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

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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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