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

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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.

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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.

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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?