/or to their parents at least annually. Stephen lived in the same city as his parents, maintaining contact by visits and telephone; David lived in a separate suite in their home. All members of the family except David held university degrees and all had chosen different occupations and interests. Family members described themselves as very independent ("everybody's all been into their own thing") but also supportive of one another ("everybody's there to listen").

Margaret was assessed in the same tertiary diagnostic clinic as Rose Tanaka; in Margaret's case, the symptoms prompting this consultation were increasing word-finding difficulties. Margaret described herself as having been aware of these problems for as long as six years prior to the decision to seek diagnosis; John had been aware of them for approximately three years. In contrast to the Tanaka family, only the parents, Margaret and John, were involved in the decision to seek assessment. Each of their four children reported having been aware of Margaret's word-finding difficulties for about a year but, prior to hearing that their mother was seeking assessment, none had fully realized the extent to which these difficulties were causing concern for their parents. Assessment yielded a diagnosis of primary progressive aphasia, a term that was unknown to all family members prior to hearing it in the context of Margaret's difficulty. The diagnosis itself caused some consternation in the family (particularly the word "progressive") as no one really understood its implications, nor could they easily find sources of information to guide them in knowing what to expect for Margaret. The diagnosis prompted a coming together of the whole family, as both daughters returned for a visit with their parents and brothers for mutual support and to plan what they could for an uncertain future.

At the time of this study, the primary problems that all family members described were with conversation. Margaret's speech (characterized on the basis of her interview) was nonfluent, with frequent word-finding problems marked by both silent and filled pauses (some as long as 30 seconds), as well as difficulty in formulating sentences. While she very occasionally drew on nonverbal resources to help with word-finding (e.g., going to look for an item that she was unable to describe verbally), she rarely, if ever, used other strategies such as gesture, writing, or drawing to support her speech; in the course of the study, there were no instances, either observed or reported, when family members prompted her to do so. While her comprehension appeared to be good, John reported that he was becoming aware of occasional problems in comprehension; he was also becoming concerned about the possibility of subtler changes in judgement and reasoning. In joint conversations, John often spoke for his wife; he and other family members reported that this was a long-standing interactional pattern that predated (and for a short time masked) Margaret's progressive aphasia, but was now one of necessity rather than choice (see Purves, 2009, for a detailed analysis of John's "speaking-for" behaviours).

In other areas of everyday activities Margaret and her family reported few problems. For several years, her primary occupation had been painting, and she continued to produce and sell her work (although finally giving up participating in art shows during the course of the study). She was still able to do all the cooking and other housework (although with increasing help from John). However, she noted changes in her ability to play the piano, and she was no longer able to read music to learn new pieces (but still able to do so for familiar pieces). Reading too was becoming more difficult, so that she was reading less. While John was aware of these latter changes, their children appeared not to be.

Changes in conversation: Interview findings.

A key theme associated with conversation with Margaret that emerged across all interviews was "difficulty." In Margaret's interview, the word appeared repeatedly, exemplified in this quote about conversations with others: "I am uh finding them uh quite difficult, um and I - I um (20 sec. pause) I'm finding them quite difficult." John too characterized communication with Margaret in terms of difficulty, saying: "the amount of verbal communication that goes on between us has decreased markedly as a result of this, because it's so difficult now." David, describing conversations between himself and his mother explained: "they don't go anywhere. It's so painfully *difficult*."

All members of the Thompson family also acknowledged the need to support Margaret in communication and talked about the various ways in which they did that in their own conversations with her. While some of the differences in family members' coping strategies reflected differences in their opportunities for conversation with Margaret, some also reflected differences in their interpretations of the significance of difficulty. Examination of each individual's perceptions of his or her own accommodation to changes in communication with Margaret reveals those differences and sheds light on the different meanings of conversation for family members.

John and Margaret: Frustrating communication and lost conversations.

For John and Margaret, difficulty in conversation was an ever-present part of everyday life, affecting the interaction between them and their joint interaction with others. The impact of Margaret's declining communication abilities on the latter type of interaction was much less; in John's words, "there's been some effect - but not a great effect." They continued to visit with friends who were aware of her disorder and, as described above, John accommodated to Margaret's declining participation by taking over more of the conversation. For Margaret, difficulty did not preclude the possibility of good conversation. In describing visits with some of those friends, she commented: "I have uh {greak} great ...conversations with them, and al..al..al..although um... uh..I have difficulty with that um..conversations." Her comments suggest the importance of conversation as a social activity, an end in itself, where difficulty could be transcended.

Nonetheless, there were some shared social activities that Margaret gave up, and John extended her withdrawal to include himself. In describing how Margaret no longer felt able to continue participating in a discussion group they had both attended, he explained: "I could have gone myself. It would not have been a problem, but I really didn't want to go without her." As Margaret withdrew from their shared activities, so too did John, rather than transforming those activities into his own.

While John acknowledged some changes in their social life together associated with Margaret's declining communication, their impact seemed relatively small compared to the impact on their communication together: "where the real problems lie/ is between Margaret and I - we can't communicate as well as we used to." John characterized these problems in several different ways. For example, while acknowledging Margaret's frustration, he also described his own frustration in not being able to work out what Margaret was trying to tell him, explaining "I'll say 'I don't know what you're getting at' because she'll leave out the most important word, or she will say something that creates the wrong impression and leads me in a different direction than she's trying to go." At other times, he could work out her meaning, relying on "second guessing" or by Margaret pointing to something. Nevertheless, the frustration associated with communication failures was a major theme in his interview.

A second theme that emerged in the interview with John was the sense of loss associated with diminishing conversation between him and Margaret. This loss was in part mitigated by their long-standing relationship as a couple, which to some extent precluded the need for talk: "it's now difficult enough, that – that we tend to know what's going on with each other, and there's lot of things that just don't have to be said." This theme pointed to the status of conversation as something more than just talk, echoing Margaret's reference to "great conversation." When describing conversations between himself and Margaret over a meal, for example, he commented: "Not – not conversation in the normal sense of the word. Yes, there will be questions asked, and questions answered, and things like that, and ..yeah..it – there would have been far more before this happened - far far more." Good conversation was itself an accomplishment that was, for him, an important part of family life that he talked about on several occasions. For instance, he described how, when his children's friends used to come for dinner:

"The friends would comment to them afterwards that we had the most interesting conversations around our dinner table, and it's true that we used to have very – be very wide-ranging and so on, and that largely does not happen anymore, because it can't."

Margaret's declining communication skills precluded such conversation between just the two of them. Although John never described this change explicitly in terms of loss, his juxtaposition of the importance of conversation and its absence clearly supports this interpretation.

David and Christine: A preference for joint interaction.

Both David and Christine described a pattern of interaction with Margaret that allowed them to take advantage of the long-standing pattern of their parents' communication, with John often speaking for both of them. Christine, living at a distance, spoke most often with her parents by speaker telephone: "I'm usually mainly talking to my dad, but my mother is listening, so my mother's *there* - she'll usually say hello and I'll usually say 'how are you', you know 'fine' and not too much else." She described a similar pattern in face-to-face conversations during this and her most recent visit with her parents: "mostly it was just my dad, and she would occasionally put in a word or, you know, laugh and whatever, but - you know." She consciously tried to include her mother by supporting her passive participation, recognizing at the same time the possibility of a sense of excluding her: "I've tried to address both of them as though I'm not just – you know, but it is something – it is something you notice." The alternative, however, was to risk frustration: "but I don't want to ask specific questions - things like that... - or to talk about something that's just gonna 'cause frustration.." For Christine, sparing her mother from frustration and avoiding having to cope with it herself outweighed the benefits of one-to-one conversation, so that she tended not to seek such interactions. When they did occur, such as when her mother answered the telephone and her father was not there, they were difficult: "that's even more - more complex because there's - it's slow going and kind of belaboured I guess." She described such conversations as one-sided: "when I do have any sort of conversation with my mother it's more one-sided. I don't want to put her in an awkward position where she gets more frustrated that she can't say things." Her allusion to "any sort of conversation" suggests that such exchanges were not wholly satisfying as conversations.

David, living closest to his parents with more frequent opportunities for conversations with them, gave a description of his mother's participation in those conversations that echoed his sister's: "she's there in spirit, but she just has such a hard time conversing in an open casual dialogue with people that she just stays out of it." Like Christine, he was aware of the possibility of exclusion: "I feel bad for her, because you know of course depending on who's sitting around the table we're probably talking about something that she's not all that interested in, you know? It's just - just the way it works." He too, weighing inclusion against frustration, avoided risking frustration for his mother by not asking questions in dinner table discussions that he might once have asked: "I can't really ask her now because it's just almost – I feel like I'm not even being nice when I do." He too did not seek out opportunities for one-to-one conversation with his mother: "there are chances, but they don't go anywhere." When such chances did occur he, like his father, tried to support her: "I just try to use body language and I try to help her out if she's trying to say something, you know - if she's looking for a word." For David, however, there were pitfalls in that approach too: "I try not to be too overly helpful, because I don't want to choose the wrong word. I frequently see my dad go down that road and of course that just gets my mom even more irritated." Instead, he elected to respect his mother's gradual withdrawal from participating in conversation: "I respect her space, and I respect her will to not be stressed out."

David and Christine both described a long-standing tendency for their mother to become stressed quite quickly. Neither was willing to trigger even more stress for her in their efforts to accommodate to her declining communication ability. Both, instead, decided to forego opportunities for one-to-one conversations, preferring to have their conversations with her in their father's company. In those conversations, she could choose silence, which, though still noticeable, was more in keeping with former family conversation patterns.

Stephen and Angela: Keeping conversations going.

In both Stephen's and Angela's descriptions of conversations with their mother, "difficulty" was characterized in terms of Margaret's struggle, not as a characteristic of the conversations themselves. For both, the most troubling consequence of her diminishing communication ability was not her frustration but, rather, the risk of increasing isolation. As Angela described: "progressively she's being cut off from some parts of the world," with Stephen commenting: "she must feel bad, like she's possibly not important because she can't talk." Both acknowledged that while there were other ways in which Margaret could express herself (for example, through her art), they were not as powerful as talk itself; in Angela's words "when it comes to everyday things, the precision of language - you just can't beat it." Their comments suggest that each viewed conversation as a fundamental part of relationship and so, for both, whatever conversation could be achieved took on greater value. In Stephen's words: "I've heard her say just maybe a few small sentences to me lately, but they meant a lot to me." Angela, after describing a particularly meaningful exchange that her mother initiated when Angela first arrived to visit, made a similar comment: "so that was just kind of neat, because even though that's a very small number of words - but it's what's behind it."

While there were similarities in the way in which Stephen and Angela talked about the importance of conversation, there were differences in how they accommodated to their mother's decreasing participation. Stephen, with many more opportunities than Angela had for face-to-face conversation with his mother, described how he worked to keep her in the conversation. Like David, he acknowledged that during dinner time conversations with his brother and father and mother, his mother participated little. However, his strategy differed from David's: "I always make sure I ask her questions. I don't care if she answers me or not. I'll keep asking her questions. I'll ask just as many questions to my mother, as I will my father." For Stephen, the act of asking itself was important: "I don't think because she can't answer me that she doesn't – I don't think that I shouldn't talk to her." In asking her questions, he tried to accommodate to her difficulty in answering while still acknowledging her capabilities: "I keep the questions – I mean I don't keep the questions simple, but I make sure that they're something that can be answered easily." Stephen also developed strategies for telephone calls when his mother answered: "I'll – I'll generally just carry on a conversation. I'll tell her about what's going on. Sometimes I'll answer my own questions 'cause I'm pretty sure I know what she's going to answer me." Although his mother's participation appeared to be limited, Stephen's description does not emphasize one-sidedness, as Christine described. Rather, it suggests a two-party conversation in which he also took his mother's part when she could not, highlighting the act of conversation itself, rather than its substance.

Angela, in contrast to her siblings, did not focus on the challenge of sustaining conversation with her mother, but spoke instead about the importance of silence: "when someone has a condition like this, you have to be - just be comfortable with silence." Angela had had fewer opportunities than her siblings for one-to-one conversations with her mother in the previous year and a half, and because our interview took place near the beginning of her visit she had few examples of how she approached such opportunities. However, in describing conversations with someone else she knew who had difficulty in communicating, she remarked: "he also requires effort to put a sentence together but when they're together, boom - they all come out like that. But you have to wait – and he has things to say." Her comments suggest that, for her, silence could be an integral part of conversation, rather than a mark of its absence.

Summary of interview findings.

In summary, findings from the Thompson family interviews revealed that for all members of the family, the impact of primary progressive aphasia was greatest on conversations with Margaret, with few other changes in everyday family life described. Family members also described drawing on long-standing patterns of interaction to keep Margaret included in conversations, albeit in different ways. Finally, all family members also recognized and described how these changes in conversation presented challenges in their ongoing relationships with Margaret and, for her children in particular, led to concerns about her becoming ever more isolated, even within their family.

Discussion

Talk is the bedrock of social life, an integral part of human relationship. For family, the most fundamental of social groups, disruption to talk such as that associated with dementia is disruption in the complex weave of roles and relationships that is continually renewed and reconstructed through that talk. The ethnographic family systems approach described in this paper reveals this complexity by drawing on interview data to foreground the perspectives of individuals within the context of their family life and conversations together. Findings highlight the meanings that family members, individually and collectively, ascribed to changes in conversation that they associated with dementia. While those meanings are of course specific to each particular family, they nonetheless offer new insights into the impact of dementia on family communication and caring. These insights are particularly relevant for speech-language pathologists because, first, as Holland (2007) suggests, speech-language pathologists have a central role in counselling individuals with communication disorders and their families and, second, because the first step in the counselling process "involves trying to understand how the world looks to the client" (p. 11). In this discussion, we begin by highlighting key findings that emerged from analysis at the level of the individual. We then discuss insights gained from analysis of each family as an interactive system. Finally, we explore the implications of our findings for speech-language pathologists and other health professionals who may be involved in counselling families of people with dementia.

Communication Changes from the Perspectives of Individual Family Members

All individuals in each family (including the persons with dementia) identified and described changes, first, in the communication abilities of that person and, second, in the nature of their conversations together (with the possible exception of Rose, for this latter point). While there were some differences in the ways in which family members described those changes, there were nevertheless striking similarities in the meanings that individual family members gave to them. A dominant theme that emerged from interviews in both families was the intricate interweaving of conversation and relationship. In each family, some participants acknowledged this interweaving through descriptions of their conscious efforts to find ways to maintain conversations with the person with dementia. In each family, other participants acknowledged it through characterizations of their talk with the person with dementia as not really being conversation. The iterative process of analyzing all interviews within each family led to a deeper understanding of this finding, emphasizing how conversation contributed to the unique status of each family member's relationship with the diagnosed person and, furthermore, how changes in familiar patterns of talk were experienced with a sense of loss.

In foregrounding the perspectives of family members themselves, these findings bring a new dimension to understanding the impact of communication changes in dementia. The effects of dementia (in particular AD) on conversational abilities of individuals with these diagnoses have long been recognized, and the impact of those effects on individual family caregivers is well documented. Findings of studies incorporating interviews, questionnaires, and/or focus groups (e.g., Orange, 1991; Powell, Hale, & Bayer, 1995; Savundranayagam et al., 2005; Small et al., 2000) have shown clearly that changes in everyday communication are a source of distress and burden for family caregivers; however, such studies in general have taken communication breakdowns as their starting point, seeking to elicit family members' perceptions of those breakdowns and of the strategies (successful or unsuccessful) that they use to overcome them (e.g., Orange, 1991; Powell, Hale, & Bayer, 1995; Small et al., 2000) or to measure their impact on caregiver burden (e.g., Savundranayagam et al., 2005). In the current study, family members were clearly aware of the nature and frequency of problematic conversational behaviours. However, in taking as its starting point the way in which family members themselves constructed and reflected on the meanings associated with these changes in conversation, this study foregrounds the importance of conversation as a fundamental part of relationship. In doing so, it highlights that at least for these two families, it was not only changes in the nature of conversation breakdowns but also changes in the nature of conversation itself that contributed to feelings of loss.

Insights Gained from Exploring Family as a System

As described in the introduction, a key feature of a family systems approach lies in the exploration of how the multiple perspectives held by individual family members intersect and overlap in ways that are sometimes congruent and sometimes conflicting. In this study, although the theme of conversation as relationship emerged from interviews with all participants, there were differences among individuals within each family that illustrate how multiple meanings held by family members interact to characterize the family as a system. In each family, the ways in which each individual perceived his or her conversational relationship with either Rose or Margaret were unique, but collectively they captured a broad range of overlapping conversational goals, challenges, and strategies. Furthermore, some described their conversations with either Rose or Margaret within the context of the family as a whole, acknowledging their own conversational needs as well as those of other family members and, particularly in the case of the Thompson family, drawing both on new strategies and on long-standing family patterns of communication to meet those needs.

Although both families acknowledged the impact of conversational changes on their family life, an obvious key difference between the two families was the extent to which these conversational changes emerged as an issue of primary concern. For the Tanaka family, Rose's diagnosis of AD was associated with many changes in roles and responsibilities in addition to changes in their conversations together. In talking about the impact of AD on their family life together, their descriptions generally focused much more on the realignments necessitated by Rose's declining ability to carry out many of her former activities than on the conversational changes and challenges associated with her AD. In the Tanaka family, communication, though affected, was not the central issue of concern. In contrast, for the Thompson family, conversational challenges were by far the dominant feature in their discussion of the impact of progressive aphasia on daily life. This finding could reflect the impact of progressive aphasia on Margaret's language relative to her other abilities, which at the time of this study were relatively well-preserved; however, it could also reflect the importance of conversation for this family in their everyday life together, reflected in interview findings describing the high value they placed on conversation itself as a shared activity. While this value was stronger for some family members than for others, it nevertheless characterized the family as a whole.

A further point to make with respect to findings from both sets of family interviews concerns the term "caregiver." In keeping with the goal of seeking to understand the impact of dementia from the perspectives of family members, the word "caregiver" was deliberately avoided in recruitment notices, consent forms, or interview questions. In all 11 interviews, no family member self-identified as a caregiver, and the term itself only appeared once, in Maria Tanaka's somewhat qualified designation of her father as "more of a caregiver." From these families' perspectives, supporting the person with dementia, including managing conversation challenges, was not associated with caregiving; it was a feature of their relationships within the family. Moreover, even though in both families, all family members acknowledged that it was the husband who provided the most support, supporting the person with dementia was a shared responsibility across all family members as part of a network of supporting one another.

The possibility that family members may not self-identify as caregivers until others designate them as such is consistent with findings reported by O'Connor (2007). In O'Connor's study, most participants described first recognizing what they were doing as caregiving when they encountered the term in the health care context (e.g., information pamphlets, support groups, interactions with health care professionals). Also, several participants described the role of caregiving in terms of "taking over everything" (p. 168), suggesting both qualitative and quantitative differences between caregiving and relational caring. Further, participants described both positive and negative aspects of being designated as a caregiver (e.g., easier access to services as a positive aspect; guilt about 'taking over' and loss of familiar relationship as negative aspects).

Several points arise from this discussion of terminology. First, a relatively widespread tendency in health care practice and research to describe family as a single individual designated as 'family caregiver' (Hicks & Lam, 1999) does not necessarily reflect the lived experiences either of those individuals or, more broadly, of families themselves. Specifically, what is often lost in considering family members as caregivers is the focus on relationship that appears to be such a central aspect of family caring, instead treating family caregivers and those they care for as "living in parallel life spaces" (Davies & Gregory, 2007, p. 481). In addition, there is the risk of neglecting the needs and resources of the entire family system in which family caring (and caregiving) is often embedded. Finally, needs of family members who are considered primarily in terms of caregiving may be subsumed under a broad umbrella that includes both formal and informal caregiving, such that the unique needs of family members risk being overlooked. For instance, while strategies to improve communication for formal caregivers may well be appropriate for family too (as evidenced in Maria's report of learning effective communication strategies from a pamphlet about dementia), they do not necessarily address the relationally-based needs of family members struggling to cope with the gradual loss of long-standing patterns of conversation.

A final point to make with respect to the two families on which the above findings are based is to emphasize again that not only are they two particular families, but also that they are two particular families each at a particular moment in time. It is possible, even likely, that as time and disease progresses, one or more individuals in each family would begin to self-identify as caregivers. It is possible that for a different family, the experience of language loss associated with primary progressive aphasia could be less, or more, devastating than for the Thompson family, or that, in contrast to the Tanaka family, the impact of communication changes associated with mild to moderate AD could overshadow changes in abilities to carry out familiar everyday activity. The particular experiences of each family in this study are specific to that family. What we can learn from them is not what families in general think about the impact of disorders such as AD and progressive aphasia. Rather, we can learn how approaching each family as a system and seeking to understand the world from the perspective of those within that system can give us new insights into how those disorders may be experienced and interpreted.

To date, there are relatively few published accounts of single case studies that take a systems approach to understanding families' experiences of any disorder affecting communication (in addition to Brewer, 2005, cited above regarding dementia, see Pollner & McDonald-Wikler, 1985 for a provocative example from the developmental literature). There is a need in the research literature for more such studies, as each one has the potential to offer new perspectives on familiar problems.

Implications for Intervention

The family systems approach taken in this study to explore changes in communication associated with dementia from the perspectives of individuals within each family as a whole offers insight into how such an approach might inform the development of interventions within a family-centred framework. First, in considering the perspectives of members of the Thompson family, for whom communication impairment was by far the most significant problem affecting their daily lives together, there is a clear need in such cases for direct intervention to support and sustain whatever communication is possible. At present, however, there is evidence to suggest that intervention services for this population are widely under-developed (Taylor, Kingma, Croot, & Nickels, 2009). For the Thompson family, certainly, there were few direct services available at the time for Margaret and others in the family to support her declining communication abilities. In contrast to the Tanaka family, who could at least identify community-based resources for information and support, a key issue for members of the Thompson family was the lack of such resources that were relevant for them. The need for such services and resources is attracting growing recognition, and intervention for progressive language impairment, whether associated with progressive nonfluent aphasia, semantic dementia, or a language-dominant presentation of Alzheimer disease, is an area of emerging practice for speech-language pathologists. In a review of studies incorporating impairment- and activity/participation-based interventions for progressive aphasia, Croot and colleagues found evidence for some improvement for impairment-based interventions (although gains were not maintained without practice) and, perhaps more importantly in the context of family-centred practice, improvements in everyday communication effectiveness for some activity/participation interventions, particularly those involving family members in interventions (Croot, Nickels, Laurence, & Manning, 2009). Three studies in particular (Cress & King, 1999; Murray, 1998; Rogers, King, & Alarcon, 2000) highlight the importance of involving family in supporting intervention strategies, including the identification of personally relevant activities and vocabulary that needed to be addressed. Given the progressive nature of progressive language impairments, and considering the very different ways in which they may evolve, a family-centred approach to intervention, based on the needs and resources of the family as a system, may be particularly appropriate for this population.

A second point regarding intervention that emerges from the perspectives of the Tanaka and Thompson families is the role of the speech-language pathologist in communication counselling. As Holland (2007) points out, for many families of individuals with dementia, counselling needs may be addressed by health professionals across a wide spectrum of services. Nevertheless, speech-language pathologists have a particularly valuable contribution to make, given the impact of changes in conversational relationships on families. Findings from this study suggest that, in working with family members to develop interventions to reduce conversational breakdowns and/or enhance the success of repairs, there may also be a need for counselling with respect to feelings of grief that accompany the loss of familiar patterns of conversation. By combining these strategies, clinicians can help family members to identify evolving definitions of what constitutes a good conversation with the person with dementia. At the same time, the clinician can help family members to find ways to meet their own unmet conversational needs either within or beyond their family.

Third, by adopting a family systems approach to intervention, speech-language pathologists can work with the family to identify how different members can contribute to supporting the conversation needs of the family as a whole. Families obviously differ in the extent to which they need support to develop such strategies; for example, they were already evident in the Tanaka family, although they were not explicitly acknowledged as such. However, families seeking support for communication issues may need help in identifying the possibilities for such strategies within their own family.

Finally, as Burns (1996) and Holland (2007) suggest, the extent to which speech-language pathologists can take on family-centred approaches to intervention, including counselling, for people with dementia and their families is constrained by numerous factors, including those imposed by the work setting itself. Nevertheless, intervention for this population as an emerging area of practice may be most effective when we take as our starting point, to whatever extent we can, the perspectives of all those who constitute a particular family.

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End Notes

[1] See Croot (2009) for a discussion of classification systems used for progressive aphasia and their relevance for speech-language pathologists; see Gorno-Tempini et al. (2011) for further evolution of terminology.

[2] The term "Alzheimer's" is used deliberately in describing family members' perspectives, as this is the term that they used themselves.

Authors' Note

Correspondence concerning this article should be addressed to Barbara Purves, School of Audiology and Speech Sciences, University of British Columbia, 2177 Wesbrook Mall, Vancouver, British Columbia. V6T 1Z3 Email: purves@audiospeech.ubc.ca

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APPENDIX A

The following questions formed the interview guide for semi-structured interviews with participants.

For establishing context and for exploring understanding of diagnosis:

Tell me about (your) / (family member with AD/PA)'s diagnosis.

Prompt questions: What diagnosis does the person / you have? What do you think that means?

Tell me about the events that led up to (you) / (family member with AD/PA) being given that diagnosis.

Prompt questions: Did you or someone else in your family notice something wrong? What happened then?

Tell me about your relationship with other family members.

How has (your) / (family member with AD/PA)'s being diagnosed affected you and your family life?

For exploring perceived changes in conversation interaction:

How has it affected your conversations with that person / other members of your family?

Prompt question (for family members of person with AD/PA): Given __________'s diagnosis, do you find yourself questioning what s/he says?

Hearing Loss among Individuals with Dementia: Barriers and Facilitators to Care

La perte auditive chez les individus atteints de démence : les facteurs nuisibles et favorables aux soins

Tammy Hopper
Patti Hinton

KEY WORDS
HEARING LOSS
ADULTS
DEMENTIA
LONG-TERM CARE

Abstract

Hearing loss is highly prevalent among older adults with dementia, particularly those in long-term care settings. Unfortunately, barriers exist that may prevent many individuals with dementia from participating in necessary hearing health care. Barriers include the fact that older adults do not always seek help for their hearing loss and care partners may not recognize hearing loss because communication problems associated with hearing loss and dementia often overlap. Even when hearing loss is identified, individuals with dementia may not be referred for further evaluation of hearing because of a lack of awareness of available intervention strategies beyond hearing aids, and a tendency for care partners to minimize the negative effects of hearing loss. To facilitate hearing health, audiologists and speech-language pathologists need to assist care partners of individuals with dementia in understanding the signs, symptoms and impact of hearing loss on daily life. Further, clinicians need to adapt hearing assessments and design holistic interventions to meet the specific needs of people with dementia. The purpose of this paper is to review the recent literature on this topic, with a focus on key issues in hearing health care for individuals with dementia and hearing loss, as well as assessment and intervention strategies to promote hearing and communication.

Abrégé

La perte auditive est très répandue chez les adultes âgés atteints de démence, particulièrement chez ceux se trouvant en milieu de soins à long terme. Malheureusement il y a des obstacles qui peuvent empêcher beaucoup de personnes atteintes de démence de recevoir des soins nécessaires en santé auditive. Les obstacles incluent le fait que les adultes âgés ne cherchent pas toujours à avoir de l'aide pour leur perte auditive, et les partenaires de soins peuvent ne pas reconnaître la perte auditive parce que les problèmes de communication associés à la perte auditive peuvent être aussi reliés à la démence. Même quand une perte auditive est identifiée, des individus atteints de démence peuvent ne pas être référés pour une évaluation de l'audition à cause d'un manque de sensibilisation aux stratégies d'intervention disponibles, au-delà des appareils auditifs, et à cause d'une tendance qu'ont les partenaires de soins à minimiser les effets négatifs de la perte auditive. Pour faciliter la santé auditive, les audiologistes et les orthophonistes doivent aider les partenaires de soins des personnes atteintes de démence à reconnaître les signes et les symptômes de la perte auditive ainsi que les impacts de la surdité sur la vie quotidienne. De plus, les cliniciens doivent adapter les évaluations de l'audition et concevoir des interventions holistiques pour répondre aux besoins particuliers des personnes atteintes de démence. Le but de cet article est de passer en revue la littérature récente sur ce sujet en mettant l'accent sur les principales questions de soins de santé auditive pour les personnes atteintes de démence et de perte auditive, ainsi que sur les stratégies d'évaluation et d'intervention visant à promouvoir l'audition et la communication.

Tammy Hopper
Department of Speech Pathology and Audiology
Faculty of Rehabilitation Medicine
University of Alberta
Edmonton, AB
Canada

Patti Hinton
St. Joseph's Health Care London - Parkwood Site
London, Ontario,
Canada

Hearing loss may be defined as an impairment in auditory functions, such as sound detection and speech discrimination, which result from structural changes to peripheral and/or central auditory systems (Hickson & Scarinci, 2007). Age-related hearing loss (ARHL) is a complex condition that results from multiple causes. Current findings support the theory that metabolic presbycusis, or atrophy of the lateral cochlear wall and stria vascularis, is the predominant cause of ARHL in older humans (Schmiedt, 2010). Other factors also contribute to ARHL, particularly noise exposure, which is common in western society, and ototoxic drugs, both of which preferentially affect the outer hair cells in the basal coil of the cochlea (sensory prebycusis) (Schmiedt, 2010). Most ARHL in humans results from a combination of metabolic and sensory presbycusis and is characterized by mild, flat loss at low frequencies coupled with steeply sloping high-frequency loss above ~1 kHz (Schmiedt, 2010).

Hearing loss is one of the most prevalent health conditions in the world (World Health Organization, WHO, 2000) and ARHL is particularly widespread. Among community-dwelling adults, Gates et al. (1995) reported that 30% of those 65-74 years and 50% over 75 years had a hearing loss, Dalton et al. (2003) reported that 50% of individuals in their sample (aged 53-97) had hearing loss, and Cruickshanks et al. (1998) reported hearing impairment among 46% of 3743 adults in their sample (mean age = 65.8 years). For older adults living in long-term care (LTC) environments, hearing loss may be even more prevalent, ranging from 70-83% (Schow & Nerbonne, 1980; Voeks, Gallagher, Langer, & Drinka, 1990; Weinstein & Amsel, 1986). Given that the fastest growing segment of the world population is adults over age 65 (Kinsella & Velkoff, 2001), hearing loss will continue to be a major health concern in the coming years.

Like hearing loss, dementia is increasing in incidence and prevalence as the population ages. Dementia is a syndrome that can be caused by many diseases ('all-cause' dementia). According to McKhann et al (2011), all-cause dementia is diagnosed in an individual when there are cognitive or behavioral symptoms that interfere with the ability to function at work or at usual activities, that represent a decline from previous levels of functioning and performing, and are not explained by delirium or major psychiatric disorder. The cognitive or behavioral impairment involves a minimum of two of the following domains: (a) impaired ability to acquire and remember new information, (b) impaired reasoning and handling of complex tasks and poor judgment, (c) impaired visuospatial abilities, (d) impaired language functions (speaking, reading, writing), and (d) changes in personality, behaviour and comportment.

Probable Alzheimer's disease is the most frequent cause of dementia ('AD dementia') and is diagnosed when an individual meets the criteria for a dementia diagnosis, plus insidious onset of symptoms, clear-cut worsening of cognition by report or observation, and initial and most prominent cognitive deficits in one of the following categories: amnestic presentation, (memory systems are primarily impaired), or nonamnestic presentation (language, visuospatial and executive functions are primarily affected) (McKhann et al., 2011). The amnestic presentation of AD dementia is the more common of the two types.

According to the Alzheimer's Society of Canada report, *Rising Tide: The Impact of Dementia on Canadian Society* (2010), approximately 100,000 new cases of dementia are diagnosed each year in Canada and this number is expected to more than double over the next 20 years. Approximately 500,000 people in Canada are living with dementia, and 55% of individuals over the age of 80 are estimated to be affected (Alzheimer Society of Canada, 2010). The situation is similar in other countries. In the United States, more than five million people currently have a diagnosis of dementia, including one in eight individuals over 65 years old, and almost half of all people over the age of 85 years (Hebert, Scherr, Bienias, Bennett, and Evans, 2003; Plassman et al., 2007).

The high prevalence of hearing loss and dementia among older adults means that the two health conditions will often co-exist (Chartrand, 2005; Kricos, 2009). Although much research has been devoted to hearing and aging, relatively little research exists on the topic of hearing and dementia specifically. The purpose of this paper is to summarize some of the recent literature in this area, with a review of key issues, a discussion of barriers to hearing health care for individuals with hearing loss and dementia, and assessment and intervention strategies to address these barriers. The general term 'dementia' is used throughout the paper to refer to Alzheimer's disease and related dementias, and the focus is on individuals in the middle to later stages of cognitive decline, many of whom live in LTC settings.

Barriers to Hearing Health Care for Individuals with Dementia

Many older adults who have hearing loss do not seek help for it. In fact, Oyler (2012) reports that only 20% of older adults with hearing loss who might benefit from treatment actually receive it, and many delay intervention until their activity limitations are quite severe. One reason for delay in seeking treatment is that hearing loss in aging is insidious and progresses slowly, such that affected individuals consider it a normal part of aging (Oyler, 2012; Weinstein, 2000) and do not readily acknowledge the loss as a problem. Health care professionals may share this assumption. Gilliver and Hickson (2011) reported that 60% of medical practitioners who were in a position to refer older adults with hearing loss to an audiologist agreed with the statement that hearing loss is a normal part of aging that does not require treatment.

For individuals with dementia, the situation is compounded by the fact that hearing loss can be difficult to identify because symptoms of untreated hearing loss and dementia often overlap (Chartrand, 2005; Kricos, 2009; Palmer, Adams, Bourgeois, Durrant & Rossi, 1999)) (see Table 1). In AD, for example, cognitive impairment causes anomia, repetitiousness, discourse processing problems (conversational topic initiation, maintenance and repair), and, eventually, severely restricted verbal output (see Bourgeois and Hickey, 2009 for a review). As Bayles and Tomoeda (2007) note, individuals with moderate to severe AD are frequently disoriented and confused, often forgetting what they have seen and heard as well as their own intentions. These limitations and restrictions lead to frequent communication breakdowns.

Age-related hearing loss can cause similar communication problems, primarily as a result of difficulties with speech comprehension. In fact, one of the earliest symptoms reported by older adults with hearing loss is difficulty understanding speech, particularly in settings with multiple speakers and/or background noise (Hickson & Scarinci, 2007; Pichora-Fuller, 2003). Older adults with hearing loss often repeatedly request repetition of speech (Caissie, Dawe, Donovan, Brooks, & MacDonald, 1998), confuse spoken messages and experience difficulty maintaining conversations (Garstecki, 1981). Because group communication situations are particularly problematic, older adults with hearing loss may withdraw from such conversations or avoid them entirely (Dalton, et al., 2003; Morgan, Hickson & Worrall, 2002).

It is difficult to determine the relative contributions of ARHL and cognitive impairment to speech comprehension difficulties among older adults with dementia. In typical aging, researchers have noted that ARHL accounts for most of the speech-recognition problems of older adults in quiet settings; however, the elevated thresholds associated with presbycusis only partially account for the difficulty older adults experience in noise (Humes & Dubno, 2010; Pichora-Fuller, 2003). Whereas typically aging older adults can use semantic context to improve speech comprehension and compensate for hearing loss in adverse listening conditions (Pichora-Fuller, 2008), individuals with moderate to severe dementia and ARHL have significant cognitive impairments that potentially limit the benefits of top-down processing to compensate for reductions in speech audibility. This hypothesis remains to be addressed in future research.

In mild dementia, when the focus is on differential diagnosis of the cause of cognitive impairment, it is imperative that audiologists conduct a full evaluation of hearing status prior to evaluation of cognition (Chartrand, 2005; Weinstein, 2000). Neuropsychological tests used to help diagnose dementia are heavily biased

Table 1. Overlapping presentation of communication problems and psychosocial consequences of dementia and untreated hearing loss in older adults

	Dementia	Untreated Hearing Loss
Problems understanding speech that is complex, fast or presented in noise	Orange (1995); Rochon, Waters and Caplan (1994); Small, Kemper and Lyons (1997)	Wingfield, McCoy, Peele, Tun and Cox (2006); Tun (1998)
Impaired conversational abilities	Ripich and Terrell (1988); Tomoeda and Bayles (1993)	Caissie et al. (1998); Garstecki (1981)
Withdrawal from social activities/social isolation	Potkins et al. (2003)	Weinstein and Ventry (1982); Hull (1992)
Presence of depression, anxiety	Bierman, Comijs, Jonker and Beekman (2007)	Cacciatore et al. (1999)

(Adapted from Chartrand, 2005)

towards spoken language. Thus, hearing loss may disadvantage the individual with dementia, making cognitive function seem worse than it is (Kricos, 2009), a finding previously reported by researchers (Weinstein & Amsel, 1986).

In moderate to severe dementia, cognitive impairment may mask the negative effects of hearing loss. In Hopper, Bayles, Harris and Holland (2001), 55 LTC residents with dementia failed a pure-tone hearing screening, however only 15 were identified as having impaired hearing. These findings are similar to those reported by Voeks et al. (1990) who found that only 16% of the 198 patients in the study were identified as having a hearing loss by a physician or nurse, despite the fact that 54% had moderate to profound losses across frequencies. Garahan, Waller, Houghton, Tisdale and Runge (1992) also reported that most LTC residents with hearing loss have no institutional documentation of the problem. This lack of awareness of hearing loss among LTC residents with dementia obviously limits residents' access to hearing health care.

Even when the hearing loss is identified, referrals for further evaluation and/or intervention may not be made (Durrant, Gilmartin, Holland, Kamerer, & Newall, 1991; Kricos, 2009). Hopper et al. (2001) reported that among the 15 LTC residents with dementia and an identified hearing loss, none was referred to an audiologist or speech-language pathologist (S-LP) for follow-up. Although the reasons for lack of referrals are unclear, they are likely similar to those offered to explain the small minority of community-dwelling older adults who seek hearing health care. Another potential reason is a lack of awareness of available treatments for hearing loss. Care partners may assume that the only intervention available is a hearing aid, and that the audiologist's primary goal is to prescribe one. Amplification is, indeed, an effective, evidence-based treatment strategy for the sensory deficit of hearing loss (Weinstein, 1996). Also, hearing aid use has been shown to confer a benefit on older adults' health-related quality of life (Chisholm et al., 2007) and may be associated with a decrease in caregiver-identified problem behaviours among community-dwelling individuals with dementia (Palmer et al., 1999). Nevertheless, as noted by several authors (Boothroyd, 2007; Hickson & Scarinci, 2007; Oyler, 2012), the scope of practice of an audiologist is holistic and extends beyond hearing aids to include consideration of activity limitations/participation restrictions and environmental and personal factors (WHO, 2001) that contribute to hearing health.

A further barrier to hearing health care for individuals with dementia in LTC may be that care partners minimize the effects of hearing loss on communication and psychosocial functioning of the residents in their care (Smith & Kricos, 2003). Care partners may relegate hearing loss to an issue of lesser importance, behind more pressing care needs related to hygiene, nutrition, safety, and pain management. However, hearing loss must be acknowledged as a priority health concern as well. The negative psychosocial consequences of untreated hearing loss (e.g., depression) can have a profound impact on quality of life (Kochkin & Rogin, 2000). Moreover, hearing loss may interfere with the ability of individuals with dementia to participate in cognitively stimulating activities that improve affect, engagement, behaviour and perhaps slow cognitive decline over time (Chapman, Weiner, Rackley, Hynan & Zientz, 2004). Finally, hearing loss may seem innocuous to care partners until they realize that its presence among individuals with dementia has been associated with an increased rate of cognitive decline over time as compared to individuals with dementia and relatively normal hearing (Peters, Potter & Scholer, 1988).

In summary, the previously mentioned issues act as barriers to the use of audiology services by older adults with hearing loss and dementia. To facilitate hearing health, audiologists and S-LPs need to help care partners of individuals with dementia and hearing loss to understand the signs, symptoms and impact of impaired hearing on daily life. In addition, care partners should be taught to use strategies to moderate the communicative impact of hearing loss. Demonstrating the benefits of communication programs for individuals with dementia on a case-by-case basis is often the most effective way to increase awareness and change negative assumptions about the ability of individuals with dementia to benefit from treatment (Bourgeois & Hickey, 2009). The first step in such a process is a comprehensive assessment of hearing.

Issues in Hearing Assessment for Individuals with Dementia

Impairment-based assessment. When cognitive decline is mild, individuals with dementia will generally be able to participate in standard audiological assessment protocols. However, when cognitive decline is moderate to severe, individuals with dementia can be difficult to test. They may not understand test directions, may lack the ability to be conditioned to the testing protocol, may experience anxiety, and be unable to tolerate headphones. Additionally, among residents in LTC settings, dementia rarely occurs in isolation, such that residents present with multiple co-morbid health conditions, including visual impairments and physical mobility issues (Kaye, Harrington, & LaPlante, 2010) that can make the testing a challenge.

In a recent study of audiology assessments in nursing home residents, approximately half of whom had a diagnosis of dementia or "dementia-characterized behaviours" (p.532), only 16/307 residents (5%) were able to complete a full, traditional audiometric assessment protocol that included air and bone conduction testing from 500 to 4000 Hz, speech reception threshold and speech recognition testing, and establishment of uncomfortable and most comfortable listening level of speech (Burkhalter, Allen, Skaar, Crittenden and Burgio; 2009). Although Durrant et al. (1991) reported that individuals with moderate to severe AD participated successfully in hearing testing, their sample size was limited (n=10) and the authors added a caveat that the participants needed encouragement at times, which suggests some difficulties were encountered.

For these reasons, a traditional standard assessment of hearing will often need to be adapted. According to the American Speech-Language-Hearing Association (ASHA; 1997), *Guidelines for Audiology Service Delivery in Nursing Homes*, adaptations to hearing testing are recommended to ensure that the evaluation is tailored to the individual's cognitive status and functional abilities. Burkhalter et al. (2009) went further, stating that modifications of general procedures established by ASHA and the American Academy of Audiology for other difficult-to-test populations (such as pediatric populations) could be applied to audiology assessment procedures for LTC residents, including those with dementia.

The second author of the current paper (PH) has used several modifications when evaluating hearing in individuals with dementia who are unable to participate in the traditional test battery. For example, if Speech Recognition Threshold (SRT) testing is unsuccessful, audiologists may obtain Speech Awareness Thresholds (SAT) and extrapolate results to SRT. Wilson and Margolis (1983) stated that SRT is generally 6 to 10 dB higher than SAT among individuals with normal hearing. However, they note that the relationship between speech recognition and awareness varies as a function of testing context and participant characteristics, and thus, it is not possible to state the difference between SAT and SRT with a single number that is applicable to all situations.

Modifications to the stimuli used in speech audiometry may also increase the likelihood of successful testing with individuals who have dementia. Familiar names and other vocabulary items that are personally meaningful to the individual may be used as an alternative to spondee words. The use of such stimuli may decrease cognitive processing effort, reduce demands on impaired attention and memory systems, and facilitate appropriate responding.

Response mode may also need to be adapted during testing. For pure-tone audiometry, if the individual with dementia has difficulty following spoken instructions, audiologists may try doing 'team testing' in which another person who is familiar to the resident with dementia (staff, family member) provides physical cuing to hand raise during pre-test conditioning trials. In all behavioural testing situations, clinicians need to be aware of the time of day when the individual appears most alert and responsive, plan to conduct testing over multiple sessions or days to control for fatigue, and avoid testing after medications are given that may have sedative side-effects.

With appropriate modifications, many individuals with moderate to moderately-severe dementia can be tested behaviourally. However, in the absence of reliable results from behavioural measures, the presence of acoustic reflexes, auditory brainstem responses and otoacoustic emissions may be used to infer 'functional' hearing.

Activity/Participation-based assessments. A plethora of measures exist to assess activity limitations/participation restrictions related to hearing loss. Questionnaires and rating scales are commonly used (see Worrall & Hickson, 2003 for a review). However, in moderate to severe dementia, individuals may not be aware of their hearing loss or be able to communicate about the impact of hearing loss on their everyday lives. Therefore, it is essential that care partners provide their perspectives on the issue. One example of a scale that can be completed by care partners of individuals with dementia in LTC settings is the *Nursing Home Hearing Handicap Index: Staff Version* (Schow & Nerbonne, 1977). It is a 10-item questionnaire with a 5-point Likert scale response format to which care partners rate level of agreement with statements related to residents' hearing in different contexts. Less structured approaches to soliciting care partner input are also suitable, such as interviews, which can yield rich information on problems associated with hearing in everyday activities. Weinstein (2000) provides an abbreviated list of questions that can be asked of caregivers to help identify hearing impairment, limitations and restrictions, including the following: Does the individual have the volume of the television set high? Does the individual ask for frequent repetitions or say "what" often? Does the individual hear the doorbell or telephone ring? Does the individual give incorrect answers to questions? Does the individual smile a lot during conversation, but not participate in discussions?

Additionally, systematic observation of residents in LTC may provide important information on patterns of communication interactions and potential problems during ADLs (Bourgeois & Hickey, 2009) that are related to hearing and may be amenable to treatment.

Intervention

Earlier intervention is generally agreed to yield better outcomes for older adults with hearing loss. For older adults with typical cognitive functioning and those with mild dementia, it is beneficial to initiate hearing health care before further cognitive or other age-related health declines occur (Donahue, Dubno & Beck, 2010). Although little has been written regarding interventions specifically for individuals with dementia, some aspects of aural rehabilitation can be modified to address the unique needs of individuals with hearing loss and dementia. For example, Boothroyd (2007) outlined four components of aural rehabilitation as follows: management of sensory deficits, instruction in the use of technology and control of the listening environment, perceptual training, and counseling to address quality of life issues related to residual hearing impairments. All components can be used in aural rehabilitation for individuals with dementia. The focus, however, is necessarily shifted to rely heavily on care partners, particularly in the management of sensory deficits via amplification, and control of the listening environment. Examples of these approaches will be discussed in the section that follows.

Amplification: An Impairment-based Approach

Hearing Aids. Based on a comprehensive assessment, the audiologist will determine if an individual with ARHL is a candidate for a hearing aid. As mentioned previously, hearing aids are an effective treatment for many adults with hearing impairment yet many individuals delay in seeking treatment of this sort. For individuals with dementia, hearing aid use may be even more limited (Cohen-Mansfield & Infeld, 2006; Durrant et al., 1991). To encourage successful use of hearing aids by individuals with dementia, certain practical considerations are necessary.

There is a large literature on the hearing aid fitting process, from pre-selection and pre-fitting to post-fitting education and counseling (see Weinstein, 2000 for a review). Although the focus in fitting a hearing aid is foremost on audiometric considerations (data collected during the assessment process), non-acoustic factors are particularly important for individuals with dementia and interact with acoustic factors to influence successful hearing aid use (Pichora-Fuller & Singh, 2006; Weinstein, 2000). These include hearing aid related characteristics such as style and complexity of controls, as well as cognitive ability of the older adult and degree of dependence for care.

In general, style is a personal preference and many older adults desire smaller, less visible aids such as in-the-ear and in-the-canal models. However, the second author has found that behind-the-ear (BTE) aids may be a better style choice for adults with dementia. BTE aids are bigger and therefore easier to handle, which is important for older adults who may have deficits in vision (Erber, 2003) as well as hand function and manual dexterity (see Singh, 2009 for a review).

Regardless of style, Palmer et al. (1999) recommend using hearing aids with automatic volume controls and a minimal number of programs for adults who have cognitive impairments. Additionally, because individuals with dementia in LTC are generally dependent upon others for hearing aid insertion and operation, relatively simple controls and directions will make it easier for care partners to use and care for hearing aids.

A significant challenge to hearing aid use among individuals with dementia and hearing loss in LTC settings is the potential for hearing aids to be damaged and lost. In studies involving several LTC facilities, researchers found that 30 – 70% of hearing aids were not working and/or were in need of repair (Bradley & Molloy, 1991; Thibodeau & Schmitt, 1988). Healthcare professionals who work in LTC settings anecdotally report many instances of misuse and misplacement of hearing aids. For example, individuals with dementia may worry about losing their hearing aids and thus “put them in a safe place” which they later cannot recall. Staff members also worry about losing expensive hearing aids, and therefore may not use the aids or only use them selectively. In a recent conversation with a son of a woman with dementia and hearing loss, the son told the S-LP that he took his mother’s hearing aids home, on recommendation of the staff, because her worry over losing the aids was becoming disruptive and staff members did not want to be responsible for having to replace the aids if they were lost. In other facilities, health professionals have noticed several pairs of hearing aids in plastic bags in drawers and on towel carts, the hearing aids unlabeled and their owners unknown.

Certain protocols are necessary to minimize loss and damage to aids. These strategies represent environmental modifications that facilitate hearing aid use. First, hearing aids should be labeled, with the help of an audiologist, to ensure that any warranty is not voided by improper labeling. Second, an otoclip should always be used to attach the aid to the wearer’s clothes. Third, a routine needs to be established when removing aids and storing them until the next use. To address this, the second author has been involved in the 'Blue Box Project' initiated at St. Joseph's Hospital - Parkwood site, to reduce the loss and damage to at-risk items such as hearing aids, eyeglasses and dentures. Once consent is obtained from the patient's substitute decision maker, an inexpensive plastic storage tray is placed out of reach at the patient's bedside. The individual items are checked off on the tray's label and care partners place these items in the box when not in use (see Figure 1). Outcomes of the Blue Box Project have been positive in that fewer items are misplaced and patients wear the items more consistently.

Figure 1. Blue Box Project

Another useful strategy to promote hearing aid care has been provision of regular maintenance of patients' hearing aids on a rotating basis throughout the facility. The second author and a representative from a community dispensing clinic perform this service, which is particularly important for individuals with dementia who are often unable to report any malfunctioning of equipment to care partners. The frequency and number of aids requiring external servicing by manufacturers has dropped considerably since the routine maintenance strategy was implemented, resulting in devices functioning more consistently and less time for patients to spend without hearing aids.

Post-fitting education is an important part of aural rehabilitation programs. Whether the adult with dementia has a hearing aid upon admission to LTC, or acquires one while a resident, the audiologist and S-LPs should ensure that staff members receive the necessary instruction in hearing aid care and that there is a strategy for follow-up and referral should problems arise. It is important to remember that individuals who are longtime hearing aid users may be able to maintain independent use and care of their aids well into the progression of their dementia. Routine aspects of hearing aid use may depend primarily on procedural or non-declarative memory, which has been shown to be relatively preserved in AD as compared to declarative memory (Bäckman 1996; DeWeer et al., 1994). The earlier such routines are created and the more they are practiced, the more resistant to forgetting they become, underscoring the importance of early intervention.

Assistive Listening Devices. Assistive listening devices (ALD) may be used as a supplement or an alternative to hearing aids. These types of devices generally comprise a remote microphone that is placed close to the sound source, and a signal transmission system that occurs through hard-wired and wireless systems, the latter including FM radio waves, infrared light waves and electromagnetic energy (Sandridge, 1995). The benefit of ALDs is that the sound reaches the individual with hearing loss without attenuation or interference from noise (Kaplan, 1996). Thus, ALDs are helpful for listening in group situations, in the presence of background noise and when listening to the radio and television, all of which are reported as activity limitations by older adults with hearing loss. Pichora-Fuller (1997) provides a review of the use of ALDs in LTC settings. Although not specific to individuals with dementia, many of the recommendations apply to residents with and without cognitive impairment.

It is advantageous to have more than one type of ALD available and to try different types in various listening situations to determine suitability for each individual. Two options for ALDs that have been used by the authors of this paper are the Sennheiser AudioPort (Sennheiser.com) and the Williams Sound PocketTalker™ (williamssound.com); several other good models are also available. As with hearing aids, the education and involvement of care partners are integral to the proper use of ALDs. Trial use over several weeks during daily routine can help care partners to determine improvements in auditory awareness (e.g., awareness of sounds in the environment), communication, and behaviour.

Education of Communication Partners: An Environment-focused Approach

Environmental factors include physical, social, and attitudinal variables that are part of a person's everyday life (WHO, 2001). For people with dementia, who become dependent on others for their care, the attitudes, knowledge and behaviours of care partners can be significant barriers or facilitators of communication functioning (Byrne & Orange, 2005). Because individuals with dementia are unable to intentionally modify their own communication behaviours, education is necessarily focused more on the communication partner than on the person with dementia.

The literature contains many examples of aural rehabilitation programs for older adults with hearing loss (See Pronk et al., 2011, for a recent review), yet few, if any, have been focused exclusively on individuals with dementia. Erber and Heine (1996) review important components of an education program for care partners of older adults with hearing loss in LTC. They highlight the importance of cerumen removal, and the use of hearing aids and ALDs in addition to education about hearing loss and its impact on communication and psychosocial functioning, education also includes, information on how and when to refer to an audiologist or, initially the S-LP, for screening, and details on modification of the physical environment to promote hearing-friendly communication settings. An integral part of training for care partners is the use of facilitative strategies to prevent and repair communication breakdowns when they occur. One of these facilitative strategies involves the use of clear speech.

Clear speech is a method of speaking that is used to enhance comprehension of spoken language by individuals with hearing loss. Clear speech is defined relative to conversational speech (Uchanski, 2005), which tends to be rapidly produced, often imprecise and 'surprisingly under-articulated' (Wingfield & Tun, 2001). From this speech stream, listeners must identify words, activate their meanings and determine syntactic and semantic structure at the phrase, sentence and discourse levels (Wingfield & Tun, 2001). Clear speech is characterized by accurate, precise production of sounds in each word, natural voice stress, and phrasing (Schum, 1996), which helps mark word boundaries. Clear speech rate tends to be moderate/normal, rather than fast or artificially slow.

Researchers have studied the acoustic characteristics of clear speech and its effect on speech perception by individuals with hearing loss and found facilitative effects (see Caissie & Tranquilla, 2010, for a review). However, published data on the use of clear speech with individuals who have hearing loss and dementia is lacking. Clear speech may be particularly beneficial for individuals with dementia because some of the components of clear speech, such as the use of pauses to moderate speech rate and stress on key words, may also be beneficial to reduce demands on working memory and increase auditory comprehension in individuals with dementia (Small, Kemper & Lyons, 1997). Further research is necessary to address questions related to treatment efficacy and effectiveness for older adults with different profiles of cognitive and sensory functioning.

In the meantime, Caissie and Tranquilla (2010) describe a clear speech training program that they have used in previous research (Caissie et al., 2005) with typically aging older adults with hearing loss and their spouses. The training is based on a model proposed by Tye-Murray and Witt (1997) and includes formal instruction, guided learning and real-world practice. They note that clear speech should be paired with other listener-focused approaches including conversation breakdown repair strategies and physical environmental modifications. Again, there is overlap between these strategies (see Table 2), recommended for individuals with hearing loss, and the strategies recommended for repairing conversation with individuals who have dementia, a point emphasized by Chartrand (2005).

In summary, the interventions reviewed in this paper were limited to impairment-based approaches to manage the sensory deficit of hearing, as well as environmental modifications (i.e., changing the physical environment to minimize the chances of hearing aids

Table 2. Conversational repair strategies and environmental modifications recommended for facilitating communication with individuals with dementia and those with hearing loss

Repeat and/or rephrase
Simplify message content; highlight key words
Supplement spoken language with nonverbal and written communication
Use a moderate, rather than slow or fast rate of speech
Speak face-to-face
Signpost/highlight when changing a conversational topic
Avoid noisy, reverberant environments
Limit group conversations and focus on one-on-one/dyadic conversations
Reduce distractions

being lost or damaged; caregiver education in clear speech) to facilitate speech comprehension and general communicative functioning of individuals with hearing loss and dementia. Other types of interventions may be appropriate, such as those directed at activity/participation levels of function, and need to be considered in the context of client need/wishes, current best research evidence and clinician expertise (Sackett, Rosenberg, Gray, Haynes, and Richardson, 1996). Indeed, audiological intervention for older adults with dementia should help to increase performance of activities of daily living as well as improve overall quality of life (Schneider, Pichora-Fuller, & Daneman, 2010).

Case Studies

In the following section we illustrate the use of specific interventions through case study descriptions. Each of the case studies is based on an actual client with dementia living in LTC. In the first case, we demonstrate how audiologists and S-LPs can act as consultants to care and in the second, we show the importance of trial use of amplification to promote positive hearing outcomes.

Mr. B

Mr. B was a 92 year old retired carpenter who lived in a LTC facility. At the time of referral to the S-LP, he had lived in the LTC for one year. Prior to admission, Mr. B lived at home alone but received frequent help from his daughter who was concerned for his safety. In addition to long-standing hearing loss, Mr. B had multiple medical conditions, including atherosclerosis, renal insufficiency, osteoarthritis, and moderate cognitive decline associated with dementia.

In the six months after admission, his formal caregivers and his daughter noted changes in his daily behaviour and demeanor. Generally, Mr. B was considered to be gregarious, a man who was friendly and liked to socialize.. However, he had begun to display aggressive, agitated behaviours during interactions in the dining room, in the activities room and in the hallway. He had also become resistant to care and often became angry during daily tasks such as dressing. At the time of referral to the S-LP, he had stopped eating meals in the dining room and spent much of his day in his room, by himself, either sleeping or staring out the window.

The registered nurse and physician reviewed Mr. B's medical chart to rule out potential medical causes (e.g., new medications, worsening of general cognition) that might account for changes in his behaviour. Subsequently, at a care plan meeting, the registered nurse requested a screening by the S-LP with the goal of identifying if/how staff members could improve their communication strategies to decrease Mr. B's apparent frustration, and increase successful social interactions and compliance with care tasks. Mr. B's daughter was in attendance and told the S-LP that her father had hearing aids but did not like to wear them. He had owned bilateral, in-the-ear aids for almost two years but had never worn them consistently. Once he was admitted to the LTC facility, he refused to wear them at all.

An audiology evaluation was requested with the purpose of assessing any change in his hearing status, the condition of his hearing aids and additional options for intervention. In this case, Mr. B was ambulatory and had a supportive family member to take him to an audiology clinic in the community, thus, access to diagnostic hearing health care was not an issue.

The audiologist who had previously evaluated his hearing and prescribed his hearing aids re-evaluated his hearing and checked the aids. The aids were in working condition. At that time, an appointment for follow-up was made to ensure that Mr. B was adjusting to the use of his hearing aids and the audiologist provided additional information to Mr. B's daughter regarding care of hearing aids within the LTC setting, which she shared with the LTC nursing staff. The audiologist also provided printed information on hearing aid care for Mr. B's medical chart and the S-LP worked with the nursing home staff on effective communication strategies (listener-directed and environmental modifications) to increase successful interactions.

Positive outcomes were achieved, with Mr. B becoming more engaged in daily life activities, and less resistant to care. Mr. B needed encouragement to wear his hearing aids, and still sometimes refused, but did wear them more frequently than he had in the past. Nursing staff reported being more comfortable with handling the hearing aids, which had previously been an issue and a barrier to their use. The S-LP, with knowledge of hearing and communication, was a referral source for the audiologist, who acted in a consultative capacity. Together with the resident, his family and formal caregivers, the goal for improved communication was met.

Jack

Jack was an 86 year old veteran of World War II who was admitted to LTC with a diagnosis of multi-infarct dementia. Jack demonstrated high levels of anxiety, refusing to leave his bedside for any reason. In addition to his anxiety, he was verbally very disruptive, speaking loudly and demonstrating constant verbal self-stimulation behaviors. The audiologist began initiating use of a PocketTalker™ amplifier during brief visits at bedside. Over several appointments, the audiologist was able to gain sufficient trust to get Jack to participate in a more formal assessment and obtained a minimal amount of behavioural test data. These results were sufficient to determine the presence of a previously undiagnosed moderate to severe sensorineural hearing loss and prescribe behind-the-ear hearing aids. His use of loud speech decreased, and the verbal self-stimulation ceased. Although some anxiety remained, eventually, Jack developed a trusting relationship with a paid companion who was instructed by the audiologist regarding use of appropriate anticipatory and repair communication strategies. They successfully attended recreational activities within the facility, including ceramics and outings including attendance at the local fall fair.

Conclusions and Directions for Future Research

Hearing loss is under-recognized and under-treated in individuals with dementia, particularly those who live in LTC settings. Although barriers to accessible hearing health care currently exist, audiologists and S-LPs can collaborate to ensure appropriate services are available. Through such collaborations, individuals with dementia and hearing loss may have more successful communication interactions with care partners, and become more actively engaged in daily life. More research is needed on the effectiveness of amplification and other aural rehabilitation strategies as used specifically with individuals who have dementia at different stages of cognitive decline and in different living settings. Future research should also include a focus on developing and testing modified audiology evaluation protocols for use with older adults with cognitive impairment.

Undoubtedly, increased access to audiologists is a necessary area for advocacy. If access to services does improve, and more adults with hearing loss seek the services of audiologists, there will be a shortage of qualified professionals to meet their needs (Donahue et al., 2010). Given the aging population and the projected increased need for audiological services for older adults, Donahue et al. discussed the move by professional organizations in the U.S. to train and certify audiology assistants and technicians in an "effort to maximize productivity of the most highly trained individuals" (p. 4). This model is one that would be especially helpful in ensuring that older adults in institutional care environments receive needed services, where limited access to audiologists is a current and growing problem. Audiologists are not typically employed on-site in LTC settings and in the vast majority of cases, work as consultants who visit the LTC setting only rarely (Lubinski, Stecker, Weinstein & Volin, 1993; Worrall & Hickson, 2003). In a Canadian context, audiologists may need to rely more on S-LPs and other staff in LTC to carry out programs, under a consultative model in which audiologists provide services and appropriate staff training on a rotating basis across care facilities within health regions.

The relationship between hearing loss and dementia is receiving increased attention. As communication professionals, S-LPs and audiologists must work together to conduct research and educate the general public and healthcare policy makers on the central importance of the ability to hear and to communicate to encourage active aging (WHO, 2002) by older adults with chronic health conditions, such as dementia.

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Authors' Note

Correspondence concerning this article should be addressed to Tammy Hopper, Ph.D., Associate Professor, Department of Speech Pathology and Audiology, Faculty of Rehabilitation Medicine, University of Alberta, Edmonton AB, T6G 2G4. Email: Tammy.hopper@ualberta.ca

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Formal Caregivers' Perceptions of Effective Communication Strategies while Assisting Residents with Alzheimer's Disease During Activities of Daily Living

Les perceptions formelles des stratégies de communication efficaces qu'ont les soignants lorsqu'ils assistent des résidents atteints de la maladie d'Alzheimer dans le cadre des activités de vie quotidienne

Rozanne Wilson
Elizabeth Rochon
Carol Leonard
Alex Mihailidis

KEY WORDS
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PERCEPTIONS
COMMUNICATION STRATEGIES

Abstract

This article describes caregivers' perceptions of communication strategies that are useful in their care practice when assisting individuals with moderate and severe Alzheimer's disease (AD) during the completion of activities of daily living (ADLs). A total of 10 formal caregivers participated in one-hour semi-structured focus group interviews (FGIs) conducted at two different long-term care (LTC) locations (n = 5 at each location). To identify the strategies caregivers perceived to be effective, content analysis was the primary method used to examine the FGI data. Particular attention was given to identifying the frequency and extensiveness in which caregivers made reference to communication strategies during the FGIs. Caregivers discussed a total of 33 strategies that they perceived to be useful when assisting residents with moderate and severe AD during the completion of ADLs. The majority of the communication strategies discussed (64%) were task-focused and the most frequently mentioned strategies included the use of negotiation and explaining one's actions to the resident. Greeting the resident was the most frequently discussed social strategy. In addition, two emergent themes containing a total of 12 strategies were identified, with the most frequently mentioned being establishing eye contact, familiarity with the resident, and postponing the task. Caregivers' perceived use of communication strategies indicates that person-centred dementia care is a central aspect to facilitating the completion of ADLs.

Abrégé

Cet article décrit les perceptions qu'ont les soignants des stratégies de communication utiles dans leur pratique de soins lorsqu'ils assistent des personnes modérément et sévèrement atteintes de la maladie d'Alzheimer au cours des activités de vie quotidienne. Un total de dix soignants a participé à des entrevues semi-structurées de groupes de discussion d'une heure tenues à deux centres de soins de longue durée (n=5 à chaque endroit). Pour identifier les stratégies que les soignants percevaient comme efficaces, on a privilégié l'analyse de contenu pour examiner les données recueillies lors des entrevues. On a porté une attention particulière à l'identification de la fréquence et de l'étendue des références faites par les soignants aux stratégies de communication pendant les entrevues. Les soignants ont discuté un total de 33 stratégies qu'ils percevaient utiles dans leurs interactions avec des résidents modérément et sévèrement atteints de la maladie d'Alzheimer pendant le déroulement d'activités de vie quotidienne. La majorité des stratégies de communication discutées (64 %) ont été soumises aux groupes de discussion et les plus fréquemment mentionnées comprenaient l'utilisation de la négociation et de l'explication des actions posées aux résidents. La salutation adressée au résident était la stratégie sociale la plus fréquemment discutée. En plus, deux thèmes émergents contenant un total de 12 stratégies ont été identifiés ; les plus fréquemment mentionnées sont l'établissement d'un contact visuel, la familiarité avec le résident ou la résidente et la remise de la tâche à plus tard. L'utilisation des stratégies de communication par le soignant indique que les soins axés sur la personne dans les cas de démence sont un aspect central menant au bon déroulement des activités de vie quotidienne.

Rozanne Wilson
Department of Speech-Language Pathology,
University of Toronto
Toronto, ON
Canada
Toronto Rehabilitation Institute,
Toronto, ON
Canada

Elizabeth Rochon
Department of Speech-Language Pathology,
University of Toronto
Toronto, ON
Canada
Toronto Rehabilitation Institute,
Toronto, ON
Canada

Carol Leonard
Audiology and Speech-Language Pathology
Program, School of
Rehabilitation Sciences,
University of Ottawa
Ottawa, ON
Department of Speech-Language Pathology,
University of Toronto
Toronto, ON
Canada

Alex Mihailidis
Department of Speech-Language Pathology,
University of Toronto
Toronto, ON
Canada
Toronto Rehabilitation Institute,
Toronto, ON
Canada

Alzheimer's disease (AD) is a progressive neurodegenerative disease and is the leading cause of dementia, accounting for 63% of all dementias diagnosed in Canada (Alzheimer Society of Canada, 2010). AD is clinically diagnosed with the criterion of having an insidious onset that leads to the development of multiple cognitive deficits that worsen with disease progression. More specifically, the hallmark clinical symptoms of AD are memory impairment coupled with disturbances in language, executive functioning, and motor activity that significantly impact an individual's social and occupational functioning (Diagnostic and Statistical Manual of Mental Disorders 4th ed., text rev (DSM-IV-TR) (American Psychiatric Association, 2000). Memory and language declines affect the communication abilities of individuals with AD. For instance, semantic problems, including word finding difficulties, reduced verbal fluency, and comprehension impairments are well documented (Appell, Kertesz, & Fisman, 1982; Karantzoulis & Galvin, 2011; Kempler, 2005; Kempler, 1991; Geldmacher, 2009) and these impairments impact the capacity to communicate. In addition to social participation, communication is a fundamental component to completing instrumental activities of daily living (IADLs) (e.g., managing finances or planning activities). Moreover, as AD progresses, managing the completion of basic activities of daily living (ADLs) becomes problematic, creating the need for caregivers to become increasingly involved in supporting individuals during routine daily tasks (e.g., personal hygiene). Unfortunately, given the characteristic cognitive deficits that manifest in AD, communication difficulties inevitably arise and ensuing breakdowns in communication can strain the relationship between caregivers and individuals with AD (Savundranayagam, Hummert, & Montgomery, 2005; Williamson & Schulz, 1993).

At the moderate to severe stages of AD, placement in long-term care (LTC) often becomes necessary to manage the complex care requirements of individuals with declining cognitive and functional abilities. Formal caregivers (e.g., personal support workers [PSW]) are directly responsible for ensuring that the daily care needs of residents with AD are met. Given the declines in memory, language, attention, executive functioning, and visuospatial skills, formal caregivers experience many challenges (e.g., breakdowns during the steps of a task) when assisting individuals with AD in tasks that depend on these capacities. Further, communication is fundamental to fostering co-operative care during the caregiver-AD dyad interaction; however, the declining language skills in residents with AD further complicate the cognitive and functional declines. To help caregivers achieve their care practice goals and to help residents experience optimal quality of care, several recommended communication strategies have been made available to caregivers as guidance during caregiver-AD resident encounters (e.g., Alzheimer Society of Canada, 2010; Hopper, 2001; Lee, 1991; Ripich, Wykle, & Niles, 1995; Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997; Zientz et al., 2007). Some typical recommended communication strategies reported in the caregiving literature include the use of short-simple sentences, speaking slowly, asking one question or giving one instruction at time, using yes/no questions or simple-choice questions, using verbatim repetition, giving time to respond, establishing eye contact and eliminating environmental distractors (e.g., Lee, 1991; Sheldon, 1994; Small, Gutman, Makela, & Hillhouse, 2003). Some of these strategies have been individually examined and have been shown to support the caregiver-AD communication dyad. For example, improved sentence comprehension in individuals with AD has been documented when paraphrased or verbatim repetition was provided (Small, Kemper, & Lyons, 1997) and the use of one proposition at a time has been shown to improve comprehension as compared to the use of multiple ideas in a sentence (Rochon, Waters, & Caplan, 1994; Rochon, Waters, & Caplan, 2000). Further, the use of closed-ended questions has been investigated while observing conversations between caregivers and individuals with AD, with findings demonstrating that this strategy supports successful discourse (e.g., Small & Perry, 2005; Tappen et al., 1997). However, to date, few studies have examined effective communication strategies best suited for the procedural discourse (i.e., discourse focused on how to do something) occurring between family caregivers and spouses with AD during the completion of ADLs (Small et al., 2003) and between formal caregivers assisting residents with moderate to severe AD during the completion of ADLs (e.g., Hammar, Emami, Engström, & Götell, 2011; Wilson, Rochon, Mihailidis & Leonard, 2012).

With respect to communication strategies examined in the LTC setting, several communication training programs have been developed and have demonstrated effectiveness (e.g., Burgio et al., 2001; Dijkstra, Bourgeois, Burgio, & Allen, 2002; McCallion, Toseland, Lacey, & Banks, 1999; Ripich et al., 1995); however, these training programs have some limitations. For instance, the training programs contain some communication strategies that have yet to be examined individually for effectiveness. In addition, some of these studies evaluating training programs include residents with dementia without a confirmed diagnosis of probable AD. Importantly, dementia is an umbrella term used to describe acquired cognitive impairment (Weiner, 2009) and there are several causes of irreversible dementia, each with distinguishable language and cognitive characteristics. For example, in vascular dementia, the second leading cause of dementia (Hebert et al., 2000), less impaired language function with greater executive functioning impairments, and less impaired memory as compared to individuals with AD has been observed (Looi & Sachdev, 1999). Conversely, in semantic dementia, language deficits occur in the absence of significant cognitive impairments and these language impairments are slowly progressing (Maxim & Bryan, 2006). Thus, findings from studies that include residents with dementia may not be applicable to the language and functional impairments typical of individuals with dementia of the AD type. Additionally, the training programs have not been examined in the context of assisting residents with moderate to severe AD specifically during the completion of ADLs.

Research has been done to examine communication between LTC staff (e.g., nurses or PSWs) and residents (e.g., Caris-Verhallen, 1998; Caris-Verhallen, Kerkstra, & Bensing, 1999), with findings indicating that caregivers and residents participate in more task-focused communication as compared to socio-emotional communication, during which they utilize eye contact and affective touch to establish communication interactions. Only a few studies have examined communication between formal caregivers and residents with moderate to severe AD (e.g., Williams & Tappen, 1999; Tappen et al., 1997). For instance, Williams & Tappen (1999) examined conversations between caregivers and residents with moderate to severe AD to explore the possibility for the development of therapeutic relationships in advanced AD. Findings from this study indicated that, despite advanced disease progression, therapeutic relationships were fostered during conversations between caregivers and individuals with AD.

In terms of perception of effective communication strategies, some research has explored the viewpoints of family and formal caregivers' experiences around communicating with individuals with AD (e.g., Richer, Roberto, & Bottenberg, 1995), with findings indicating the importance of individualized interventions. Others have focused on the perceptions of formal caregivers when assisting LTC residents (e.g., Medvene & Lann-Wolcott, 2010) or when communicating with persons with AD (e.g., Beach & Kramer, 1999; Savundranayagam, Ryan, Anas, & Orange, 2007). For example, Medvene and Lann-Wolcott (2010) explored nurses aides' communication behaviours when working with LTC residents by interviewing nurses aides to examine which communication strategies caregivers discussed using in their care practice. Findings indicated that "giving positive regard" was the most frequently discussed strategy and was used by all participating nurses aides. While this study explored nurses aides' perceptions of effective communication strategies for LTC residents, the discussions were not specific to assisting residents with AD. To our knowledge, no studies have examined caregivers' perceptions of effective communication strategies with a specific focus on assisting residents with moderate and severe AD during the completion of ADLs; and yet, the completion of ADLs comprises the bulk of caregiver-resident interactions in the LTC setting.

The purpose of this research was to describe formal caregivers' perceptions of communication strategies that are effective when assisting individuals with AD residing in LTC, at the moderate and at the severe impairment levels, during the successful completion of ADLs. This research was conducted as part of a larger observational comparison study designed to investigate communication strategies employed by formal caregivers assisting residents with moderate and severe AD during the completion of an activity of daily living (Wilson, Rochon, Mihailidis, & Leonard, manuscript accepted). The data presented in this paper are complementary to the larger observational study and provide the opportunity to help clarify or explain the observational data. The specific aims of this article were: (1) to identify which task-focused communication and social strategies, defined a priori, caregivers consider useful when assisting individuals with AD; and (2) to report any emergent themes, consisting of strategies that caregivers perceive to be effective, that were not included in the previously developed coding scheme.

Method

Research Design

A descriptive study design was employed to examine caregivers' perceptions of the communication strategies that they utilize while assisting residents with moderate and with severe AD during completion of daily tasks. To address the purpose of this research, formal caregivers participated in a one-hour semi-structured focus group interview (FGI). FGI is a useful method to collect qualitative data, which can be quantified, on a topic of interest (McLafferty, 2004). A non-probability criterion-based purposive sampling procedure was implemented to select formal caregiver participants, as this sampling procedure is suitable for the comprehensive study of a phenomenon of interest that is supported by the deliberate choice of participants because of their expert knowledge (Creswell & Plano Clark, 2007; Forman, Creswell, Damschroder, Kowalski, & Krein, 2008; Tongco, 2007). All participating formal caregivers were responsible for the direct care of individuals with moderate to severe AD, thus were deemed expert care providers of individuals with AD who could contribute to the understanding of effective communication strategies for this client population. All caregivers who participated in an FGI also participated in our larger observational study (Wilson et al., manuscript accepted).

Participants and Setting

A total of 10 formal caregivers (personal support worker (PSW) = 9; registered nurse = 1) from two different LTC settings participated in a single one-hour semi-structured FGI. Five other caregivers had consented to participate in the FGIs; however, four could not attend due to scheduling conflicts and one caregiver had taken a health-related leave of absence after consent was obtained. At each LTC location, five caregivers participated in the FGIs, which is considered an appropriate sample size to generate data (McLafferty, 2004; Rabiee, 2004). Across the two LTC locations, formal caregivers did not significantly differ on age, years of education, years in current professional title, and years working with residents with AD.

Table 1 summarizes the characteristics of the participants. Nine of the caregivers were female, all caregivers worked the day shift, and all were responsible for the daily care of residents with moderate and severe AD. Further, to be included in this study, caregivers had to speak English comfortably and have worked with individuals with AD for at least one year. All caregivers involved in the FGIs were recruited as participants in a larger project which measured caregivers' actual use of task-focused (verbal and non-verbal) and social-focused communication strategies while assisting individuals with moderate and severe AD during the completion of an ADL -- toothbrushing.

Ethics Approval

Ethics approval was granted by the University of Toronto Research Ethics Board (REB) and by Toronto

Table 1. Characteristics of Formal Caregivers Participating in the Focus Group Interviews (N = 10)

Professional Title	Years in Current Professional Title	Years Working with Individuals with AD	Years of Education	Age (Years)
PSW	2	2	13	30
PSW	5	5	17	37
PSW	25	25	18	62
RN	32	24	13	57
PSW	25	25	15	52
PSW	40	22	12	58
PSW	7	4	16	34
PSW	11	3	15	35
PSW	14	8	15.5	43
PSW	7	7	18	38
Mean (*SD*) Range	16.82 (*12.9*) 2 - 40	12.51 (*10.1*) 2 - 25	14.7 (*1.7*) 12 - 18	44.6 (*11.6*) 30 - 62

Note. *PSW = Personal support worker. RN = Registered nurse. There was no difference between caregivers on their overall references made to strategies when grouped by years of experience working with individuals with AD: Group 1 = ten years or less experience (n = 6) and Group 2 = 20 years plus experience (n = 4), U = 10.5, z = -.32, p = .75.*

Rehabilitation Institute REB, which is affiliated with one of the participating LTC facilities. Oral and written information was provided to caregivers. Written consent was signed by all caregivers in this study. All participants were informed that participation in this study was voluntary and that one could withdraw at any time without any impact on their work status.

Procedure

Data collection.

Two one-hour on-site FGIs were conducted with participant caregivers, one FGI at each LTC facility. FGIs were conducted after completion of data collection for our observational study (Wilson et al., manuscript accepted). To ensure consistency, each FGI was led by the same externally hired professional moderator who had experience conducting FGIs in the health care setting (e.g., biotechnology and life sciences research) and each FGI was also attended by the first author to take field notes. The FGIs followed a semi-structured interview format consisting of a pre-determined question guide comprised of open-ended questions and their probes. The question guide was structured to focus caregivers to generate a discussion based on which communication strategies caregivers perceive as useful when assisting individuals with moderate and severe AD during completion of ADLs. The FGIs started with an introduction to the purpose of the discussion and a general knowledge question to begin the discussion: "What comes to mind when you think about your experience communicating with individuals with AD during your daily care routine?" Following the introduction, two main broad questions were posed to participants in each FGI: (1) "Which verbal and non-verbal communication strategies come to mind that you think are useful, or effective, when assisting individuals with AD during daily care tasks?" and (2) "Do you think that there are some communication strategies that may be better suited for individuals with moderate AD and for those individuals with severe AD?" Across both FGIs, the aforementioned broad questions were posed to the caregivers. However, in instances where the moderator felt it necessary, probes were given to explore or clarify participant discussion that was deemed important to the study and if the caregivers requested an example of a daily task, toothbrushing was the ADL suggested as a guide to their discussion. Following the discussion of the guided questions, caregivers were asked to rate the effectiveness of nine communication strategies that were previously found to frequently occur while formal caregivers assisted residents with AD during the successful completion of handwashing (Wilson et al., 2012). Using a 10-point scale, 1 being *the least effective*, 5 being *moderately effective*, and 10 being *very effective*, caregivers rated the following strategies for residents with moderate and severe AD: (1) present one idea or instruction at a time, (2) use closed-ended (yes/no) questions, (3) use paraphrased repetition, (4) use the resident's name, (5) use encouraging comments (verbal praise), (6) point to objects relevant to the task, (7) demonstrate the step of the task using gestures, (8) hand objects to the resident (tactile prompt), and (9) use guided touch. The FGIs were video-recorded (but participants' faces were not visible, at their request). Data collection for this research project took place between September 2010 and February 2011.

Data analysis

Transcription and data coding.

The FGIs were orthographically transcribed verbatim by a professional transcription service and each transcript was checked for accuracy by the first author. Also, all field notes were typed out for later interpretation. To address the primary aim of this research, directed content analysis was deemed the appropriate method (Hsieh & Shannon, 2005). Hsieh and Shannon (2005) describe this approach to content analysis as having the goal of extending or validating existing research and this approach has been used to explore nurses aides' perceived communication behaviours with nursing home residents (Medvene & Lann-Wolcott, 2010). Following the review of discussions relevant to the research aims, each of the caregiver's statements in these discussions was segmented based on a reference or, in some instances, multiple references made to a communication strategy (units of analysis) in a given discussion. Following unitization of each of the caregiver's comments, a multidimensional observation coding scheme (MOCS) was used to identify communication strategies discussed by the caregivers. MOCS is a comprehensive coding scheme that was developed based on the current empirical literature regarding communication and individuals with AD (e.g., Rochon et al., 2000; Small et al., 1997; Small et al., 2003) and was adapted from a coding scheme used to examine which task-focused communication strategies formal caregivers employ during the completion of an activity of daily living (Wilson et al., 2012; Wilson et al., manuscript accepted). MOCS was also utilized for the quantitative content analysis of the observational data collected as part of the larger study that preceded this research. MOCS consists of three dimensions that contain specific communication strategies that may be utilized during the completion of ADLs: (1) task-focused communication strategies, (2) social communication strategies, and (3) miscellaneous (MISC) categories. The task-focused communication strategies dimension contains a total of 19 communication strategies falling under one of two sub-categories, verbal and non-verbal body language (e.g., gestures and touch). Six communication strategies were classified as social in nature and four codes were included in the MISC dimension. See Table 2 for a detailed description of the communication strategies included in the MOCS, which were described by caregivers during the discussion stemming from guided questions provided to them. Examples provided in Table 2 relate to the task of toothbrushing and these examples were generated from the larger observational study. All decisions regarding MOCS codes and code definitions were made a priori.

To summarize, the first step of the analysis involved segmenting the transcripts to include the discussion surrounding caregivers' perceived use of communication strategies while assisting individuals with AD. The next step in the analysis was coding each of the relevant statements with the predetermined codes outlined in the MOCS. Finally, any communication strategy that did not fall under MOCS dimensions was coded as a strategy that fell under emergent themes.

Table 2. Caregivers' Perceived Use of Communication Strategies Included in the Multidimensional Observation Coding Scheme (MOCS)

Communication strategies	Definition	Example: toothbrushing
Dimension 1: Task-focused		
Verbal strategies		
One proposition	Single direction, request, or instruction present in caregiver's utterance to assist resident during steps of the task (e.g., step-by-step instructions)	"Please turn on the water."
Verbatim repetition	Caregiver repeats previous message (all content words or entire utterance) within same utterance or in immediate next utterance (task related)	"Turn the tap on, turn the tap on. "
Paraphrased repetition	Caregiver restates previous message for clarification (related to steps of the task)	"Turn the taps on. Turn the taps to get some water."
Introduce task	Caregiver indicates to the resident that they are going to brush his or her teeth (at beginning of the task)	"We are going to brush your teeth now."
Explanation of actions	Caregiver explains what they are going to do with the resident during steps of the task	"I am going to help you turn the water on now."
Use of resident's name	Caregiver addresses residents by their first or last name during steps of the task to gain their attention	"Ms. X, here is the toothbrush"
Negotiation	Dialogue between the caregiver and the resident to reach an agreement or to meet the needs of both individuals during completion of the task	"Okay, after we finish brushing, I will get you a cup of tea."
Encouraging comments	Verbal praise, reassurance, optimism directed toward resident while participating in the task	"You're doing a good job!"
Multiple verbal strategies	Caregiver utilizes more than one verbal communication strategy within an utterance.	"Mr. X, can you turn the water on?"
Combination of verbal and visual strategies	Caregiver utilizes "talk and show" method during steps of the task	"Brush your teeth {caregiver gestures toothbrushing motion at the same time}."

Non-verbal strategies		
Hand object to the resident	Caregiver provides object to resident as a tactile prompt for the resident	Caregiver hands towel to the resident
Guided touch	Caregiver uses physical touch to guide resident through a step of the task	Caregiver guides resident's hand to the toothbrush
Comfort touch	Caregiver uses touch to indicate support or reassurance during a step of the task	Caregiver touches the resident's shoulder
Attention touch	Caregiver uses touch to gain or re-gain the attention of the resident when "off-task"	Caregiver touches the resident's hand to indicate that it is time to begin brushing
Demonstration gesture	Caregiver illustrates, with action, how to perform a step of the task	Caregiver demonstrates how to brush teeth
Pointing	Caregiver visually indicates direction of an object necessary for the step of the task	Caregiver points to the location of the toothpaste
Dimension 2: Social		
Greet resident	Caregiver greets resident upon initial contact	"Hello Ms. X, how are you today."
Compliment resident	Caregiver compliments resident, building rapport or validating resident	"You look nice today."
Caregiver responds to resident	Caregiver acknowledges, agrees, shows empathy or responds to a comment, request, or statement made by the resident	"I know you are looking forward to lunch today."
Dimension 3: MISC		
Full physical assistance	Caregiver uses full physical assistance during the step of the task	Caregiver brushes the resident's teeth
Redirection	Caregiver redirects resident to keep on task	Caregiver guides resident to water instead of towel

Note. The complete set of codes (n = 33) included in the MOCS is reported in Wilson, Rochon, Mihailidis, and Leonard (manuscript accepted). "Quantitative Analysis of Formal Caregivers' Use of Communication Strategies while Assisting Residents with Alzheimer's disease During Oral Care". This Table only includes the codes that were referred to by at least one caregiver during the FGIs.

Transcription and MOCS agreement. As part of the larger study, agreement analysis was performed on all transcripts. The first author independently transcribed a random selection of 20% of the transcripts. Total percent (point-by point) agreement was computed as follows: A/ (A + D) x 100, which is the total number of agreements divided by total number of agreements and total number of disagreements multiplied by 100 (see for review House, House, & Campbell, 1981). Acceptable agreement was demonstrated for words (84.3%) and utterance segmentation (80.0%). After agreement for transcript content was established, the first author and a trained research assistant (clinical speech-language pathology student) independently coded the segments containing caregivers' references to communication strategies that they use in their care practice. Codes applied to these segments were either the communication strategies defined in the MOCS or those that were novel strategies reported by caregivers. The agreement analysis was performed on half of the total number of segmented units caregivers produced (n = 51 utterances). MOCS codes and strategies categorized within the emergent themes demonstrated an acceptable 88.2 percent occurrence agreement (occurrence agreements/ occurrence agreements + disagreements X 100) between the two coders.

Results

An analysis of the transcripts derived from the FGIs indicated that formal caregivers discussed a variety of communication strategies that they perceive to use in their care practice. Specifically, caregiver guided interviews generated narratives that were segmented into a total of 102 units (each unit referring to one or more strategy) that contained a total of 137 references made to strategies that caregivers perceived to be useful when assisting residents. Importantly, with respect to our research aims, 83 (60.6%) of the total references made to strategies were contained within MOCS and 54 (39.4%) of the total references made were categorized under one of the two emergent themes: general communication strategies and general care strategies. Moreover, the references caregivers made to strategies were identified by a total of 33 strategy codes, with 64% of these coded strategies (n = 21) defined in the MOCS. In the subsequent sections, the results are presented with respect to our research aims. In addition, the findings regarding caregivers' perceived use of strategies as a function of disease severity and caregivers' effectiveness ratings for a set of task-focused communication strategies are presented.

Communication Strategies Defined by *MOCS*

Of the total segments (n = 102 units) that were derived from the FGI narratives, over three-quarters (81.4%) contained at least one strategy that was defined a priori in MOCS. Broken down further, 65.7% of these strategies were identified as falling under the dimension of task-focused communication strategies, 11.8% were categorized as social strategies, and 3.9% were categorized as MISC. With respect to the strategies identified utilizing the MOCS (n = 83) , the majority of strategies were categorized as verbal task-focused communication strategies (55.4%), while 25.3% were task-focused non-verbal strategies, 14.5% were social strategies, and 4.8% were MISC. The task-focused verbal communication strategies that caregivers most frequently discussed were: (1) using negotiation, (2) explaining their actions to the resident, and (3) using the resident's name to gain their attention. With reference to negotiation, caregivers perceived this strategy to be essential to their care practice and indicated that negotiation is intimately linked to understanding a resident's preferences, needs, and personal history. In addition, supplying residents with their preferred food choices was a common method of negotiation. The most frequently discussed non-verbal task-focused communication strategies were: (1) using visual demonstration, and (2) handing an object to the resident (tactile prompt). Finally, the most frequently used social strategy was greeting the resident. Table 3 provides examples of caregiver narratives pertaining to the most frequently discussed task-focused and social communication strategies identified with the MOCS. These narrative examples were generated in response to the guided questions presented to the caregivers during the FGIs.

Table 3. Examples of Caregivers' Comments Pertaining to the Most Frequently Discussed Communication Strategies

Communication strategy	Narrative example
Task-focused	
Negotiation	You use it to bargain or negotiate with them. [For example] we tell them "okay brush your teeth and afterward we'll go for coffee and get you some treats."
Explanation of actions	Tell every instruction you will do. [For example] like every instruction you got to do, you just tell them.
Use of resident's name	When you start, just call them by their last name.
Demonstration gestures	What I noticed, working with residents, I find the non-verbal because of the language barrier... that doing demonstration. [For example] wanting them to brush their teeth you do the demonstration and when you put the socks on or whatever, I give a demonstration on myself for what I want them to.
Hand object to the resident	..... I will have to do the brushing of the teeth or I put the brush in the hand and ask them to do it. Right away you know [their severity level].
Social	
Greet resident	We always greet them when we go into their rooms in the morning

In terms of the extensiveness of references made to the communication strategies defined in advance (i.e., the number of individual caregivers that express the use of the same communication strategy), the strategies that exhibited the greatest level of extensiveness during the FGIs were the use of negotiation (90%), the caregiver explaining their actions to the resident (60%), the caregiver demonstrating or gesturing an action to the resident (50%), and the caregiver greeting the resident (60%). In addition to individual references each caregiver made to communication strategies during the FGIs, there were also instances of group consensus during the FGIs whereby all caregivers agreed that the strategy was useful. The six communication strategies that were identified in this way were: (1) negotiation, (2) use the resident's name, (3) paraphrased repetition, (4) verbatim repetition, (5) greet the resident, and (6) respond with empathy to the resident's requests, statements, or needs. Table 4 summarizes the findings for the communication strategies formal caregivers commented on that were identified utilizing the MOCS.

Table 4. Frequency and Extensiveness of Formal Caregivers' Perceived Use of Communication Strategies

Communication strategies (n = 21)	Frequency	Relative Frequency (%)	Extensiveness (%)
1. Task-focused			
Verbal			
One proposition	3	3.6	20
Verbatim repetition	2	2.4	10†
Paraphrased repetition	2	2.4	10†
Introduce task	2	2.4	20
Explanation of actions	9	10.8	60
Use of resident's name	4	4.8	20†
Negotiation	17	20.5	90†
Encouraging comments	2	2.4	20
Multiple verbal strategies	5	6	40
Non-verbal			
Hand object to the resident	4	4.8	20
Guided touch	3	3.6	20
Comfort touch	2	2.4	20
Attention touch	3	3.6	30
Demonstration gesture	5	6	50
Pointing	2	2.4	20
Verbal and visual strategies	2	2.4	20
2. Social			
Greet resident	8	9.6	60†
Compliment resident	1	1.2	10
Caregiver responds to resident	3	3.6	10†
3. MISC			
Full physical assistance	3	3.6	10
Redirect resident	1	1.2	10

Note. Relative frequency is the total frequency of a given communication strategy relative to the total number of communication strategies commented on by the formal caregivers included in the MOCS (total = 83). Extensiveness refers to how many of the participating caregivers commented on the use of the same communication strategy in their care practice. †Denotes that a group consensus was expressed regarding the usefulness of a given strategy.

Emergent Themes

Data from the FGIs led to the identification of two main emergent themes, which, combined, contained a total of 12 strategies that caregivers perceived to be useful in their care practice when assisting individuals with moderate to severe AD during the completion of ADLs. The two emergent themes were: (1) general communication strategies, and (2) general care strategies. General communication strategies were classified as communication strategies caregivers discussed that were not included in the MOCS and that were considered to be applicable to all circumstances of communication, thus not necessarily task-driven (e.g., giving time for resident to respond). General care strategies were classified as strategies that caregivers discussed that were applicable to their general approach to care, which they use across contexts and are not specific to communicating with residents. Further, general care strategies may indirectly support the completion of ADLs (e.g., knowing the resident's preferences). For each strategy, Table 5 provides a definition and an example of a segment of the narrative that made reference to the emergent strategy during the discussion generated when the guided questions were presented to the caregivers. Caregivers made a total of 54 references to these strategies and at least one of these strategies was present in 52.9% of the unitized segments. Of these novel strategies, 20.6% were categorized in the emergent theme of general communication strategies and 32.3% were categorized in the emergent theme of general care strategies.

Table 5. Emergent Themes Caregivers Perceived to be Useful While Assisting Residents with AD during the Completion of ADLs

Strategies (n = 12)	Definition	Narrative example
1. General communication strategies		
Be patient	Provide time for the resident to respond to a request, instruction, or general communication attempt	"Be patient with them and give them time [to respond]."
Focus the resident	Gain the resident's attention and use strategies (e.g., proximity) to help maintain his or her focus during the activity	"The more cognitively impaired the resident is, the harder it is to get their attention, we have to try to put ourselves in front of the resident, get him to look at me and get their attention."
Environmental cues	Use stimulation available in the resident's environment as cues to support participation in the activity	"I'd go in [to the resident's room] and say good morning, good morning, I'd put the light on, just to let him feel like it's the sunshine coming down."
Eye-contact	Establish eye-contact to introduce yourself to the resident, to connect with the resident, and to gain the resident's attention	"They see us on a daily basis and they will remember our face. They don't remember anything else but they'll remember your face. Look at them [eye contact] and as soon as they see you, they say *Oh it's you again, okay*".
Para-verbal monitoring	Monitor the tone, pitch and pace of the voice when communicating with the resident	"[Be] calm [and] soft when you talk with them. Be caring and show empathy, so [when] you communicate, you talk to them gently and they [will] cooperate better."
Interpret non-verbal communication	Be aware of a resident's use of non-verbal communication (i.e., body language, such as gestures and facial expression), and help to interpret the message	"They're responding non-verbally and you try to understand and respond verbally but it's up to them, depending on their cognitive ability to get what you're saying and actually respond back."

2. General care strategies		
Familiarity	Being familiar with the resident by knowing their personal preferences and personal history assists in meeting the resident's needs and interpreting his or her behaviour	"This is where their personal history comes in. If the person was never a morning person, why even introduce mornings to this person when they're never a morning person, and then oh this person never has supper, why would you introduce supper, You understand, You're giving them things they don't normally have."
Interpret behaviour	Be aware of a resident's actions to verify that they are compliant and /or understand	"You check their understanding [and] if they are compliant to what you're doing."
Assess mood	At the beginning of each encounter, assess the resident's mood and decide the best action to take following his or her response	"You need to check how their mood is in the morning. [For example] when you greet you will know, when you say good morning, they might say go away or get out of my room."
Assess for restiveness	At the beginning of each encounter, assess for any restive behaviour and consider the management of aggressive responses	"For example, at first you see that a resident is very aggressive, so right away we know you have to tender him."
Request assistance	Ask for assistance from another caregiver because the resident may respond to a different person	"They might say yes to someone else, and then you go back [to finish the task]."
Postpone / repeated attempts	When communication or non-compliance difficulties arise, postpone completing the task and repeat the attempt to complete the task at a later time	"We usually leave them and go somewhere else and come back, and if we have to we'd just leave and postpone again."

The general communication strategy that was most frequently commented on in the FGIs was the use of eye contact, while the most frequently mentioned general care strategies were (1) familiarity and (2) postpone the task/ repeated attempts. Moreover, caregivers indicated that establishing eye contact is always the first strategy they use to communicate with a resident with AD and that residents with cognitive impairments still respond to a familiar face. In terms of familiarity, caregivers expressed that this is an essential component to their care practice, as knowing a resident's preferences helps the caregiver to select the best approach (i.e., implement an effective communication strategy) to support a resident during the completion of ADLs. Caregivers also discussed postponing completion of a task when the resident is non-compliant or indicates that they want to participate at a later time, as a strategy that acknowledges and validates the resident's needs.

With respect to the notion of extensiveness, postponing the task was discussed by 40% of the caregivers. Though not initially expressed by each caregiver as being a strategy that she used, all caregivers agreed that the following three strategies are useful during the completion of ADLs: (1) eye contact, (2) interpret non-verbal communication, and (3) familiarity. Table 6 reports the frequency and extensiveness of the strategies in detail.

Differences in Strategies Used with Moderate and Severe AD

During the FGIs, caregivers were asked to respond to the following question: Do you think that there are some communication strategies that may be better suited for individuals with moderate AD and for those individuals with severe AD? Specific to this guided FGI discussion, 70% of the caregivers provided input. In

Table 6. Frequency and Extensiveness of Formal Caregivers' Perceived Use of Strategies Included in the Emergent Themes

Strategies (n = 12)	Frequency	Relative Frequency (%)	Extensiveness (%)
1. General communication strategies			
Be patient	2	3.7	20
Focus the resident	3	5.6	10
Eye-contact	8	14.8	30†
Environmental cues	2	3.7	10
Para-verbal monitoring	3	5.6	20
Interpret non-verbal communication	3	5.6	30†
2. General care strategies			
Familiarity	11	20.4	30†
Interpret behaviour	1	1.9	10
Asses mood	5	9.3	30
Assess for restiveness	4	7.4	30
Request assistance	3	5.6	30
Postpone task / repeated attempts	9	16.7	40

Note. *Relative frequency = total frequency of a given emergent strategy/ total number of strategies (n = 54). †Denotes that a group consensus was expressed regarding the usefulness of a given strategy.*

general, caregivers commented that they use a variety of strategies, with the selection of verbal or non-verbal strategies being based on each individual's cognitive level, needs, and personal preferences. Caregivers also indicated that, regardless of the cognitive severity level, they utilize the following approach to completing ADLs with residents: (1) greet the resident, (2) introduce the task, (3) explain their actions, and (4) repeat instructions when necessary. However, caregivers did make some distinction between strategies that were considered to be more useful during the completion of ADLs depending on the resident's level of cognitive impairment. With respect to moderate AD, caregivers identified four strategies that they perceive to be best suited for this severity group: (1) familiarity, (2) handing an object to the resident, (3) giving one instruction at time, and (4) using negotiation. Also, caregivers indicated that more challenges can arise (e.g., non-compliance) when assisting these individuals during ADLs because, in some instances, the resident will respond with non-compliance to the caregiver's requests and, in some encounters, there is little to no response to the caregiver's attempts to help with a given task. Interestingly, caregivers indicated that providing closed-ended questions (yes-no response) is not helpful to their care practice because, when a resident responds "no", they would then have to find alternative ways to encourage the resident to participate in a given task. Caregivers also expressed that negotiation, supported by knowing the person's history and preferences, is a key strategy that is used to complete daily tasks.

Conversely, when assisting individuals with severe AD, postponement of the task (repeated attempts), interpreting non-verbal behaviour, using the resident's name, and employing full assistance were identified as more appropriate strategies. Also, caregivers agreed that they continue to verbalize their actions, greet residents, and talk generally (e.g., social communication) to residents with severe AD even when residents no longer have the capacity to respond. However, caregivers discussed the difficulty in gaining the attention of individuals with severe AD. They indicated that an increased reliance on non-verbal behaviour when interacting with these individuals was important. Such non-verbal behaviours included positioning themselves in front of the resident and establishing eye contact. Caregivers also discussed relying less on negotiation as a strategy of choice as the disease progressed. Instead, they noted that postponement of the task was the main strategy they used when assisting residents with severe AD, particularly when a resident demonstrated resistive (i.e., non-verbal non-compliance) or aggressive behaviour, which was noted to be most problematic when assisting residents with severe AD. Finally, caregivers indicated that assisting individuals with severe AD is less difficult than assisting those with moderate AD because they generally have to provide full-assistance to these residents and verbalized non-compliance rarely occurs.

Effectiveness Ratings

Formal caregivers were asked to rate, on a scale of 1 to 10 (10 = most effective), the effectiveness of nine task-focused communication strategies (verbal = 5 and non-verbal = 4) that have been previously reported as frequently used when caregivers assist individuals with moderate and severe AD during an ADL (Wilson et al., 2012). Medians are reported in this section, as the median is the more appropriate statistic to report for ordinal scales and for non-parametric tests (Field, 2009). The highest ranked verbal strategies for both severity groups were the use of encouraging comments (moderate: $Mdn = 9.5$, $IQR = 1.0$; severe = $Mdn = 8.5$, $IQR = 2.0$), using the resident's name (moderate: $Mdn = 8$, $IQR = 2.0$; severe = $Mdn = 9.5$, $IQR = 2.3$), and giving one instruction at time (moderate: $Mdn = 8.5$, $IQR = 2.3$; severe: $Mdn = 9$, $IQR = .2.0$). For the moderate group, the verbal strategy for which caregivers provided the lowest rating was using closed-ended questions ($Mdn = 7$, $IQR = 2.3$) and the lowest rated verbal strategy for the severe group was the use of paraphrased repetition ($Mdn = 7.5$, $IQR = 2.0$).

Overall, caregivers rated the effectiveness of non-verbal strategies lower than verbal strategies. In terms of assisting residents with both moderate and severe AD, caregivers provided the highest rating for the strategy of guided touch (moderate: $Mdn = 7$, $IQR = 2.3$; severe: $Mdn = 5.5$, $IQR = 2.0$). Further, when assisting residents with severe AD, caregivers rated handing an object to the resident ($Mdn = 3$, $IQR = 1.5$), pointing to an object ($Mdn = 4$, $IQR = 4.5$), and demonstrating ($Mdn = 4$, $IQR = 2.3$) as least effective.

In order to examine differences between caregiver ratings for each strategy when assisting those with moderate versus severe AD, a Mann Whitney U test was conducted. There was no significant difference in caregivers' effectiveness ratings for all the verbal strategies. However, significant differences were present for caregivers' ratings of non-verbal strategies. Caregivers rated the following non-verbal strategies as significantly more effective when assisting individuals with moderate AD than when helping those individuals with severe AD during ADLs: (1) pointing ($Mdn = 6.5$, $IQR = 2.3 > Mdn = 4$, $IQR = 4.5$; $U = 5$, $z = -2.1$, $p = .037$); (2) demonstrating ($Mdn = 6$, $IQR = 2.3 > Mdn = 4$, $IQR = 2.3$; $U = 2$, $z = -2.8$, $p = .013$); and (3) handing an object to the resident ($Mdn = 6.5$, $IQR = 1.5 > Mdn = 3$, $IQR = 1.5$; $U = .5$, $z = -2.8$, $p = .004$).

Discussion

The purpose of this study was to elucidate the perceptions of formal caregivers with respect to which communication strategies they find effective when assisting residents with moderate and severe AD during the completion of ADLs. While previous investigations have focused on examining formal caregivers' use of a selection of communication strategies during conversation with individuals with moderate to severe AD (e.g., Savundranayagam et al., 2007; Tappen et al. 1997), the present study provides a detailed description of formal caregivers' perceived use of a variety of strategies, the majority of which were task-focused, specific to the completion of ADLs. A key finding was that, in addition to task-focused and social communication strategies, caregivers incorporate broader communication and care strategies than originally reported in the literature that has examined caregivers' use of communication strategies when assisting individuals with AD during the completion of ADLs (Small et al., 2003; Wilson et al., 2012). For instance, while the use of a variety of task-focused communication strategies has been previously observed during the communication occurring between caregivers and individuals with AD during the completion of ADLs (e.g., provide one instruction at a time), findings from this study bring added value to this literature, as caregivers highlighted the importance of the broader care context surrounding communication during ADLs (e.g., being familiar with the resident). That is, the strategies that caregivers discussed appear to fall along a continuum, with some of these strategies representing more of a "micro" approach to communication during daily care routines (i.e., strategies specific to completing ADLs) and some of the strategies representing more of a "macro" approach to communication and care (i.e., general communication strategies (e.g., eye-contact) and general care strategies (e.g., postponement)). These two approaches appear to be intimately connected in the sense that strategies that caregivers report using in their general care practice provide underlying support for the implementation of individual communication strategies. A striking illustration of this finding is caregivers' reference to the general care strategy of familiarity, or knowing the resident's preference and personal history, and the selection of strategies individualized to the resident's needs. Negotiation was the most frequently discussed task-focused strategy and being familiar with the resident and understanding their needs is essential to employing this particular strategy effectively.

The results indicated that caregivers perceive that they use numerous task-focused communication strategies, some of which have been previously reported in the empirical literature. For example, formal caregivers ranked highly the use of one proposition (i.e., one instruction or idea) at a time with residents with moderate and with severe AD. They also indicated with a consensus that paraphrased repetition and verbatim repetition were useful strategies when assisting residents with AD during the completion of ADLs. Of note, while paraphrased repetition was the lowest ranked verbal strategy for individuals with severe AD, the ranking of this strategy was still moderately high (*Mdn* = 7.5). Importantly, reduced number of propositions (Rochon et al., 1994) and repetition (Small et al., 1997) have been shown empirically to increase comprehension in individuals with AD). In addition, the most frequently mentioned non-verbal strategy was the use of demonstrating gestures to support the verbal message. The use of gestures was investigated by Pashek and DiVenere (2006), who showed that gestures enhance comprehension of verbal messages in individuals with mild to moderate AD. During the FGIs, the most common strategies that formal caregivers discussed as being useful when assisting residents with AD included: (1) negotiation; (2) familiarity; (3) explaining their actions to the resident; (4) postponing completing the task when difficulties arise; (5) greeting the resident; and (6) establishing eye contact with the resident. These findings indicate that caregivers perceive that a combination of task-focused, general communication strategies, and general care strategies is an effective approach to assisting residents with moderate and severe AD during the completion of ADLs.

Negotiation was the strategy that caregivers most frequently discussed and was often commented on in relation to being familiar with the resident. This notion appears to incorporate the idea of coaxing in order to achieve a mutually satisfactory solution (see also Small & Montoro-Rodriguez, 2006). Beach and Kramer (1999) also reported that caregivers perceived compliance gaining strategies, which included negotiation and understanding the resident's preferences, as a core communication strategy useful when interacting with residents with AD. Further, being familiar with a resident's personal history and preferences, and acknowledging their individual needs have been shown to be essential components to enhancing relationships between care providers and residents in LTC (McGilton, 2002; McGilton et al., 2003; Richter et al., 1995). Furthermore, therapeutic relationships with residents with moderate to severe AD can be created (Williams & Tappen, 1999), which has the potential to improve residents' quality of care (Anderson, Taha, & Hosier, 2009; Bowers, Esmond, & Jacobson, 2000; Nakrem, Vinsnes, & Seim, 2011), and improve job satisfaction for LTC staff assisting individuals with dementia (Moyle, Murfield, Griffiths, & Venturato, 2011).

Another communication strategy that may reinforce interpersonal relationships is the use of positive feedback during caregiver-resident interactions. Caregivers in this study referred to the use of encouraging comments and providing sufficient time for residents to respond. Indeed, Medvene and Lann-Wolcott (2010) explored experienced nurses aids' perceived communication behaviours in the LTC setting and reported the key finding that giving what they call "positive regard" to residents was the most frequently utilized strategy. Furthermore, investigations into the effects of caregiver communication training intervention on conversation content in the LTC setting supports caregivers' use of positive statements, providing simple instructions, and making conversational content personally relevant to the resident (e.g., Bourgeois, Dijkstra, Burgio, & Allen, 2004; Burgio et al., 2001; Dijkstra et al., 2002; McGilton et al., 2009) as effective strategies when communicating with residents with AD. For example, Dijkstra and colleagues (2002) reported that caregivers' use of one instruction at time, positive feedback, giving sufficient time for the residents to respond, and individualizing the content of the conversation benefited individuals with moderate and severe AD. Together, reported findings on the use of communication strategies during conversation support key findings in this current study, indicating that there may be a similarity between communication strategies used during the completion of ADLs (i.e., task-driven communication) and those used during conversation.

When assisting residents with moderate as compared to severe AD, formal caregivers in this study indicated a perceived distinction between the effectiveness of a sub-set of the strategies. Interestingly, the distinction may reflect caregivers' knowledge and experience with the declining cognitive and functional abilities that are apparent with the progression of AD (see Appell et al., 1982; Bayles & Tomoeda, 1994; Bayles, Tomoeda, & Trosset, 1992; Bayles & Tomoeda, 1991). In terms of interacting with residents with moderate AD, caregivers commented on a larger selection of strategies that are useful in their care practice, including task-focused verbal strategies (e.g., using negotiation and providing one instruction at a time), task-focused non-verbal strategies (e.g., handing an object to the resident) and general care strategies (e.g., familiarity). Conversely, although caregivers agreed that verbalizing with residents should continue when assisting individuals with severe AD, caregivers discussed the usefulness of only a few strategies when assisting residents with severe AD, outside of full assistance. Specifically, the general care strategy of postponing the task and repeating at a later time, the general communication strategy of interpreting the resident's non-verbal behaviour, and the task-focused verbal strategy of using the resident's name were discussed.

Caregivers' effectiveness ratings for task-focused non-verbal communication strategies indicated that the strategies of demonstrating or gesturing an action, pointing to an object, and handing an object to the resident were better suited for individuals with moderate AD, whereas full assistance for individuals with severe AD was the more typical approach discussed during the guided interviews. Taken together, caregivers' ratings of effective communication strategies imply a perceived shift from non-verbal strategies that act as a prompt to complete the step (i.e., assume resident can participate with the assistance of the strategy) to full assistance and no independent participation of the resident. Of note, the fact that there were no significant differences found among the verbal strategies that were rated highly by the caregivers may be attributed to a ceiling effect. On the other hand, it must be noted that the strategies selected for rating were chosen from among those found to be frequently used in our previous work (Wilson et al., 2012), and thus a high rating for all these strategies was not unexpected. Finally, it is important to note that, while the frequency data and the effectiveness ratings appear to display divergent findings for the use of encouraging comments, providing one instruction at a time, and guided touch, it is possible that this finding reflects the nature in which the data were generated. That is, the frequency data were produced in response to open-ended questions, included in the semi-structured FGI, which allowed for a broad range of responses from the caregivers. In this scenario, the aforementioned communication strategies may not have readily came to the minds of the caregivers when they reflected on their care practices. Conversely, the effectiveness ratings placed caregivers in a situation where they were directly asked about a given strategy and had to reflect on their use of that specific strategy in their care practice. Thus, it may be possible that a limitation associated with self-report data (e.g., failure to recall) during the semi-structured interview process, generated different information but not necessarily divergent findings.

Across all strategies coded, the most frequently discussed strategies suggest formal caregivers incorporate a person-centred approach to dementia care (Kitwood, 1997) when assisting residents with AD during the completion of ADLs (see also Brooker, 2004). According to Kitwood's theory of dementia care (1992; 1993; 1997), while individuals with AD exhibit declining cognitive abilities, they are also more than cognitive beings in that they maintain aspects of their emotional being and are apt to participate socially in relationships; thus, dementia care should emphasize recognition of personhood, (e.g., uniqueness of a person's history and their need for relationships) during the cooperative reciprocal exchanges occurring during their care. Kitwood (1997) identifies five principle components of positive interactions in person-centred dementia care that has implications for communication: (1) recognizing the person as a unique individual; (2) negotiating by consulting an individual on preferences and choices; (3) validating an individual by acknowledging their emotions and responding with empathy; (4) collaborating by aligning oneself with an individual to engage in a task; and (5) facilitating by enabling the use of remaining abilities (see also Ryan, Bryne, Spykerman, & Orange, 2005). Interestingly, caregivers in this study employed strategies that support each of the key positive interactions identified in person-centred dementia care. With respect to recognition, caregivers identified that they always greet the resident and use the resident's name at the beginning of every encounter. Caregivers also indicated that using eye contact and positioning themselves in front of the resident are an essential communication strategy in their care practices. Negotiation is another positive interaction approach in person-centred dementia care and caregivers in this study reported using the strategy of negotiation during ADLs the most frequently. Further, being familiar with the resident's needs and preferences maximizes the potential for successful negotiation. Caregivers' use of postponing the task supports the positive interaction of validation. By postponing the task, typically in response to non-compliance or resistive behaviours, caregivers acknowledge the desires or needs of the residents with AD. Facilitation and collaboration are features of positive interactions in person-centred dementia care that are closely linked to the completion of ADLs. Caregivers commented on the use of a variety of task-focused (verbal and non-verbal) communication strategies that support residents' participation in their own self care. For example, caregivers frequently reported that they explain the steps of the task to residents, even in circumstances where residents do not have the cognitive capacity to respond, which supports their participation in the task. Caregivers also discussed the use of demonstration in conjunction with instructions as a useful strategy to help residents during the task, which is a strategy that supports the resident by assuming that they can use this strategy to initiate autonomous participation in the step of the task. Interestingly, caregivers' overall effectiveness ratings for verbal task-focused communication strategies were higher than the effectiveness ratings provided for non-verbal strategies. This finding suggests caregivers still perceive verbal communication strategies as more effective, or necessary, in their care practice regardless of disease severity. This may relate to the person-centred approach to care, as caregivers' continued use of verbal communication may indicate the they understand the importance of treating the persons with AD as individuals and as social beings who interact with others primarily by means of verbal communication. Thus, relational communication is essential to the quality of care and quality of life for individuals with AD.

Additionally, caregivers' perceived use of strategies appears to coincide with the framework outlined by the Communication Enhancement Model (Ryan, Meredith, MacLean, & Orange 1995; Orange, Ryan, Meredith, & MacLean, 1995). The Communication Enhancement Model provides a framework for a comprehensive approach to communicating with older adults with speech, language, or hearing impairments and has been applied as an intervention to enhance communication in individuals with AD (Orange & Colton-Hudson, 1998). This model emphasizes the importance of individuals' interactions in their environment and how these interactions are important determinants of health care, health promotion and well-being. Further, the framework for this model, which includes offering a supportive environment (physical and social), meeting individual needs of the person with AD, and employing appropriate communication accommodations by avoiding over-accommodation (e.g., elderspeak, (Williams, Kemper, & Hummert, 2003; Williams, 2006; Williams, Herman, Gajewski, & Wilson, 2009)) has been used as part of a communication enhancement and training intervention for individuals with AD and their clinicians (e.g., Orange & Colton-Hudson, 1998). Caregivers in the current study commented on a variety of strategies (i.e., task-focused communication strategies, general care strategies, and general communication strategies) that they use to support communication with individuals with AD during the completion of ADLs. Moreover, as outlined by the Communication Enhancement Model framework, caregivers expressed the importance of being familiar with residents in order to understand their needs, which in turn helps caregivers to select strategies that are best suited to the individual needs of the residents. Finally, caregivers indicated that they distinguish between their use of communication strategies as a function of disease severity, indicating that they may be attempting to appropriately match communication accommodations to the individual's cognitive status.

Before concluding, it must be acknowledged that possible limitations to the study exist, concerning the use of FGI data. Firstly, although a major advantage of self-report data is that participants can describe their own experiences rather than relying on inferences made from observational data alone, a disadvantage of self-report data is that participants may fail to recall (e.g., possibly under report the frequency of strategies used). Another disadvantage of self-report data is that social desirability effects may create the possibility that caregivers discuss particular strategies because they are more socially acceptable. Thirdly, it is recognized that this method of collecting data can be influenced by the dynamics of the group, such as individuals who tend to dominate a discussion and those who may be less inclined to speak in a group setting. In addition, although the caregivers were a homogeneous sample and the number of individuals per focus group (i.e., 5) that was used is considered an appropriate sample size to generate data, a total of three focus groups is preferable (McLafferty, 2004; Rabiee, 2004). Finally, we acknowledge that we could not examine whether different professional caregivers might have differed in their self reported use of strategies because the group was small and included only one nurse in comparison to nine PSWs. Future research could investigate this factor.

Clinical Implications

The results of this study provide further support for the importance and the use of targeted and individualized strategies that enhance communication between formal caregivers and individuals with AD. The results add to existing findings in that caregivers endorsed the use of previously reported strategies in the literature, many of which would be recommended by speech-language pathologists. Furthermore, other strategies that were previously unidentified in the literature emerged. Taken together the results provide direction for speech-language pathologists to educate caregivers on how to optimize communication with individuals with AD during ADLs.

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Authors' Note

Correspondence concerning this article should be addressed to Elizabeth Rochon, Department of Speech-Language Pathology, University of Toronto, #160 – 500 University Avenue, Toronto, ON, M5G 1V7. Email: elizabeth.rochon@utoronto.ca

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Training family care partners to communicate effectively with persons with Alzheimer's disease: The TRACED program

Pour former les partenaires de soins familiaux à communiquer efficacement avec les personnes atteintes de l'Alzheimer : le programme TRACED.

Jeff Small Jo Ann Perry

KEY WORDS
COMMUNICATION
ALZHEIMER'S DISEASE
TRAINING
EDUCATION
FAMILY

Abstract

The majority of persons with Alzheimer's disease (AD) live with a family member in the community. Among the challenges that AD introduces in a family the most significant may be its impact on communication. Family members typically have a long history of interpersonal communication habits which they relied on prior to the onset of AD. When confronted with the changing cognitive and social behaviours of the person with AD, however, family members may not know that they could alter their own communication behaviour to accommodate to their loved one, and even if they do, they may not know how to accommodate effectively. To address this need for family care partner education and training, several communication-based programs have been developed and evaluated. In this article we present a new program, Training in Communication Enhancement for Dementia (TRACED), that integrates two empirically, theoretically informed, and complementary approaches to enhancing communication in family care partnering contexts. Specifically, TRACED combines principles of compensating for the cognitive and communication limitations of the person with AD alongside connecting with the person on a relational level by affirming, supporting, and enhancing the person's expression of self in everyday interactions, and recognizing the importance of family communication patterns. The TRACED training program ensures that compensatory strategies are practiced in meaningful person-supporting communication activities, and that connecting strategies are conveyed using appropriate accommodating behaviours. Following our presentation of TRACED, we report findings from a phase one pilot study that demonstrated the feasibility of TRACED and led to improvements in its content and delivery. Lastly, we consider how interventions such as TRACED could be made more accessible to families and other care partners in the community.

Abrégé

La majorité des personnes atteintes de la maladie d'Alzheimer vivent dans la communauté, avec un membre de leur famille. Le défi le plus significatif qu'une famille doit relever est l'impact de la maladie d'Alzheimer sur la communication. Les membres de la famille ont typiquement une longue histoire d'habitudes de communication interpersonnelle sur lesquelles ils se fiaient avant l'apparition de l'Alzheimer. Cependant, une fois confrontés aux changements de comportements cognitifs et sociaux de la personne atteinte de la maladie, les membres de la famille peuvent ne pas savoir qu'ils peuvent modifier leur propre comportement de communication pour accommoder l'être cher et, même s'ils le font, ils peuvent ne pas savoir comment l'accommoder de façon efficace. Pour répondre à ce besoin d'éducation et de formation du partenaire de soins familiaux, plusieurs programmes axés sur la communication ont été mis sur pied et évalués. Dans cet article nous présentons un nouveau programme, TRACED (librement traduit par « Formation pour améliorer la communication dans les cas de démence »), qui intègre deux approches complémentaires, empiriquement et théoriquement informées, pour l'amélioration de la communication dans des contextes de partenariat en soins familiaux. Spécifiquement, TRACED combine les principes de compensation en fonction des limites cognitives et communicatives de la personne atteinte de l'Alzheimer, parallèlement à la connexion avec l'expression de soi de la personne dans ses interactions de tous les jours, et la reconnaissance de l'importance des modèles de communication familiaux. Le programme de formation TRACED fait en sorte que les stratégies compensatoires soient pratiquées dans les activités de communication ayant un sens pour la personne et qui l'aident, et que les stratégies de connexion soient transmises en adoptant des comportements d'accommodation appropriés. À la suite de notre présentation de TRACED, nous rapportons des données tirées de la première étape d'une étude pilote qui a démontré la faisabilité de TRACED et qui a mené à des améliorations dans son contenu et son déroulement. En dernier lieu, nous considérons comment des interventions telles que TRACED pourraient être rendues plus accessibles aux familles et autres partenaires de soins dans la communauté.

Jeff Small, Ph.D.
Associate Professor
School of Audiology and Speech Sciences,
University of British Columbia,
Vancouver, BC
Canada

Jo Ann Perry, Ph.D.
Associate Professor Emerita
UBC School of Nursing,
Vancouver, BC
Canada

Introduction and Background

Communication can be challenging for individuals with Alzheimer's disease (AD) and those with whom they interact. Firsthand accounts of individuals living with dementia often refer to the impact of memory loss on the person's ability to follow conversations and stay connected to their social world (e.g., Henderson, 1998; Taylor, 2007). Family members of persons with AD also report difficulty maintaining good communication throughout the disease course (Bayles & Tomoeda, 1991; Murray, Schneider, Banerjee, & Mann, 1999; Orange, 2001; Rosa et al., 2010; Small, Geldart, & Gutman, 2000). Moreover, difficulty in communication has been shown to be associated with conflict in relationships, social isolation and depression, burden and stress for care partners, and an increased need to seek outside care support (Braun, Mura, Peter-Wight, Hornung, & Scholz, 2010 ; Clark, 1991; Hendryx-Bedalov, 1999, 2000; Mitrani & Czaja, 2000; Murray et al., 1999; Orange, 1991; 2001; Orange & Colton-Hudson, 1998; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Rabins, Mace, & Lucas, 1982; Richter, Bottenberg, & Roberto, 1993; Richter, Roberto, & Bottenberg, 1995; Savundranayagam Hummert, & Montgomery, 2005; Schulz et al., 2002; Small, Montoro Rodriguez, & Kemper, 1996; Small, Geldart, Gutman, & Clarke Scott, 1998; Small et al., 2000; Speice, Shields, & Blieszner, 1998; Williamson & Schulz, 1993). An extensive 14-nation investigation on dementia reported that "more carers were distressed by the loss of understanding and conversation than by having to take on responsibility for their partners' basic activities of daily living" (Murray et al., 1999, p.664). Considering that the majority of persons with AD live at home with a family member, the need to address communication issues in a family context is of utmost importance (Alzheimer's Association, 2004; Zarit, Parris-Stephens, Townsend, & Greene, 1998).

Family Communication and Dementia

Family members of persons with AD often have a long history of interacting with the affected person and have long-standing habits and patterns of interaction to which they give little or no thought until illness related difficulties become evident. In addition, some family members have insights into their partner's communication needs and preferences but do not know how to use this knowledge effectively. Because dementia brings about considerable changes in cognitive and psychosocial functioning, family members may find that the communication skills and/or awareness they used to rely on are no longer adequate to meet the new challenges they face (Farran, Loukissa, Perraud, & Paun, 2003; Magai, Cohen, & Gomberg, 2002). Moreover, research has found that care partners' perceptions of how they communicate with a person who has AD do not always coincide with their actual communication behaviours (McCann, Gilley, Hebert, Beckett, & Evans, 1997; Small, Gutman, Makela, & Hillhouse, 2003), and that some of these behaviours are not conducive to positive communication outcomes (Orange, 1991; Orange, Lubinski, & Higginbotham, 1996; Perry & Small, 2006; Ripich, Ziol, Fritsch, & Durand, 1999; Small & Perry, 2005; Small et al., 2003). In a recent survey of 112 family care partners of persons with AD on their medical, educational and psychological needs, the desire to develop effective care partner-to-patient communication skills was the most frequently expressed need by respondents (Rosa et al., 2010). For these reasons, there is an urgency to provide care partners with education and training that will enable them to develop 1) a greater awareness of and sensitivity to their own communicative behaviours and how these shape the quality of interactions with persons who have AD, and 2) new skills and strategies for fostering positive communication (Cohen-Mansfield, 2005).

Education and Training for the Care Partner

In this article, we present a recently developed and piloted communication intervention program called "TRACED"—Training in Communication Enhancement for Dementia. The philosophy of TRACED emanates from a biopsychosocial perspective on communication, addressing not only the impairments to communication faced by the person with the AD, but also the impact on others who interact with that person, and the impact of others' attitudes and behaviour toward the person (Dewing, 2008; Downs, Clare, & Anderson, 2008; Kitwood, 1997; Greenwood, Lowenthal, & Rose, 2001; O'Connor et al., 2007; Sabat, 2006). In so doing, this approach to communication encompasses all levels of functioning in the World Health Organization's International Classification of Functioning, Disability and Health (ICF, World Health Organization, 2001). Within the ICF framework, the effects of impairments at the cognitive level on the person's participation in activities of daily living and in social contexts is mediated by both the person's psychological make-up (e.g., self concept; emotional responses to the impairment; coping strategies) and support from the environment (e.g., compensatory aids such as enhanced sensory encoding; social partners' accommodations). Whereas a strongly supportive context can minimize the negative impact of the impairments on a person's functioning, an unsupportive context may lead to excess disability. Hence, a comprehensive intervention to improve communication in an AD caregiving context should address multiple levels of functioning, including body level impairments and activity and participation limitations and restrictions (for further discussion, see Byrne & Orange, 2005a; Clare, 2008).

Communication Strategies

Several communication-focused training programs for AD care partners have been developed and evaluated. However, a recent systematic review of communication interventions for AD care partners revealed that there are very few investigations that have targeted family members who care for relatives with AD in their home (Zientz et al., 2007). Most focus the interventions on health care providers who have no personal history with the person with AD and rely instead on communication skills that are gained as part of professional education. Moreover, although Zientz et al. (2007) concluded that the findings from these studies generally “support caregiver education and training in communication strategies for individuals with dementia” (p. lxii), these and other authors have cautioned that there are theoretical and methodological limitations of this research which need to be addressed in future research (see also Byrne & Orange, 2005b).

One significant limitation in many previous interventions is that they tend to focus on the cognitive and linguistic bases of communication at the expense of the interpersonal relationship dimension of communication. While this may seem appropriate for care staff, it ignores the wealth of information that families can offer (e.g., Purves & Phinney, see this issue). For example, Judge, Yarry, Orsulic-Jeras, & Piercy (2010), Ripich and colleagues (Ripich, Ziol, & Lee,1998; Ripich et al., 1999), and Smith and colleagues (Smith et al., 2011) developed interventions which target how care partners can accommodate to the person’s linguistic and memory impairments as these affect communication. Although these interventions make reference to some aspects of relational and emotional communication, the latter are not systematically introduced as overarching principles to guide and complement the cognitive compensatory strategies. For example, Judge et al.’s (2010) ANSWER intervention includes the skills training domains of patience and acceptance, personalizing, validation, reframing, and reevaluating expectations (pp. 410-411). Likewise, Orange and Colton-Hudson’s (1998) communication enhancement program, Ripich et al.’s FOCUSED program (1998; 1999), and Smith et al.’s (2011) MESSAGE training all include strategies for how to enhance the psychosocial environment (e.g., speak to the person face to face and in a calm manner; encourage and keep the conversation going). What seems to be missing in these programs, however, is a purposeful integration of the linguistic and relational perspectives such that their interdependent contribution to everyday communication grounds all aspects of the education and skills training.

To illustrate this interdependence, there is research evidence that the type of question or prompt that a care partner uses in conversation influences not only the demands made on the care receiver’s memory and language (e.g., yes-no vs. open-ended question), but it can also reflect an attitude about how care partners view communication with the care receivers (e.g., testing their memory vs. connecting with them about shared experiences). When care partners ask a yes-no question to test the care receivers’ memory of a recent event, the response often leads to a communication breakdown (Small & Perry, 2005). On the other hand, when care partners genuinely seek information from care receivers and provide a meaningful context for the question, even questions that might be difficult to answer from a linguistic standpoint (e.g., open-ended) can be answered successfully by persons with AD (Perry & Small, 2006). In this way, the communication outcome is influenced by factors represented at each ICF level, including the cognitive-linguistic processing limitations inherent to AD (e.g., episodic and semantic memory problems), the care partners’ linguistic behaviours (e.g., type of question asked), and the care partners’ attempts to connect with and to support the retrieval of the requested information by persons with AD.

The importance of the relational (or connecting) approach to communication is demonstrated in findings from qualitative research. When care partners adopt this perspective, they enhance understanding and satisfaction of both themselves and care receivers (Orange, Ryan, Meredith, & MacLean, 1995; Small, Perry & Lewis, 2005); they minimize poor and unsatisfying communication, which contributes to learned helplessness and excessive incompetence for the person with AD (Lubinski, 1991); and they help sustain the self of the person with AD through meaningful interaction (Adams & Gardiner, 2005; O’Connor et al., 2007; Byrne & Orange, 2005b; Perry & O’Connor, 2002; Purves, 2006, 2011; Small et al., 1998; Vittoria, 1998).

TRACED (Training in Communication Enhancement for Dementia)

The basic premise of the TRACED program is that both compensatory (cognitive-linguistic) and connecting (relational-psychosocial) dimensions must be addressed and practiced together in order to enhance communication. Focusing on only one dimension will significantly compromise the benefits of care partner communication training. The distinct innovation of TRACED is its integration of empirically-based compensatory and connecting strategies within well-recognized and accepted theoretical frameworks which incorporate both of these dimensions. Specifically, TRACED is based on:

(1) care partner strategies that have been shown to be associated with positive communication outcomes, such as fewer communication breakdowns and more effective resolution of breakdowns, and supporting the self of the person with dementia and facilitating their participation in social interactions (Orange & Colton-Hudson, 1998; Orange, Van Gennep, Miller, & Johnson, 1998 ; Perry & Small, 2006; Perry & O'Connor, 2002; Small, Kemper & Lyons, 1997; Small & Perry, 2005; Small et al., 2003).

(2) principles from communication accommodation and enhancement theories (Coupland, Coupland, Giles, & Henwood, 1988; Kemper, Anagnopoulos, Lyons, & Heberlein, 1994; Ryan, Giles, Bartolucci, & Henwood, 1986; Ryan, Meredith, MacLean, & Orange, 1995; Small, 2006).

TRACED takes into account how the quality of communication between persons with AD and their care partners is influenced by a) the cognitive and communicative limitations and strengths associated with AD, b) the care partners' ways of accommodating and relating to persons with AD, and c) the context of communication. While capitalizing on care partners' years of interaction with and knowledge of the person with AD, we also recognize that this experience and knowledge can be an obstacle to change if the care partner is reluctant to acknowledge the impact that AD is having on the family member with AD. TRACED gathers this information by having the trainer elicit the care partner's "story" in order to contextualize the training; asking care partners to engage in role playing and return demonstration (in a manner that is acceptable to family relationships and roles); having the trainer review transcribed and analyzed dyad interactions with care partners; and asking care partners to use a training log to record their experience using strategies in daily communication and to discuss this feedback with the trainer. This emphasis of TRACED on contextualizing the training for each care partner resonates with Clare's (2006) recommendation that training "take into account the needs and context of each person and adapt the selection of goals and methods accordingly, with the potential for integration into a broader psychosocial intervention context" (p. 295).

The overall training goal for care partners participating in the TRACED program is that they will become aware of the knowledge and skills that they bring to the communication experience, based on family history, and also develop new knowledge and skills in using compensatory and connecting strategies in their daily communication (see Tables 1 & 2). Compensatory communication strategies are designed to minimize the impact of the linguistic and cognitive declines in AD by reducing the information processing demands on persons with AD (see Table 3; Bourgeois, Burgio, Schulz, Beach, & Palmer, 1997; Kemper et al., 1994; Kemper & Harden, 1999; Orange et al., 1996; Orange, Van Gennep, Miller, & Johnson, 1998; Ripich et al., 1999; Roberto, Richter, Bottenberg, & Campbell, 1998; Small, Andersen & Kempler, 1997; Small et al., 1998, 2003; Small & Perry, 2005). Connecting communication strategies are those in which care partners affirm the listeners' retained abilities, acknowledge their need for meaningful communication, and support and enhance the listeners' expression of self in everyday interactions (see Table 4; Clare & Shakespeare, 2004; Coker, 1998; Crisp, 1999; McGilton, O'Brien-Pallas, Darlington, Evans, Wynn, & Pringle, 2003; Perry, 2002, 2004; Perry, Galloway, Bottorff, & Nixon, 2005; Perry & Small, 2005a, 2005b, 2006; Small et al., 1998; Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997).

In TRACED, compensatory strategies are practiced in contexts of meaningful person-focused communication, and connecting strategies are conveyed using supportive compensatory behaviours. Like other behavioural training programs, TRACED includes both education and skill-building components (Bourgeois, Schulz, Burgio, & Beach, 2002; Farran, Loukissa, Perraud, & Paun, 2003; Lichstein, Reidel, & Grieve, 1994; Ripich et al., 1999; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007; Stevens & Burgio, 2000). The education component provides facts and information to care partners and is based on well-established concepts of adult learning (e.g., experiential learning) (Langer, 2002; Perry, 2002; Perry & O'Connor, 2002; Purdie & Boulton-Lewis, 2003). In particular, the education component addresses: (a) care partners' current knowledge of AD; (b) changes in cognition, language, and communication associated with AD; and (c) the relationship of these changes to the quality of interpersonal communication. Whereas the education component is standard across care partners, the TRACED skill-building is contextualized and tailored for each dyad (i.e., person with AD and family care partner), thus capitalizing on family care partner's knowledge and understanding of their partner with AD.

The skill-building component of TRACED provides opportunities for transfer and implementation of skills-based knowledge through return demonstration and practice, creative problem solving, evaluation and review, and real-time interaction with the family member with AD. The molding of connecting and compensatory strategies is designed to optimize

Table 1. Definitions and Examples of Compensatory Strategies

1) Use one-idea sentences: A one-idea sentence is an utterance that contains one verb, with one or more accompanying phrases.

Two Idea: I **moved** the telephone that **was** in the kitchen to the bedroom. (two verbs)

One Idea: I **moved** the telephone from the kitchen to the bedroom. (one verb)

Two Idea: So tell me what the weather **was** like this morning when we **went** for our walk? (two verbs)

One Idea: We had a brisk walk this morning. (one verb). How did you **like** the weather? (one verb)

2) Ask questions that do not place demands on recent memory: Recent memory involves information from activities or events that took place in the recent past (e.g., 10 minutes ago, yesterday, last week).

Questions that require retrieval of information from recent memory

Did you read the newspaper this morning?

Where did we go for a walk yesterday?

Questions that do not require retrieval of information from recent memory

Do you want to read the newspaper?

Where would you like to go for a walk?

3) Speak at a normal rate and without exaggerated intonation: The average adult speech rate is 150-175 words per minute. An easy way to calculate your own speech rate is to audio record your natural conversational speech for a few minutes and then divide the total number of spoken words by the total recording time (e.g., 450 words over 3 minutes: 450/3 = 150wpm). If your average exceeds 200wpm, then you might consider slowing your rate, particularly if the care receiver indicates that you speak too fast.

Exaggerated intonation may be associated with a heightened emotional state (positive or negative). It is important to monitor how loud your speech is and how high (or low) your pitch is because the care receiver may react adversely to what he/she perceives as negative or patronizing emotion in your voice. Again, it is important to get feedback from the care receiver and/or other family members about how they perceive your voice.

4) Eliminate distractions
This strategy is marked by an action to remove some element from the environment that appears to be distracting to the family member with AD (and/or to add something to help focus her/his attention). For example, if there is noise from outside, closing the window, or if there is a radio playing in the background, turning it off. On the other hand, if the "distraction" is something the family member with AD wishes to talk about, the care partner can redirect the conversation to that topic.

5) Use focused conversational management and repair strategies—be specific in signaling repair; avoid ambiguous reference and sudden topic shifts; repeat when necessary and according to whether the listener misunderstood vs. forgot what was said.
Communication breakdown can occur when what a care partner says is unclear or ambiguous, and/or the content is not processed adequately and/or responded to appropriately by the family member with AD (e.g., due to language or cognitive problems). Communication breakdown also can occur when an utterance by the family member with AD is ambiguous, not relevant (off topic), or not sufficiently informative (e.g., does not supply accurate information, or is vague). Whether triggered by the care partner or the person with AD, a breakdown is often accompanied by an attempt at repair, which can be initiated by either the care partner or family member with AD. Examples that illustrate the trouble source—communication breakdown—repair sequence are provided below. (PWD = person with dementia, CP = care partner)

Successful Repair of a Problem

Utterance that creates problem	PWD: **They weren't here today. (ambiguous reference—"they")**
1st cue that problem exists	CP: Who weren't here?
1st repair of problem	PWD: **John and Susan. (ambiguity is resolved by naming persons)**
2nd cue that problems still exists	CP: You mean John and Susan from Porterville? (repetition and request for affirmation)
2nd repair	PWD: **Yeah.**
Acknowledgement of repairs	CP: Oh, them.

Unsuccessful Repair of a Problem

1st problematic utterance	PWD: **They weren't here today. (ambiguous reference—"they")**
Cue for 1st problem	CP: Who weren't here? (creates a 2nd problem) (not sufficiently informative)
Cue for 2nd new problem	PWD: **Who weren't what?**
Repair for 2nd new problem	CP: Who weren't here?
	CP: Who weren't here at the university? (creates a 3rd problem) **(new ambiguous reference)**
Cue for 3rd problem	PWD: **Which university? I don't know what you're talking about.**
No repair of any problems	CP: Neither do I.
	PWD: I'm all mixed up.

Table 2. Definitions and Examples of Connecting Strategies

Strategy	Researcher Definition	Dictionary Definition	Exemplars	Conversational Samples*
Encourage	Makes comments that sustain participation	To inspire with courage, animate, inspirit; to embolden, make confident.	Prompting and cuing; direct statement of support or belief in outcome, validating, agreeing.	CP: You got it…good for you. Okay! Successfully accomplished mission.
Invite	Suggests joining in the activity/conversation using a style that makes it easy	To ask (a person) graciously, kindly, or courteously. To ask for something or say that something should be welcomed	Giving a choice; asking about a preference; restating; providing an explanation; using an open-ended style that doesn't sound like "testing".	CP: Did you notice how nice the sweet peas were smelling…and those in the kitchen–how nice they smell? PWD: Yeah. CP: We should bring in some more shouldn't we? PWD: Good idea…make use of them. CP: Maybe when we're done here we can go get another bouquet.
Facilitate	Pick up and build on words or ideas shared by the family member	To render easier the performance of (an action), the attainment of (a result); …to make something easy or easier to do.	Supplies a possible answer or approach but does not answer for.	PWD: Maybe we, maybe we, to tell her, you know? CP: Do you mean we should call her? PWD: Yeah.

Orchestrate	Provides guidance rather than directives in order to move partner to success.	To combine harmoniously, like instruments in an orchestra... to organize a situation or event unobtrusively so that a desired effect or outcome is achieved.	Uses context and/or demonstration to enable family member to accomplish activities.	[Dyad is setting the table] CP: I'll give you plates and you place them. PWD: Ummm thank you. CP: You've got to set them in the right place like...you would...that's right. That's good!
Repair	Provides context for unconnected statements or develops a topic that was introduced out of context	To restore to good condition by renewal ... or by re-fixing what has given way; to mend.	States lack of understanding, seeking clarification of meaning, makes connections with past or with something familiar and continues the exchange	[CP misunderstands PWD] CP: We were talking about me and you going to Victoria. Is that what you're talking about? PWD: No. CP: Oh, you're not talking about that... is it about what we're doing today?
Partner	Comments indicate a caring, shared history	To make a person a partner; to join or associate with someone...somebody who takes part in an activity or undertaking with somebody else	Using affectionate term, nickname; drawing on history or shared memories; teasing gently, telling a story or doing an activity together	CP: And we played the odd game of keno. PWD: Oh yeah. CP: And drink coffee down at the casino. PWD: Oh yeah...we liked to go to the casino...all the people were so nice.
Honor	Shows respect and politeness; not patronizing	To confer dignity upon; to regard or treat with respect	To use speech patterns, words, gestures, and facial expressions that demonstrate and acknowledge reverence, esteem and value	[CP examines PWD's injured knee] CP: Oh your poor knee–we must remember to get Dr. X to look at it. Let me see it now...I was thinking it was swollen but it's not.

** (PWD = person with dementia, CP = care partner)*

the dyad's interactional style, and as mentioned previously, takes into consideration family history, the context of communication, and the communicative needs and goals of the dyad, among other factors (Nolan, Ingram, & Watson, 2002; Purves & Phinney, see this issue; Schulz et al., 2003). In particular, the specific communication patterns and goals of the dyad are identified through interviews with each member of the dyad (see "Contextualizing Session" in Appendix A), on assessments of the language and communication abilities of the person with AD (e.g., Bayles & Tomoeda, 1993), and on trainers' analyses of their weekly conversations in training. Based on these data, dyad-specific demonstration and practice activities are developed and adapted to meet individual needs and to help care partners bring normally implicit communicative behaviours to explicit awareness so that they can be modified. The TRACED strategies that care partners do not employ routinely, but which could be used effectively, are emphasized in training activities (see Table 3 for examples of strategies in use, and Appendices A & B for an overview of TRACED activities and a sample training session). The education and skill-building goals of TRACED are: to increase care partner's awareness of and appreciation for the program's philosophy and person- and context-specific approaches to communication, to advance care partner's knowledge using adult-based learning strategies, to modify expectations according to the dyad's context, and to facilitate changes in the care partner's behaviour (Perraud, Farran, Loukissa, & Paun, 2004). To accomplish these goals, we agree with Stevens and Burgio (2000) that "having caregivers accept full responsibility for communication with the person with AD is the most significant step in training" (p.63).

TRACED Pilot Study

While the theoretical and empirical bases of TRACED are well-grounded, what is less clear is how feasible it is to deliver the training in a manner that has the potential to facilitate change in care partners' longstanding communication habits. To assess the feasibility of implementing the TRACED protocol with family care partners, we conducted a phase one pilot study that offered six weekly training sessions to six care partners and their spouses with ADRD (see Appendix A for an overview of the training activities). There were two

Table 3. Strategies (*in italics*) used in conversation between care partner (CP) and person with AD (PWD).

Discussing a visit to the doctor

CP: So we are going there tomorrow at 2:30. (*one idea sentence; provides information to remind date and time*)

PWD: Is that at Dr. [name of doctor]'s?

CP: Yes.

PWD: Well, that will be nice, because I've called upon him as a patient.

CP: As a patient, yes. (*Picking up on and reflecting back on spouse's comments*)

PWD: Yes and he was very good.

CP: Yes. What did you like about him? (*One idea open-ended question that gets at PWD's feelings rather than recall of specific episodic information*)

PWD: The fact that he seemed sort of not just full of himself, but I think that he's not having difficulty with other people.

CP: OK. Do you like him better than Mr. [name]? (*One idea yes/no question. Gives name to help PWD remember*)

Reminiscing about trip

CP: What part of Australia did you really like the best? (*one idea open-ended question that doesn't require recall of specific episodic facts*)

PWD: Coast.

CP: The coast? That was the drive you mean? The drive that we took? (*one idea sentence that picks up and builds on "Coast"*)

PWD: Yeah.

CP: When we had the car? (*one idea question, continues to build on "The drive"; no abrupt topic shift*)

PWD: Mmm hmm.

CP: Yeah, we drove from Cairns to… Brisbane, I think. (*one idea sentence*)

PWD: Yeah.

CP: Yeah. Stops along the way. (*partnering in a way that includes PWD in story*)

PWD: ( )

CP: Yeah. Nice country.

PWD: ((laughs)) Yeah.

CP: You like it? (*one idea yes-no question that gets at PWD's feelings*)

PWD: Oh yeah. ( )>

CP: What'd you really like about it? (*one idea open-ended question that probes further about PWD's feelings*)

PWD: The simplicity of the young--of the people.

CP: I like the people too. I like the weather. (*one idea sentences; encourages and honors PWD by acknowledging and affirming his perspective*)

PWD: Yeah.

CP: Yeah. Nice country.

trainers with master's degrees in adult education, and/or gerontology and experience working with people with dementia and their families. Each trainer worked with different care partners, and was accompanied by an assistant who engaged the spouse with dementia in meaningful activities while the care partner received training. In its original delivery, the TRACED program ran up to 2.5 hours in length. Feedback from care partners and trainers indicated that a more appropriate time frame would be 1.5 to 2 hours, which is the target length of the revised TRACED sessions. All participants spoke English as their primary language. Care partners' ages ranged from 59-73 years (M = 66 years), and spouses with AD from 64-81 years (M = 72). Years of education of care partners ranged from 11-18 (M = 14), and for spouses with AD from 9-22 (M = 15). Five spouses with AD were diagnosed with AD, and one with mixed dementia, and had MMSE scores ranging from 16-22 (M = 18). All were taking dementia medications (Aricept or Reminyl). One care partner and one spouse with dementia did not provide their education level, and MMSE scores were unavailable for two spouses with dementia.

This study enabled us to a) pre-test and refine the content and delivery of the TRACED intervention based on feedback from family care partners and their spouses with AD, and b) evaluate the study protocols, including the proposed recruitment strategies, eligibility criteria, data collection procedures, study measures, and the training content. To evaluate the content and process of TRACED, we employed several measures, including interviews and questionnaires that addressed the care partners' perceptions of strategy use, the care partners' and spouses' perceptions of the quality of their communication, the functional abilities of the person with AD, and the psychosocial well-being of each. The quality of communication was examined by conducting qualitative analyses of recorded observations of care partners interacting with their spouses. Feedback was collected from care partners and their spouses regarding the acceptability and usefulness of the intervention in terms of both content and process (delivery). In addition, the trainer and assistant kept detailed field notes regarding 1) experiences and challenges associated with recruitment, 2) the length of time required to administer questionnaires, conduct interviews, and provide training, and 3) experiences and difficulties in delivering the intervention.

Results

Our analyses of the pilot study data indicate that we largely achieved our pilot study objective of determining the feasibility of implementing TRACED with family care partners. We collected and examined feedback from participants, trainers, and referral agencies to determine the appropriateness and effectiveness of the training content and delivery and recruitment strategies. A descriptive analysis by the authors of care partners' and trainers' comments indicated that in general care partners understood the purpose of the TRACED communication strategies and attempted to employ these when interacting with their family member with AD. Although our sample was small, and the intent was not to systematically measure outcomes, analyses of transcripts indicated some pre- to post-training changes in strategy use, such as increased use of one-idea sentences and building on words. In addition, care partners made comments about the positive impact the training had on the quality of communication with their family member (see Table 4).

Challenges and recommendations by trainers and care partners for change in the content and delivery of TRACED included the following: 1) the instruments used to measure the impact of training need to be as brief and relevant to the participants' daily lives as possible; 2) change some of the wording of training content so that it is more intuitive and comprehensible for a non-professional audience, and include more examples of new concepts; 3) to ensure realistic expectations, identify the care partner's motivation for participating by asking him/her "What would you like to get out of this training?"; 4) the optimal training session duration should be 1.5 hours; and 5) identify and control for factors in the training environment that might undermine the care partner staying focused (e.g., distractions in the home such as phone ringing, noise inside or outside, interruptions of other family members). In terms of recruitment, some challenges reported by trainers and community partners were the diverse language backgrounds of prospective participants and obtaining accurate information about dementia diagnosis of participants referred through community agencies. A strategy recommended for enhancing recruitment of family members was to offer opportunities for face-to-face dialogue with prospective participants in an information session.

The above recommendations were incorporated in the revised TRACED protocol in order to increase face validity and trainer and care-partner rapport, and maximize care partner buy-in and effort during training. In retrospect, the components of TRACED that appeared to work best were offering the training in the home of participants (i.e., convenient for dyad), the contextualization session as a bridge to training, and the review of dyad transcripts during training as a mechanism for self-reflection and discovery. The most apparent challenges in delivering TRACED related to

Table 4. Feedback from Care Partners who participated in the TRACED pilot study

Care Partners' comments in response to questions about:

Training Content

- "Relevant"
- "Meaningful"
- "Useful"
- "Gave me lots to think about"
- "I feel more in control"
- "I feel I can connect better with spouse"
- "Relates directly to me and my experience"

Training Forms

Communication Strategies information sheet

- "Very helpful, great to have my own copy, good to check with when I am trying something new"

Care partner Log sheet to record strategy use between training sessions

- Care Partners reported mixed use and varied responses—some liked the idea of keeping a record, others didn't have the time

Information Sheet on Alzheimer's Disease

- "Very helpful, especially to link the problem with the behaviour"

Delivery

- One dyad had all sessions 2 weeks apart, and commented that this gave more time to think about things and practice
- Very happy to have Trainers come to their home, they did not need to go out, easier to schedule sessions

the demographic diversity of the population, differences in care partner needs and preferences around training (e.g., willingness to engage in role play), and conducting training in a home setting where distractions are ubiquitous.

Overall, the phase one study demonstrated the feasibility of recruiting and training family care partners for a communication intervention, and it resulted in the evaluation and revision of the TRACED protocol. Based on the promising outcomes of our phase one feasibility study, the next step would be to assess the impact of TRACED by conducting a phase two study in order to "optimize procedures, discern the most appropriate candidates for treatment, and further explore the potential efficacy of the treatment" (Beeson & Robey, 2006,p. 162).

Future Directions

Although follow-up research is warranted to examine the efficacy of TRACED, we believe the phase one findings and revisions of the protocol provide a foundation for adapting the TRACED training and manual for use by community service providers who work with families (e.g., home health care workers; hospital-based geriatric counseling and education outreach staff; cf. Young, Manthorp, Howells, & Tullo, 2011). In adapting TRACED for health care professionals, and others in clinics and assessment units, the teaching strategies would be modified to build on participants' knowledge of the communication process as learned in most health care education programs. Some factors to consider in adapting the TRACED protocol for community settings are: 1) the duration of training (i.e., there may need to be shorter and/or fewer training sessions to accommodate service provider time constraints); 2) the influence of the service provider's experience, personality, and training background on understanding and effectively delivering TRACED (e.g., the concepts and principles of TRACED may need to be elaborated on/simplified for persons who do not have background knowledge in these areas); and 3) methods to monitor efficiently and evaluate progress by the trainees (e.g., use of self-report and/or real-time observations). One approach to developing an adapted version of TRACED would be to consult with a variety of community service providers. This could take the form of focus group discussions, in order to identify their needs and constraints in implementing a program like TRACED. Actual training could then be implemented using a train-the-trainer approach so that key individuals from community agencies are trained how to train their staff (e.g., Fitzgerald et al., 2009).

As an alternative to an in-person care partner training program, Smith et al. (2011) created an instructional DVD for family and institutional carers. The DVD content focuses on educating care partners on "compensatory strategies to assist with memory function and facilitative strategies to help maintain communicative function" (p. 261). In particular, it includes vignettes of scripted role acting, interactive opportunities for the viewer to consider the use or non-use of strategies in these vignettes, and commentary from a discipline specialist to highlight strategy use or non-use. Supplementing the video is a summary booklet which is intended to help either family or professional care partners retain and apply the content in their own caregiving experience. An obvious benefit of packaging a communication education program in DVD format is that it can be widely disseminated and used with a relatively small investment of time and resources. Some limitations are that (a) it only involves "education" and not "skill-building" components, and (b) by using scripted vignettes and actors, the payoff (of using strategies) as perceived by care partners may not be as compelling as if they were to see scripts of their own use or non-use of strategies. Given the importance of "experiential" learning, particularly for older adults, we believe a care partner communication intervention should provide opportunities for transfer and implementation of skills-based knowledge accompanied by constructive feedback (as is done in the TRACED program). Perhaps during training a DVD could be created which demonstrates some of the care partner's use of TRACED strategies when interacting with the person with AD. This DVD could also serve as a means of reinforcing and maintaining communication goals once training is completed.

Smith et al. (2011) comment that the DVD program can be delivered either individually or in group settings. Advantages of a group setting for education and training are that it is more efficient in delivering the training and it provides opportunities for trainee-to-trainee learning and rapport. The down side is that less individual attention can be given to each care partner's context and needs as well as provision of feedback, which may lead to less uptake of and benefit from the training content. One meta-analysis reported that caregivers in group interventions showed less improvement in outcomes (e.g., caregiver burden) than caregivers in individualized interventions (Sorensen, Pinquart, Habil, & Duberstein, 2002), and the authors suggest that this may be due to "individual interventions [being] somewhat more effective at adapting the topics and methods of the intervention to individuals' specific caregiving concerns" (p. 367).

In conclusion, sustaining meaningful communication when a person has Alzheimer's disease can have far-reaching consequences. Past research has demonstrated the significant role of communication in enabling persons with AD to continue participating in activities of daily living and in mitigating problems that can diminish one's quality of life. Thus, we recommend that the evidence-based principles, strategies, and procedures comprising TRACED be incorporated into existing interventions. It is our vision that interventions such as TRACED be made accessible to a wide range of stakeholders involved in the continuum of care for persons with AD.

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Authors' Note

Correspondence concerning this article should be addressed to Jeff Small, Ph.D., Associate Professor, School of Audiology and Speech Sciences, University of British Columbia, 2177 Wesbrook Mall, Vancouver, BC V6T 1Z3. Email: jeffs@audiospeech.ubc.ca or to Jo Ann Perry, Ph.D., Associate Professor Emerita, UBC School of Nursing, T201 2211 Wesbrook Mall, Vancouver, BC V6T 2B5.

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Appendix A: Overview of TRACED Activities

Contextualizing Session (Week 1).

1. Trainer explains TRACED philosophy, objectives, and how the goals of TRACED could be of benefit to Care Partner;
2. Trainer dialogues with Care Partner about their respective expectations;
3. Care Partner tells his/her "story" in order for Trainer to learn the history, current context, and perspectives on communication of Care Partner.

Training One (Week 2).

1. Care Partner shares with Trainer his/her understanding of AD and its impact on their relationship and communication with the family member with AD;
2. Trainer explains the impact of AD on cognition, language and communication, how these relate to behavioural problems, and the rationale for using the compensatory and connecting strategies;
3. Care Partner has a 5 to 10 minute conversation with family member with AD.

Training Two (Week 3).

1. Trainer reviews the TRACED approach to communication and explains the compensatory strategies, using examples from the Care Partner's previous session conversation (when possible) and those contained in the training manual;
2. Role Play/Return Demonstration—Trainer demonstrates compensatory strategies and Care Partner practices these with Trainer in return;
3. Care Partner practices these strategies in a conversation with family member with AD;
4. Care Partner is given a behaviour log form to track communication problems, successes, and compensatory strategy use at home.

Training Three (Week 4).

1. Care Partner reviews and discusses log forms with Trainer;
2. Trainer discusses Care Partner's use of compensatory strategies in transcribed and analyzed conversations from Training One and Two conversations, providing verbal and written feedback on areas of strength and opportunities for further growth;
3. Trainer reviews compensatory strategies; explains and demonstrates connecting strategies and how they complement the compensatory strategies;
4. Care Partner practices connecting strategies in role play/return demonstration, and in conversation with family member.

Training Four (Week 5).

1. Care Partner reviews and discusses log forms with Trainer;
2. Trainer discusses Care Partner's use of compensating and connecting strategies in transcribed and analyzed conversations from Training 1 to 3 conversations;
3. Trainer explains and demonstrates combined use of compensatory and connecting strategies;
4. Care Partner practices these strategies in role play/return demonstration, and in conversation with family member.

Booster Session (Week 6).

1. Trainer reviews Care Partner's log forms and his/her use of TRACED strategies in previous dyad conversations, and provides training reinforcement for Care Partner in ways that further shape the strategies to meet the dyad's specific needs;
2. Trainer affirms Care Partner's progress in taking ownership of the strategies;
3. Care Partner engages in further practice, aiming to use strategies effectively with Trainer, and in conversation with family member. Trainer encourages Care Partner to continue using the log forms so that training content becomes an integral part of Care Partner's daily interactions.

Appendix B: Sample TRACED Training Session 3

I. Opening the Session

Knowledge and Skill-building Focus	Trainer Activities/Process	Tools	Time
Check in and provide overview of this session to dyad	**Trainer, Assistant, and Dyad:** • This is the third training session. • Brief and general conversation about how things have gone since the last visit • While Trainer works with Care Partner, Trainer Assistant will work with Family Member with AD in another room *Assistant leaves room with Family Member with AD to do activity (Instructions for Assistant/Family Member activities not included in this Appendix)* **Trainer presents Care Partner with overview of this session:** • Trainer will review training principles and compensatory strategies from Training Two • Care Partner and Trainer will review transcript of dyad's conversation from Training Two • Trainer will review compensatory strategies vis-à-vis transcript • Trainer will introduce, explain, and demonstrate connecting strategies and how they work as a complement to the compensatory strategies • Care Partner will practice using connecting strategies with Trainer • Care Partner will interact with Family Member in conversation • Care Partner will provide feedback on session • Wrap up session, schedule Training Session Four	Overview summary sheet	5 min

II. Feedback from Care Partner

Purpose: To hear from Care Partner about experiences between Training Two and Three (positive and negative)

Achievables:

- Care Partner is comfortable sharing experiences, and can identify at least 2 positive interactions with Family Member with AD
- When appropriate, Trainer affirms to Care Partner the challenges of responding in a positive way to difficult/negative behaviours, and offers to walk through some additional strategies that might help Care Partner

Knowledge and Skill-building Focus	Trainer Activities/Process	Tools	Time
Feedback from Care Partner regarding experiences communicating with Family Member with AD since last session (positive and negative)	Trainer asks Care Partner: 1. *How has communication been going for you and [name of Family Member with AD] this past week?* 2. *What is one (are some) positive communication experience(s) that you've had with [Family Member] since we last met?* 3. *What is one (are some) challenging communication experience(s) that you've had with [Family Member]?* 4. *Let's talk a little more specifically about some of the items that you noted on this form* (review items Care Partner has noted on Communication Log) Make transition into next part of session: *These are very helpful comments; I think it would be useful to keep them in mind as we go on to review some of the content we covered last session (Training Two)*	Communication Log (completed by Care Partner)	15 min

III. Review Content from Training Two

Purpose:

- to highlight positive Care Partner behaviours and areas for growth as indicated by the analysis of Care Partner's comments in Training Two, his/her behaviour during conversation with Family Member, and his/her comments at the beginning of this session
- to review compensatory strategies

Achievables:

- Care Partner recognizes the value of reflecting on past experience as a basis for learning how to employ effective communication behaviours
- Care Partner is able to relate compensatory strategies to positive and negative communication outcomes

Knowledge and Skill-building Focus	Trainer Activities/Process	Tools	Time
Summary of Trainer's observations from last session, including: • examples of positive communication and emphasis on what Care Partner did well and reasons why • examples of challenging communication and possible reasons for those occurring	*Trainer:* As you know we taped last session's conversation between you and [Family Member]. As I reviewed your conversation, I made notes on how the interaction went. These are some examples of positive parts of the interaction. • Review positive interactions between Family Member and Care Partner. What do you think you said that might have contributed to the positive nature of this part of the conversation? Note what Care Partner said/did that made those interactions work, emphasizing compensatory strategies used by Care Partner. • Review challenging interaction between Family Member and Care Partner. Note that communication in this part of the conversation was more challenging. What do you think you said or did, or that [Family Member] said or did, that might have led to this part of the conversation being more challenging? Note what Care Partner says, especially as this relates to strategies.	2 copies of analyzed transcriptions	10 min
Review and Practice Compensatory Strategies	We've had a chance to review the interactions you had with your Family Member last week. Now I'd like to review the communication strategies from last session with you, and see how you might use them to interact differently or even more effectively this time round. Review relevant compensatory strategies as they apply to the recorded conversation. Now that we've reviewed the strategies, let's put them into practice. Looking at the script, let's review the marked sections. How would you use one of the strategies to say this differently (point out one example from script)? Prompt Care Partner as necessary. Provide examples of how they might say something differently if needed.	Transcripts	10 min

IV. Connecting Strategies Explained and Demonstrated

Purpose:

- To review the philosophy and beliefs of TRACED as these relate to compensatory and connecting strategies
- To explain how connecting strategies complement and can enhance the benefit from compensatory strategies
- To provide Care Partner with examples of connecting strategies and how these strategies influence communication outcomes
- To provide Care Partner with opportunities to use connecting strategies, with feedback from Trainer.

Achievables:

- Care Partner conveys an understanding of the purpose of connecting strategies and the principles upon which they are based
- Care Partner demonstrates how connecting strategies could be used in previously recorded and transcribed conversation data

Knowledge and Skill-building Focus	Trainer Activities/Process	Tools	Time
Connecting strategies introduced and explained	Now that you have a better understanding of how compensatory strategies can affect communication, let's start looking at some other strategies that also are helpful and that will enhance the benefits of using compensatory strategies. The second type of strategies are called Connecting strategies. Trainer explains concept of *Connecting* Strategies: Refer back to Handouts from Training One and Two – Communication Strategies AND Beliefs of the TRACED Program to review definition. Using the Communication Strategies handout as a guide, and referring to Binder Copy, Trainer provides examples and they discuss each connecting strategy. Ask Care Partner whether he/she has used one or another strategy in her previous experience.	Communication Strategies – for Care Partners Beliefs of the TRACED program	30 min
Care Partner identifies how connecting strategies could be used in a conversation script	*Trainer presents Care Partner with a script that has samples of conversation in which connecting strategies have been or could have been used.* Let's review the marked sections, which are places where a connecting strategy would have been appropriate. How would you use one of the connecting strategies to say this differently (point out one example from script)? Prompt Care Partner as necessary. Provide additional examples of how each strategy could be implemented to improve communication.	Conversation Script	30 min

V. Practice using Connecting Strategies in Conversation with Family Member

Purpose:

- to reinforce, and to provide Care Partner with the opportunity to put into practice, the strategies discussed up to this point.

Achievables:

- Care Partner and Family Member have a conversation
- Care Partner demonstrates grasp of connecting and compensatory principles and use of strategies during conversation with Family Member

Knowledge and Skill-building Focus	Trainer Activities/Process	Tools	Time
Care Partner is given opportunity to practice strategies in a conversation with Family Member	Say to Care Partner: *Now that you've had a chance to practice with me, why don't you try using some of those same connecting strategies in a 5-10 minute conversation with [name of Family Member].* *I would like you to have an informal conversation similar to the one you had last week (in Training Two), but this time I'd like you to talk about a past shared experience. For example you could talk about your honeymoon, or a memorable holiday or trip you took together.*	Recording equipment	5-10 min

VI. Feedback from Care Partner and Wrap Up

Purpose:

- answer Care Partner's questions and schedule next session
- provide opportunity for Care Partner to comment on the content and delivery of this training session
- encourage Care Partner in the learning process.

Achievables:

- Care Partner's comments have been collected and their questions are answered
- Care Partner has a positive attitude about the training experience
- Care Partner comes away from this session with a positive attitude about communicating with Family Member

Knowledge and Skill-building Focus	Trainer Activities/Process	Tools	Time
Care Partner provides Feedback, and Trainer reinforces progress made by Care Partner to date	It's important for us to get your feedback on the content of this session, and how it was presented. *Trainer asks:* • *Was the review of information useful to you?* • *Was it helpful to practice during the conversation with [Family Member]?* • *Were the methods used in the training appropriate/effective? Was the use of the transcripts effective or helpful?* • *Which of the strategies were easy to implement? Why?* • *Which of the strategies were difficult to implement? Why?* • *Did using any of the strategies interfere with communication with [Family Member]? Which ones?* For challenges mentioned by Care Partner, discuss with Care Partner possible ways to address these. *We would like you to continue to use the <u>Care Partner Log</u> to keep a record of what strategies you try and how well they work.*	Care Partner Log Recording Equipment	5-10 min
Feedback to Care Partner	*Thank you so much for your participation in this session. From my vantage point, I've noticed that you appear to have gained confidence and are getting comfortable using the strategies, and [Family Member] seems to be more engaged in conversations. Keep up the great effort!*		
Questions	*Do you have any questions?* *Let's set a date for the next session.*		

Information for Contributors

The Canadian Journal of Speech-Language Pathology and Audiology (CJSLPA) welcomes submissions of scholarly manuscripts related to human communication and its disorders broadly defined. This includes submissions relating to normal and disordered processes of speech, language, and hearing. Manuscripts that have not been published previously are invited in English and French. Manuscripts may be tutorial, theoretical, integrative, practical, pedagogic, or empirical. All manuscripts will be evaluated on the basis of the timeliness, importance, and applicability of the submission to the interests of speech–language pathology and audiology as professions, and to communication sciences and disorders as a discipline. Consequently, all manuscripts are assessed in relation to the potential impact of the work on improving our understanding of human communication and its disorders. All categories of manuscripts submitted will undergo peer-review to determine the suitability of the submission for publication in CJSLPA. The Journal has established multiple categories of manuscript submission that will permit the broadest opportunity for dissemination of information related to human communication and its disorders. The categories for manuscript submission include:

Tutorials: Review articles, treatises, or position papers that address a specific topic within either a theoretical or clinical framework.

Articles: Traditional manuscripts addressing applied or basic experimental research on issues related to speech, language, and/or hearing with human participants or animals.

Clinical Reports: Reports of new clinical procedures, protocols, or methods with specific focus on direct application to identification, assessment and/or treatment concerns in speech, language, and/or hearing.

Brief Reports: Similar to research notes, brief communications concerning preliminary findings, either clinical or experimental (applied or basic), that may lead to additional and more comprehensive study in the future. These reports are typically based on small "n" or pilot studies and must address disordered participant populations.

Research Notes: Brief communications that focus on experimental work conducted in laboratory settings. These reports will typically address methodological concerns and/or modifications of existing tools or instruments with either normal or disordered populations.

Field Reports: Reports that outline the provision of services that are conducted in unique, atypical, or nonstandard settings; manuscripts in this category may include screening, assessment, and/or treatment reports.

Letters to the Editor: A forum for presentation of scholarly/clinical differences of opinion concerning work previously published in the Journal. Letters to the Editor may influence our thinking about design considerations, methodological confounds, data analysis, and/or data interpretation, etc. As with other categories of submissions, this communication forum is contingent upon peer-review. However, in contrast to other categories of submission, rebuttal from the author(s) will be solicited upon acceptance of a letter to the editor.

Submission of Manuscripts

Contributors should use the electronic CJSLPA manuscript submission system at http://cjslpa.coverpage.ca to submit articles. If you are unable to use the electronic system, please send a file containing the manuscript, including all tables, figures or illustrations, and references in Word via e-mail to the editor at elizabeth.fitzpatrick@uottawa.ca.

Along with copies of the manuscript, a cover letter indicating that the manuscript is being submitted for publication consideration should be included. The cover letter must explicitly state that the manuscript is original work, that it has not been published previously, and that it is not currently under review elsewhere. Manuscripts are received and peer-reviewed contingent upon this understanding.

The author(s) must also provide appropriate confirmation that work conducted with humans or animals has received ethical review and approval. Failure to provide information on ethical approval will delay the review process. Finally, the cover letter should also indicate the category of submission (i.e., tutorial, clinical report, etc.). If the editorial staff determines that the manuscript should be considered within another category, the contact author will be notified.

All submissions should conform to the publication guidelines of the Publication Manual of the American Psychological Association (APA), 6th Edition. A confirmation of receipt for all manuscripts will be provided to the contact author prior to distribution for peer review. CJSLPA seeks to conduct the review process and respond to authors regarding the outcome of the review within 90 days of receipt. If a manuscript is judged as suitable for publication in CJSLPA, authors will have 30 days to make necessary revisions prior to a secondary review.

The author is responsible for all statements made in his or her manuscript, including changes made by the editorial and/or production staff. Upon final acceptance of a manuscript and immediately prior to publication, the contact author will be permitted to review galley proofs and verify its content to the publication office within 72 hours of receipt of galley proofs.

Organization of the Manuscript

All copies should be typed, double-spaced, with a standard typeface (12 point, non-compressed font) on 8 ½ x 11 paper size. All margins should be at least one (1) inch. An electronic copy of the manuscript should be submitted directly to the editor. Author identification for the review process is optional; if blind-review is desired, the documents should be prepared accordingly (cover page and acknowledgments blinded). Responsibility for removing all potential identifying information rests solely with the author(s). All submissions should conform to the publication guidelines of the most current edition of the Publication Manual of the American Psychological Association (APA. The APA manual is available from most university and commercial bookstores. Generally, the following sections should be submitted in the order specified.

Title Page: This page should include the full title of the manuscript, the full names of the author(s) with academic degrees, each author's affiliation, and a complete mailing address for the contact author. An electronic mail address also is recommended.

Abstract: On a separate sheet of paper, a brief yet informative abstract that does not exceed one page is required. The abstract should include the purpose of the work along with pertinent information relative to the specific manuscript category for which it was submitted.

Key Words: Following the abstract and on the same page, the author(s) should supply a list of key words for indexing purposes.

Tables: Each table included in the manuscript must typedwritten double-spaced and placed at the end of the document. Tables should be numbered consecutively beginning with Table 1. Each table must have a descriptive caption. Tables should serve to expand the information provided in the text of the manuscript, not to duplicate information.

Illustrations: All illustrations to be included as part of the manuscript must also be submitted in their original file format separate from the manuscript. High resolution (at least 300 dpi) files in any of the following formats must be submitted for each graphic and image: JPEG, TIFF, AI, PSD, GIF, EPS or PDF. For other types of computerized illustrations, it is recommended that CJSLPA production staff be consulted prior to preparation and submission of the manuscript and associated figures/illustrations.

Legends for Illustrations: Legends for all figures and illustrations should be typewritten (double-spaced) on a separate page with numbers corresponding to the order in which figures/illustrations appear in the manuscript.

Page Numbering and Running Head: The text of the manuscript should be prepared with each page numbered, including tables, figures/illustrations, references, and appendices. A short (30 characters or less) descriptive running title should appear at the top right hand margin of each page of the manuscript.

Acknowledgments: Acknowledgments should be typewritten (double-spaced) on a separate page. Appropriate acknowledgment for any type of sponsorship, donations, grants, technical assistance, and to professional colleagues who contributed to the work, but are not listed as authors, should be noted.

References: References are to be listed consecutively in alphabetical order, then chronologically for each author. Authors should consult the most current edition of the APA publication manual for methods of citing varied sources of information. Journal names and appropriate volume number should be spelled out and italicized. All literature, tests and assessment tools, and standards (ANSI and ISO) must be listed in the references. All references should be double-spaced.

Potential Conflicts of Interest and Dual Commitment

As part of the submission process, the author(s) must explicitly identify if any potential conflict of interest or dual commitment exists relative to the manuscript and its author(s). Such disclosure is requested so as to inform CJSLPA that the author or authors have the potential to benefit from publication of the manuscript. Such benefits may be either direct or indirect and may involve financial and/or other nonfinancial benefit(s) to the author(s). Disclosure of potential conflicts of interest or dual commitment may be provided to editorial consultants if it is believed that such a conflict of interest or dual commitment may have had the potential to influence the information provided in the submission or compromise the design, conduct, data collection or analysis, and/or interpretation of the data obtained and reported in the manuscript submitted for review. If the manuscript is accepted for publication, editorial acknowledgement of such potential conflict of interest or dual commitment may occur within the publication.

Participants in Research Humans and Animals

Each manuscript submitted to CJSLPA for peer-review that is based on work conducted with humans or animals must acknowledge appropriate ethical approval. In instances where humans or animals have been used for research, a statement indicating that the research was approved by an institutional review board or other appropriate ethical evaluation body or agency must clearly appear along with the name and affiliation of the research ethics and the ethical approval number. The review process will not begin until this information is formally provided to the Editor.

Similar to research involving human participants, CJSLPA requires that work conducted with animals state that such work has met with ethical evaluation and approval. This includes identification of the name and affiliation of the research ethics evaluation body or agency and the ethical approval number. A statement that all research animals were used and cared for in an established and ethically approved manner is also required. The review process will not begin until this information is formally provided to the Editor.

Renseignements à l'intention des collaborateurs

La Revue canadienne d'orthophonie et d'audiologie (RCOA) est heureuse de se voir soumettre des manuscrits de recherche portant sur la communication humaine et sur les troubles qui s'y rapportent, dans leur sens large. Cela comprend les manuscrits portant sur les processus normaux et désordonnés de la parole, du langage et de l'audition. Nous recherchons des manuscrits qui n'ont jamais été publiés, en français ou en anglais. Les manuscrits peuvent être tutoriels, théoriques, synthétiques, pratiques, pédagogiques ou empiriques. Tous les manuscrits seront évalués en fonction de leur signification, de leur opportunité et de leur applicabilité aux intérêts de l'orthophonie et de l'audiologie comme professions, et aux sciences et aux troubles de la communication en tant que disciplines. Par conséquent, tous les manuscrits sont évalués en fonction de leur incidence possible sur l'amélioration de notre compréhension de la communication humaine et des troubles qui s'y rapportent. Peu importe la catégorie, tous les manuscrits présentés seront soumis à une révision par des collègues afin de déterminer s'ils peuvent être publiés dans la RCOA. La Revue a établi plusieurs catégories de manuscrits afin de permettre la meilleure diffusion possible de l'information portant sur la communication humaine et les troubles s'y rapportant. Les catégories de manuscrits comprennent :

Tutoriels : Rapports de synthèse, traités ou exposés de position portant sur un sujet particulier dans un cadre théorique ou clinique.

Articles : Manuscrits conventionnels traitant de recherche appliquée ou expérimentale de base sur les questions se rapportant à la parole, au langage ou à l'audition et faisant intervenir des participants humains ou animaux.

Comptes rendus cliniques : Comptes rendus de nouvelles procédures ou méthodes ou de nouveaux protocoles cliniques portant particulièrement sur une application directe par rapport aux questions d'identification, d'évaluation et de traitement relativement à la parole, au langage et à l'audition.

Comptes rendus sommaires : Semblables aux notes de recherche, brèves communications portant sur des conclusions préliminaires, soit cliniques soit expérimentales (appliquées ou fondamentales), pouvant mener à une étude plus poussée dans l'avenir. Ces comptes rendus se fondent typiquement sur des études à petit « n » ou pilotes et doivent traiter de populations désordonnées.

Notes de recherche : Brèves communications traitant spécifiquement de travaux expérimentaux menés en laboratoire. Ces comptes rendus portent typiquement sur des questions de méthodologie ou des modifications apportées à des outils existants utilisés auprès de populations normales ou désordonnées.

Comptes rendus d'expérience : Comptes rendus décrivant sommairement la prestation de services offerts en situations uniques, atypiques ou particulières; les manuscrits de cette catégorie peuvent comprendre des comptes rendus de dépistage, d'évaluation ou de traitement.

Courrier des lecteurs : Forum de présentation de divergences de vues scientifiques ou cliniques concernant des ouvrages déjà publiés dans la Revue. Le courrier des lecteurs peut avoir un effet sur notre façon de penser par rapport aux facteurs de conception, aux confusions méthodologiques, à l'analyse ou l'interprétation des données, etc. Comme c'est le cas pour d'autres catégories de présentation, ce forum de communi-cation est soumis à une révision par des collègues. Cependant, contrairement aux autres catégories, on recherchera la réaction des auteurs sur acceptation d'une lettre.

Présentation de manuscrits

Pour soumettre un article, les auteurs doivent utiliser le système de soumission électronique de l'ACOA à l'adresse http://cjslpa.coverpage.ca. Si vous ne pouvez pas utiliser le système électronique, veuillez envoyer par courriel un fichier Word contenant le manuscrit, y compris tous les tableaux, les figures ou illustrations et la bibliographie. Adressez le courriel au rédacteur en chef à l'adresse elizabeth.fitzpatrick@uottawa.ca.

On doit joindre aux exemplaires du manuscrit une lettre d'envoi qui indiquera que le manuscrit est présenté en vue de sa publication. La lettre d'envoi doit préciser que le manuscrit est une œuvre originale, qu'il n'a pas déjà été publié et qu'il ne fait pas actuellement l'objet d'un autre examen en vue d'être publié. Les manuscrits sont reçus et examinés sur acceptation de ces conditions. L'auteur (les auteurs) doit (doivent) aussi fournir une attestation en bonne et due forme que toute recherche impliquant des êtres humains ou des animaux a fait l'objet de l'agrément d'un comité de révision déontologique. L'absence d'un tel agrément retardera le processus de révision. Enfin, la lettre d'envoi doit également préciser la catégorie de la présentation (i.e. tutoriel, rapport clinique, etc.). Si l'équipe d'examen juge que le manuscrit devrait passer sous une autre catégorie, l'auteur-contact en sera avisé.

Toutes les présentations doivent se conformer aux lignes de conduite présentées dans le publication Manual of the American Psychological Association (APA), 6e Édition. Un accusé de réception de chaque manuscrit sera envoyé à l'auteur-contact avant la distribution des exemplaires en vue de la révision. La RCOA cherche à effectuer cette révision et à informer les auteurs des résultats de cette révision dans les 90 jours de la réception. Lorsqu'on juge que le manuscrit convient à la RCOA, on donnera 30 jours aux auteurs pour effectuer les changements nécessaires avant l'examen secondaire.

L'auteur est responsable de toutes les affirmations formulées dans son manuscrit, y compris toutes les modifications effectuées par les rédacteurs et réviseurs. Sur acceptation définitive du manuscrit et immédiatement avant sa publication, on donnera l'occasion à l'auteur-contact de revoir les épreuves et il devra signifier la vérification du contenu dans les 72 heures suivant réception de ces épreuves.

Organisation du manuscrit

Tous les textes doivent être écrits à double interligne, en caractère standard (police de caractères 12 points, non comprimée) et sur papier 8 ½" X 11" de qualité. Toutes les marges doivent être d'au moins un (1) pouce. Un fichier électonique du manuscrit doit être présenté directement au rédacteur en chef. L'identification de l'auteur est facultative pour le processus d'examen : si l'auteur souhaite ne pas être identifié à ce stade, il devra préparer un fichier électronique dont la page couverture et les remerciements seront voilés. Seuls les auteurs sont responsables de retirer toute information identificatrice éventuelle. Tous les manuscrits doivent être rédigés en conformité aux lignes de conduite les plus récentes de l'APA. Ce manuel est disponible dans la plupart des librairies universitaires et commerciaux. En général, les sections qui suivent doivent être présentées dans l'ordre chronologique précisé.

Page titre : Cette page doit contenir le titre complet du manuscrit, les noms complets des auteurs, y compris les diplômes et affiliations, l'adresse complète de l'auteur-contact et l'adresse de courriel de l'auteur contact.

Abrégé : Sur une page distincte, produire un abrégé bref mais informateur ne dépassant pas une page. L'abrégé doit indiquer l'objet du travail ainsi que toute information pertinente portant sur la catégorie du manuscrit.

Mots clés : Immédiatement suivant l'abrégé et sur la même page, les auteurs doivent présenter une liste de mots clés aux fins de constitution d'un index.

Tableaux : Tous les tableaux compris dans un même manuscrit doivent être écrits à double interligne sur une page distincte. Les tableaux doivent être numérotés consécutivement, en commençant par le Tableau 1. Chaque tableau doit être accompagné d'une légende et doit servir à compléter les renseignements fournis dans le texte du manuscrit plutôt qu'à reprendre l'information contenue dans le texte ou dans les tableaux.

Illustrations : Toutes les illustrations faisant partie du manuscrit doivent être annexer avec chaque exemplaire du manuscrit. Chaque manuscrit doit être accompagné d'un fichier électronique pour chaque image et graphique en format JPEG, TIFF, AI, PSD, GIF, EPS ou PDF, compression minimale 300 ppp. Pour les autres types d'illustrations informatisées, il est recommandé de consulter le personnel de production de la RCOA avant la préparation et la présentation du manuscrit et des figures et illustrations s'y rattachant.

Légendes des illustrations : Les légendes accompagnant chaque figure et illustration doivent être écrits à double interligne sur une page distincte et identifiées à l'aide d'un numéro qui correspond à la séquence de parution des figures et illustrations dans le manuscrit.

Numérotation des pages et titre courant : Chaque page du manuscrit doit être numérotée, y compris les tableaux, figures, illustrations, références et, le cas échéant, les annexes. Un bref (30 caractères ou moins) titre courant descriptif doit apparaître dans la marge supérieure droite de chaque page du manuscrit.

Remerciements : Les remerciements doivent être écrits à double interligne sur une page distincte. L'auteur doit reconnaître toute forme de parrainage, don, bourse ou d'aide technique, ainsi que tout collègue professionnel qui ont contribué à l'ouvrage mais qui n'est pas cité à titre d'auteur.

Références : Les références sont énumérées les unes après les autres, en ordre alphabétique, suivi de l'ordre chronologique sous le nom de chaque auteur. Les auteurs doivent consulter le manuel de l'APA le plus récent pour obtenir la façon exacte de rédiger une citation. Les noms de revues scientifiques et autres doivent être rédigés au long et imprimés en italiques. Tous les ouvrages, outils d'essais et d'évaluation ainsi que les normes (ANSI et ISO) doivent figurer dans la liste de références. Les références doivent être écrits à double interligne.

Conflits d'intérêts possibles et engagement double

Dans le processus de présentation, les auteurs doivent déclarer clairement l'existence de tout conflit d'intérêts possibles ou engagement double relativement au manuscrit et de ses auteurs. Cette déclaration est nécessaire afin d'informer la RCOA que l'auteur ou les auteurs peuvent tirer avantage de la publication du manuscrit. Ces avantages pour les auteurs, directs ou indirects, peuvent être de nature financière ou non financière. La déclaration de conflit d'intérêts possibles ou d'engagement double peut être transmise à des conseillers en matière de publication lorsqu'on estime qu'un tel conflit d'intérêts ou engagement double aurait pu influencer l'information fournie dans la présentation ou compromettre la conception, la conduite, la collecte ou l'analyse des données, ou l'interprétation des données recueillies et présentées dans le manuscrit soumis à l'examen. Si le manuscrit est accepté en vue de sa publication, la rédaction se réserve le droit de reconnaître l'existence possible d'un tel conflit d'intérêts ou engagement double.

Participants à la recherche – êtres humains et animaux

Chaque manuscrit présenté à la RCOA en vue d'un examen par des pairs et qui se fonde sur une recherche effectuée avec la participation d'être humains ou d'animaux doit faire état d'un agrément déontologique approprié. Dans les cas où des êtres humains ou des animaux ont servi à des fins de recherche, on doit joindre une attestation indiquant que la recherche a été approuvée par un comité d'examen reconnu ou par tout autre organisme d'évaluation déontologique, comportant le nom et l'affiliation de l'éthique de recherche ainsi que le numéro de l'approbation. Le processus d'examen ne sera pas amorcé avant que cette information ne soit formellement fournie au rédacteur en chef.

Tout comme pour la recherche effectuée avec la participation d'êtres humains, la RCOA exige que toute recherche effectuée avec des animaux soit accompagnée d'une attestation à l'effet que cette recherche a été évaluée et approuvée par les autorités déontologiques compétentes. Cela comporte le nom et l'affiliation de l'organisme d'évaluation de l'éthique en recherche ainsi que le numéro de l'approbation correspondante. On exige également une attestation à l'effet que tous les animaux de recherche ont été utilisés et soignés d'une manière reconnue et éthique. Le processus d'examen ne sera pas amorcé avant que cette information ne soit formellement fournie au rédacteur en chef.

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