Matched and mismatched appraisals of the effectiveness of communication strategies by family caregivers

Marie Y Savundranayagam
Joseph B Orange
Matched and mismatched appraisals of the effectiveness of communication strategies by family caregivers of persons with Alzheimer’s disease

Marie Y. Savundranayagam† and J. B. Orange‡§

†School of Health Studies, Western University
‡School of Communication Sciences and Disorders, Western University
§Lawson Health Research Institute, London ON Canada

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Abstract

Background: Communication problems stemming from Alzheimer’s disease (AD) often result in misunderstandings that can be linked with problem behaviours and increased caregiver stress. Moreover, these communication breakdowns also can result either from caregivers’ use of ineffective communication strategies, which paradoxically are perceived as helpful, or can occur as a result of not using effective communication strategies that are perceived as unhelpful.

Aims: The two primary aims were to determine the effectiveness of strategies used to resolve communication breakdowns and to examine whether caregivers’ ratings of strategy effectiveness were consistent with evidence from video-recorded conversations and with effective communication strategies documented in the literature.

Methods & Procedures: Twenty-eight mealtime conversations were recorded using a sample of 15 dyads consisting of individuals with early, middle and late clinical-stage AD and their family caregivers. Conversations were analysed using the trouble-source repair paradigm to identify the communication strategies used by caregivers to resolve breakdowns. Family caregivers also rated the helpfulness of communication strategies used to resolve breakdowns. Analyses were conducted to assess the overlap or match between the use and appraisals of the helpfulness of communication strategies.

Outcomes & Results: Matched and mismatched appraisals of communication strategies varied across stages of AD. Matched appraisals by caregivers of persons with early-stage AD were observed for 68% of 22 communication strategies, whereas caregivers of persons with middle- and late-stage AD had matched appraisals for 45% and 55% of the strategies, respectively. Moreover, caregivers of persons with early-stage AD had matched appraisals over and above making matched appraisals by chance alone, compared with caregivers of persons in middle- and late-stage AD.

Conclusions & Implications: Mismatches illustrate the need for communication education and training, particularly to establish empirically derived evidence-based communication strategies over the clinical course of AD.

Keywords: Alzheimer’s disease, communication strategies, family caregivers, trouble-source repair.

What this paper adds?

Comparisons of caregivers’ appraisals of the helpfulness of communication strategies with evidence of what works in actual conversations provides insights regarding communication education and training interventions. Matches between appraisals and actual communication strategies reveal areas where caregivers are successfully resolving communication breakdowns. Reinforcing matched appraisals should be a key component when designing communication interventions. On the other hand, mismatches illustrate the importance of targeting misconceptions surrounding communication strategies that work and do not work over the clinical course of Alzheimer’s Disease.
Introduction

Much research attention has focused on the language and communication impairments associated with Alzheimer’s disease (AD) across its three clinical stages (i.e., early/mild, middle/moderate and late/severe). During the early/mild clinical stage of AD, individuals exhibit subtle word-finding problems, and difficulty using and understanding complex language forms such as idioms, figurative forms, metaphors and similes, and sarcasm (Bayles 1982, Bayles et al. 1992, Kempler et al. 1988). In the middle/moderate clinical stage of AD, individuals demonstrate pronounced word-finding problems to express feelings/intent or to express unmet needs such that their spoken, written and gestural outputs are considered semantically empty (Bourgeois 2002, Powell et al. 1995, Ripich and Terrell 1988, Volicer and Bloom-Charette 1999). Individuals in the middle/moderate clinical stage also repeat ideas, digress off-topic in conversations, experience problems understanding multiple-step commands, and avoid multiple partner conversations (Alberoni et al. 1992, Garcia and Joanette 1997, Mentis et al. 1995, Ripich and Terrell 1988, Tomoeda and Bayles 1993). During the late/severe clinical stage of AD, individuals show a wide range of problems including limited verbal output, great difficulty understanding spoken and written language, restricted vocabulary, reiterative problems such as echolalia and pallilalia, as well as substantial problems using and understanding simple forms of grammar (Causino Lamar et al. 1994, Tomoeda and Bayles 1993).

The language and communication problems in AD across the spectrum of its three clinical stages often result in communication breakdowns, particularly in interactions between persons with AD and their family caregivers (Orange et al. 1996, 1998, Watson et al. 1999). Communication breakdowns also can result from caregivers’ use of ineffective communication strategies that they perceive to be helpful or by not using strategies that are indeed helpful in maintaining effective communication or in resolving breakdowns (Orange et al. 1998, Small et al. 2003). Caregivers’ appraisals of the perceived usefulness of communication strategies are likely to be essential in the development of interventions that enhance communication between persons with AD and their caregivers. It is possible that if caregivers consider communication strategies to be effective, they may be more likely to use them, even if their assumptions of effectiveness are incorrect or do not match what is documented in the scientific literature or observed to be effective. Caregivers who rate communication strategies as effective when they are not effective and use them in interactions may contribute to communication breakdowns, possibly leading to problem behaviours and greater caregiver burden (Murray et al. 1999, Savundranayagam et al. 2005, Small et al. 2000). Recent findings have shown that caregivers with matched appraisals for effective communication strategies exhibit lower levels of caregiver stress (Savundranayagam and Orange 2011).

Previous studies have provided clinical suggestions (McCallion et al. 1999, Santo Pietro, and Ostuni 2003) and/or evidence (Burgio et al. 2001, Haberstroth et al. 2011, Small et al. 2003, Small and Perry 2012) on communication strategies that help persons with AD to comprehend and to participate in social interactions. The conversation trouble source and repair (TSR) paradigm (Schegloff et al. 1977) has been used to examine the characteristics and frequency of communication problems, how problems are identified and resolved in conversation, and the outcome of the resolution. According to the TSR paradigm, repair initiators and repair strategies are two major types of communication strategies used to signal and to resolve breakdowns or misunderstandings. Repair initiators are used to signal that a misunderstanding has occurred (e.g., ‘What did you say?’). Repair initiators that have been shown to be helpful when communicating with a person with AD include saying ‘I don’t understand’ and asking for clarification (Ramanathan 1997, Watson et al. 1999). Asking the person with AD to repeat the statement that caused the misunderstanding also is reported as a helpful strategy (Orange et al. 1996). Questions, including open-ended, close-ended and choice questions, aid in comprehension (Hamilton 1994, Small and Perry 2005, Small et al. 2003, Wilson et al. 2012b). Offering choices of what you think the person with AD intended is helpful when the choice questions rely on semantic memory instead of episodic memory (Small and Perry 2005). Trying to figure out the meaning by directly asking ‘Do you mean …’ also is recommended as an effective repair initiator when communicating with persons with AD (Haak 2003, Orange et al. 1996, Watson et al. 1999).

Both verbal and non-verbal conversational repair strategies have been shown to resolve misunderstandings that lead to communication breakdowns in conversation (Orange et al. 1996). Expressive repair strategies that have been shown to be effective with persons with AD include verbatim repetition and paraphrased repetition (Bourgeois 2002, Gentry and Fisher 2007, Mahendra et al. 2005, Small et al. 1997, Tappen et al. 1997, Wilson et al. 2012b). Simplifying original statements by removing embedded clauses also is an effective repair strategy (Kemper and Harden 1999, Small and Perry 2005, 2012). When sentence completion is difficult due to word-finding problems, it is helpful to fill in missing words (Watson et al. 1999). However, it is equally important to include one idea in each statement instead of providing more than one proposition in a single utterance (Rochon et al. 1994, Wilson et al.
Caregiver appraisals of communication strategies

Combining verbal and nonverbal communication strategies also can be an effective way to communicate. For example, using gestures, especially those that explain or supplement conceptually what was meant (Goldfarb and Pietro 2004, Small et al. 2003, Wilson et al. 2012a, 2012b) can aid understanding. Switching the mode of communication from oral to written also is helpful for those without vision problems (Bourgeois 2002, Goldfarb and Pietro 2004). Other repair strategies that could keep the conversation going and save face of the person with AD are to pretend to understand, to go along with what the other person is saying, and to redirect to a different topic or tasks (Elvish et al. 2010, Orange et al. 2009, Smith et al. 2011, Tuckett 2012).

Communication strategies that could be ineffective with persons with AD include tuning out or ignoring, continue talking, and completing actions oneself. Moreover, these possibly ineffective communication strategies can threaten the personhood of the individual with AD (Sabat 2002). Speaking louder when there are no hearing impairments is another strategy that could be ineffective for persons with dementia because it distorts the acoustic signal (i.e., it increases the signal-to-noise ratio). Additionally, speaking louder adds increasing cognitive processing, thereby creating a signal that is even more difficult to hear and to discriminate (Hopper and Hinton 2012, Pichora-Fuller 2009). Speaking slowly is another ineffective communication strategy that burdens working memory because the person with AD must retain the whole utterance for a longer period of time (Small et al. 1997, 2003, Tomoeda et al. 1990).

Much of what is known about the effectiveness of communication strategies used with persons with AD comes from studies with family caregivers in contrived contexts and/or from task completion procedures with staff in work-based settings (Small et al. 2003, Wilson et al. 2012b). Studies using family caregivers typically include individuals with early and middle stages of AD (Orange et al. 1996, 1998), whereas studies using staff caregivers usually include persons with middle or late stages of AD (Burgio et al. 2001, Ripich et al. 1995, 1999). The purpose of the current study is to examine family caregivers’ use and the perceived helpfulness (i.e., appraisals) of communication strategies following breakdowns in natural, home-based conversation with individuals with AD as a function of disease severity. This study has two primary aims. The first is to examine the effectiveness of the communication strategies caregivers’ employed to resolve communication breakdowns. The second is to assess whether caregivers’ ratings or appraisals of the effectiveness/ineffectiveness of communication strategies were accurate with respect to the instances of communication strategy use in video recorded conversations, and for those strategies that are not observable in the video data, with respect to the published scientific literature. This is the first study that examines both use and perceptions of communication strategies with individuals with early-, middle- and late-stage AD.

Methods and procedures

Participants and procedure

The data for this study came from a multi-centre investigation that used a cross-sectional, prospective design. We sought to examine the effectiveness of communication strategies and then to compare caregivers’ perceptions of the helpfulness of communication strategies based on actual use and on literature-documented effectiveness evaluations. We collected video-recorded conversational data and survey data as part of the multi-centre study on the psychometric properties of the Perception of Conversation Index—Dementia of the Alzheimer’s Type (PCI-DAT), which is a tool that measures caregiver perceptions of conversation with their relative with AD (Orange et al. 2009). Video recordings were completed of mealtimes conversations from 15 community-dwelling family caregivers and their relatives with AD.

In this study, mealtimes was the representative activity because it is an excellent medium to facilitate conversation and to approximate everyday conversation (Goodwin 2003). The act of sharing a meal gives participants value and feelings of unity within a group (Seymour 1983). This creates an opportunity for participants to foster emotional connections as they participate in meal sharing and consumption (Keller et al. 2010, Seymour 1983). Keller et al. (2010) described the meaning of mealtimes for participants with dementia. Meal times provided participants with a chance to strengthen relationships and to give and gain support because they were in an environment where they are face to face. Mealtimes also gave participants a chance to be involved psychologically. This meant that participants with dementia and their spouse are able to communicate, reaffirm their roles in the dyad, and show care and meaning toward one another. The regularity of meal timings creates an opportunity for positive connection that can be lost in other contexts of interaction (e.g., driving, baking/cooking, etc.). Thus, mealtimes are social experiences that enable participants to converse comfortably and freely. Since sharing in meals is a daily routine, conversations recorded in this setting would be spontaneous and reflective of daily conversation. Altus et al. (2002) reported that communication doubled when participants with dementia ate meals in a family-style setting and dropped back to baseline levels when participants ate alone. Sandman et al. (1988) also noted that communication increased during mealtimes.
for their participants with dementia. For these reasons, we used mealtime settings to generate appropriate conversation samples that are reflective of daily communication.

A total of 15 dyads participated in this study. Fourteen dyads included spouse caregivers and one dyad included a daughter caregiver (table 1). Participants were recruited from local adult day centres. AD diagnosis was made in accordance with the McKhann et al. (1984) research criteria by the participants attending a neurologist, geriatrician, psychiatrist or family practitioner. The Standardized Mini-Mental State Examination (Molloy et al. 1991) was administered to participants with AD to establish the severity of AD. Six dyads included participants with early-stage AD, five dyads included participants with middle-stage AD, and four dyads included participants with late-stage AD. Of the 15 dyads that were video-recorded, mealtime conversations from 13 dyads were video-recorded during lunch and dinner and two dyads had only one mealtime conversation recorded. This resulted in a total of 28 mealtime conversations: 11 conversations with participants with early-stage AD, ten with middle-stage AD, and seven with late-stage AD. All participants completed written consent. Their legal guardian gave consent for individuals with AD if they were unable to give consent themselves. The human ethics review boards at each of the three data collection sites approved the study.

### Table 1. Demographic characteristics of the sample

<table>
<thead>
<tr>
<th></th>
<th>Caregiver (N = 15)</th>
<th>Relative with dementia (N = 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average age (range)</strong></td>
<td>76.67 (67–85 years)</td>
<td>78.73 (71–88 years)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>6 (40%)</td>
<td>8 (53.3%)</td>
</tr>
<tr>
<td>Women</td>
<td>9 (60%)</td>
<td>7 (46.7%)</td>
</tr>
<tr>
<td><strong>Kinship status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>14 (93.3%)</td>
<td></td>
</tr>
<tr>
<td>Adult–child</td>
<td>1 (6.7%)</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grade school</td>
<td>1 (6.7%)</td>
<td>4 (26.7%)</td>
</tr>
<tr>
<td>High school</td>
<td>6 (40.0%)</td>
<td>8 (53.3%)</td>
</tr>
<tr>
<td>Vocational/technical school</td>
<td>2 (13.3%)</td>
<td>-</td>
</tr>
<tr>
<td>University</td>
<td>4 (26.7%)</td>
<td>2 (13.3%)</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>2 (13.3%)</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Analysis plan

**Transcription and coding**

Mealtime conversations between participants with AD and their family members were transcribed orthographically and segmented into utterances. This study used segmented utterances according to the following definition ‘complete thought, usually expressed in a connected grouping of words, which is separated from other utterances on the basis of content, intonation contour, and/or pausing’ (Shewan 1988, p. 124). This was the same methodology and definitions outlined by Orange et al. (1996). Next, they were analysed using conversation analysis via the TSR paradigm as first described by Schegloff et al. (1977) and adapted on in AD dyads by Orange et al. (1996, 1998). The TSR paradigm was used to identify AD stage-based communication breakdowns (i.e., trouble source) and the communication strategies that caregivers used to resolve them. All utterances made by family members were coded for the following components of a TSR sequence: trouble source (a problematic utterance leading to communication breakdown), repair initiator (an utterance that signals a breakdown and the need to resolve it), and repair (a response to a repair initiator that is used to resolve a communication breakdown). Next, each repair initiator and repair strategy was coded in terms of well-defined operational definitions that linked conceptually with the communication strategies listed in the PCI-DAT. Each TSR sequence was categorized by the type of resolution that
Table 2. Caregiver appraisals of the helpfulness of communication strategies outlined by the PCI-DAT

<table>
<thead>
<tr>
<th>Communication strategies</th>
<th>Early AD</th>
<th></th>
<th>Middle AD</th>
<th></th>
<th>Late AD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Do things yourself</td>
<td>6.17</td>
<td>1.17</td>
<td>5.80</td>
<td>1.10</td>
<td>4.00</td>
<td>2.45</td>
</tr>
<tr>
<td>Repeat</td>
<td>5.50</td>
<td>1.64</td>
<td>4.60</td>
<td>1.14</td>
<td>4.25</td>
<td>2.50</td>
</tr>
<tr>
<td>Try to figure out meaning</td>
<td>5.33</td>
<td>1.03</td>
<td>4.00</td>
<td>2.35</td>
<td>4.00</td>
<td>2.45</td>
</tr>
<tr>
<td>Redirect/change activity</td>
<td>5.00</td>
<td>1.41</td>
<td>3.40</td>
<td>2.41</td>
<td>3.75</td>
<td>2.87</td>
</tr>
<tr>
<td>Give more information</td>
<td>4.67</td>
<td>2.58</td>
<td>4.00</td>
<td>1.41</td>
<td>1.50</td>
<td>1.73</td>
</tr>
<tr>
<td>Ask questions</td>
<td>4.50</td>
<td>1.87</td>
<td>3.20</td>
<td>1.48</td>
<td>1.25</td>
<td>1.26</td>
</tr>
<tr>
<td>Speak slowly</td>
<td>4.50</td>
<td>2.51</td>
<td>2.80</td>
<td>2.77</td>
<td>5.50</td>
<td>1.73</td>
</tr>
<tr>
<td>Simplify</td>
<td>4.50</td>
<td>2.51</td>
<td>4.20</td>
<td>0.84</td>
<td>4.00</td>
<td>2.45</td>
</tr>
<tr>
<td>Rephrase</td>
<td>4.33</td>
<td>1.51</td>
<td>2.60</td>
<td>1.67</td>
<td>4.50</td>
<td>1.73</td>
</tr>
<tr>
<td>Say ‘I don’t understand’</td>
<td>4.00</td>
<td>2.37</td>
<td>3.00</td>
<td>1.73</td>
<td>1.25</td>
<td>1.89</td>
</tr>
<tr>
<td>Fill in missing information</td>
<td>4.00</td>
<td>2.00</td>
<td>4.00</td>
<td>2.45</td>
<td>2.50</td>
<td>1.91</td>
</tr>
<tr>
<td>Show what you mean</td>
<td>3.83</td>
<td>2.48</td>
<td>3.40</td>
<td>0.89</td>
<td>5.00</td>
<td>1.41</td>
</tr>
<tr>
<td>Go along w/ what s/he is saying</td>
<td>3.67</td>
<td>2.07</td>
<td>3.80</td>
<td>2.17</td>
<td>5.50</td>
<td>1.73</td>
</tr>
<tr>
<td>Give choices of what you think s/he means</td>
<td>3.67</td>
<td>2.42</td>
<td>2.80</td>
<td>1.92</td>
<td>2.25</td>
<td>2.06</td>
</tr>
<tr>
<td>Gesture</td>
<td>3.50</td>
<td>2.43</td>
<td>1.80</td>
<td>1.10</td>
<td>4.25</td>
<td>3.10</td>
</tr>
<tr>
<td>Continue talking</td>
<td>3.33</td>
<td>1.75</td>
<td>2.40</td>
<td>2.30</td>
<td>2.75</td>
<td>2.75</td>
</tr>
<tr>
<td>Ask to repeat</td>
<td>3.00</td>
<td>2.00</td>
<td>2.60</td>
<td>2.19</td>
<td>2.00</td>
<td>1.83</td>
</tr>
<tr>
<td>Speak louder</td>
<td>2.83</td>
<td>2.86</td>
<td>1.80</td>
<td>1.64</td>
<td>2.25</td>
<td>2.63</td>
</tr>
<tr>
<td>Ask clarification</td>
<td>2.50</td>
<td>2.07</td>
<td>3.20</td>
<td>2.28</td>
<td>0.75</td>
<td>0.96</td>
</tr>
<tr>
<td>Pretend to understand</td>
<td>1.83</td>
<td>2.14</td>
<td>2.60</td>
<td>2.41</td>
<td>4.50</td>
<td>3.32</td>
</tr>
<tr>
<td>Tune out/ignore</td>
<td>1.67</td>
<td>2.25</td>
<td>2.20</td>
<td>2.77</td>
<td>1.25</td>
<td>1.89</td>
</tr>
<tr>
<td>Write</td>
<td>1.00</td>
<td>2.00</td>
<td>1.20</td>
<td>1.30</td>
<td>0.25</td>
<td>0.50</td>
</tr>
</tbody>
</table>

Note: PCI-DAT represents the Perceptions of Conversation Index—Dementia of the Alzheimer’s Type. The total possible score for each item is 7, where 1 = not helpful and 7 = very helpful.

reflected (1) whether or not the breakdown was resolved and (2) whether single or multiple repair attempts were used (see appendix A). Communication strategies were coded as effective if they either single-handedly resolved (i.e., most successful and simple resolution) or contributed to resolving a breakdown through the use of multiple signals and repairs (i.e., successful and simple resolution). Inter-rater reliability for coding TSR variables was assessed using Cohen’s kappa. Two raters coded four of the 28 randomly selected transcripts. The kappa statistic was 0.83 for trouble sources, 1.0 for repair initiators, 0.75 for repairs, 0.86 for resolution type and 0.87 for strategies coded using the items/categories from the PCI-DAT.

The first study aim was to identify the communication strategies that caregivers used to resolve successfully communication breakdowns. To address this aim, we calculated the total occurrences of repair initiators and repair strategies found in TSR sequences that were classified as (1) most successful and simple resolutions and (2) successful and simple resolution. As mentioned previously, the repair initiators and repair strategies were categorized in terms of the communication strategies on the PCI-DAT. Communication strategies were coded as ineffective if they did not resolve or if they exacerbated breakdowns. To identify the unsuccessful communication strategies that caregivers used to resolve communication breakdowns, we calculated to the total occurrences of communication strategies found in TSR sequences that were classified as (3) unsuccessful and simple resolutions and (4) unsuccessful and complex resolutions. Next, we calculated the proportion of communication strategies used to resolve communication breakdowns successfully and unsuccessfully as a function of disease severity. The numerator included the total number of times a specific strategy from the PCI-DAT was used by all caregivers of persons in each stage of AD. The denominator was the total number of successful and unsuccessful communication strategies used by caregivers of persons in each stage of AD.

The second study aim was to compare caregivers’ use of effective and ineffective communication strategies to their perceived ratings of effectiveness using the PCI-DAT. Some strategies were either not observed or not able to be observed but were rated using the PCI-DAT. Ratings of such communication strategies were compared with the evidence in the literature. Consistency between the communication strategies used in the video data and those reported to be used in the PCI-DAT data would support the validity of the PCI-DAT as a proxy measure for actual strategy use by caregivers. Comparisons were made between the results of the PCI-DAT
Table 3. Proportion of communication strategies used in successful resolutions

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Early AD</th>
<th>Middle AD</th>
<th>Late AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give more information</td>
<td>0.23</td>
<td>0.38</td>
<td>0.34</td>
</tr>
<tr>
<td>Repeat</td>
<td>0.16</td>
<td>0.11</td>
<td>0.32</td>
</tr>
<tr>
<td>Simplify</td>
<td>0.14</td>
<td>0.13</td>
<td>0.05</td>
</tr>
<tr>
<td>Rephrase</td>
<td>0.13</td>
<td>0.02</td>
<td>0.16</td>
</tr>
<tr>
<td>Ask to repeat</td>
<td>0.09</td>
<td>0.21</td>
<td>0.02</td>
</tr>
<tr>
<td>Try to figure out meaning</td>
<td>0.09</td>
<td>0.06</td>
<td>0.02</td>
</tr>
<tr>
<td>Fill in missing information</td>
<td>0.04</td>
<td>0.01</td>
<td>0.02</td>
</tr>
<tr>
<td>Show what you mean</td>
<td>0.04</td>
<td>0.07</td>
<td></td>
</tr>
<tr>
<td>Louder</td>
<td>0.03</td>
<td>0.04</td>
<td></td>
</tr>
<tr>
<td>Choices</td>
<td>0.03</td>
<td>0.04</td>
<td></td>
</tr>
<tr>
<td>Gesture</td>
<td>0.02</td>
<td>0.04</td>
<td></td>
</tr>
<tr>
<td>Ask questions</td>
<td>0.01</td>
<td>0.01</td>
<td></td>
</tr>
<tr>
<td>Ask for clarification</td>
<td>0.01</td>
<td>0.04</td>
<td></td>
</tr>
<tr>
<td>Continue talking</td>
<td>0.01</td>
<td>0.07</td>
<td></td>
</tr>
</tbody>
</table>

Table 4. Proportion of communication strategies used in unsuccessful resolutions

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Early AD</th>
<th>Middle AD</th>
<th>Late AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continue talking</td>
<td>0.45</td>
<td>0.23</td>
<td></td>
</tr>
<tr>
<td>Ask to repeat</td>
<td>0.30</td>
<td>0.4</td>
<td>0.23</td>
</tr>
<tr>
<td>Tune out/ignore</td>
<td>0.10</td>
<td>0.6</td>
<td>0.08</td>
</tr>
<tr>
<td>Fill in missing information</td>
<td>0.05</td>
<td>0.08</td>
<td></td>
</tr>
<tr>
<td>Ask questions</td>
<td>0.05</td>
<td>0.08</td>
<td></td>
</tr>
<tr>
<td>Try to figure out meaning</td>
<td>0.05</td>
<td>0.08</td>
<td></td>
</tr>
<tr>
<td>Repeat</td>
<td>0.15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rephrase</td>
<td>0.08</td>
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</tr>
<tr>
<td>Ask for clarification</td>
<td>0.01</td>
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</table>

ratings and TSR resolution coding, paired with the literature on effective and ineffective communication strategies. A mean rating of 5–7 on items on the PCI-DAT reflected helpful communication strategies, a mean rating of 3.1–4.9 reflected moderately helpful communication strategies, and a mean rating of 1–3 reflected communication strategies that were not helpful.

Outcomes and results

Effective and ineffective communication strategies

Table 3 reports the proportion of communication strategies used, as a function of disease severity, in successful resolutions; table 4 reports the proportions of communication strategies used, as a function of disease severity, in unsuccessful resolutions. Of the 22 communication strategies listed in the PCI-DAT, two (pretend to understand—Item #16 and go along with what s/he is saying—Item #18) could not be coded because they required knowledge of the caregivers’ intentions.

For caregivers of persons with early-stage AD, the most frequently used communication strategies found in ‘TSR sequences with successful resolutions included giving more information, repetition, simplification and rephrasing. Similarly, caregivers of persons with middle-stage AD frequently gave more information, asked to repeat, and simplified and repeated their utterances. Frequently used communication strategies by caregivers of persons with late-stage AD included give more information, repeat and rephrasing. As shown in table 3, caregivers of persons with early-stage AD used the greatest range of communication strategies compared with caregivers of persons with middle- and late-stage AD.

For caregivers of persons with early- and late-stage AD, the communication strategies that were most frequently used in TSR sequences with unsuccessful resolutions included continue talking and ask to repeat. Caregivers of persons with middle-stage AD only used two communication strategies in sequences with unsuccessful resolutions: tune out and ask to repeat. Interestingly, caregivers of persons with early- and late-stage AD used a wider range of communication strategies that were unsuccessful, compared with caregivers of persons with middle-stage AD, who only used two types of unsuccessful communication strategies (table 4).

Caregiver appraisals of communication strategies

Table 2 shows caregivers’ appraisals or ratings of the helpfulness of each communication strategy found in the PCI-DAT. Caregivers of persons with early-stage AD rated the following as the most helpful communication strategies: do things yourself, repeat, try to figure out the meaning and redirect/change the activity. Caregivers of persons with middle-stage AD only rated the communication strategies of do things yourself as the most helpful strategy, whereas caregivers of those with late-stage AD highly rated the strategies of speak slowly, go along with what s/he is saying, and show what you mean as most helpful.

According to caregivers of individuals with early-stage AD, the least helpful communication strategies were writing, tuning out/ignore, pretending to understand, asking for clarification, speaking loudly and asking to repeat. Caregivers of individuals in later stages of AD rated half of the communication strategies in the PCI-DAT as unhelpful. Specifically, caregivers of persons with middle-stage AD rated the following 11 strategies as unhelpful when communicating with their family member: write, speak louder, use gestures, tune out/ignore, continue talking, rephrase, ask to repeat, pretend to understand, speak slowly, give choices of what you think s/he means and say ‘I don’t understand’. Caregivers of persons with late-stage AD rated the following strategies as unhelpful in resolving breakdowns: write, ask clarification, ask questions, say ‘I don’t understand’, tune out/ignore, give more information, ask to repeat, speak louder, give choices of what you think
Caregiver appraisals of communication strategies

<table>
<thead>
<tr>
<th>Effective</th>
<th>Moderately helpful (3.1-4.9)</th>
<th>Not helpful (1-3)</th>
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</thead>
<tbody>
<tr>
<td>Repeat</td>
<td>Give more information</td>
<td>Ask to repeat</td>
</tr>
<tr>
<td>Try to figure out meaning</td>
<td>Simplify</td>
<td>Write</td>
</tr>
<tr>
<td>Ask questions</td>
<td>Rephrase</td>
<td>Pretend to understand</td>
</tr>
<tr>
<td>Redirect</td>
<td>Fill in missing information</td>
<td>Ask for clarification</td>
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<td>Go along w/ what s/he is saying</td>
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<td></td>
<td>Give choices</td>
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<td></td>
<td>Gesture</td>
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<td></td>
<td>&quot;I don't understand&quot;</td>
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<td></td>
<td>Go along w/ what s/he is saying</td>
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<td>Redirect</td>
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<td></td>
<td>Show what you mean</td>
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<th>Moderately helpful (3.1-4.9)</th>
<th>Not helpful (1-3)</th>
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<tr>
<td>Do things yourself</td>
<td>Slower</td>
<td>Tune out/ignore</td>
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<tr>
<td></td>
<td>Continue talking</td>
<td>Louder</td>
</tr>
<tr>
<td></td>
<td>Tune out/ignore</td>
<td>Louder</td>
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<td>Louder</td>
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Figure 1. Matched and mismatched appraisals of communication strategies by caregivers of persons with early-stage AD. PCI-DAT represents the Perceptions of Conversation Index—Dementia of the Alzheimer’s Type; and TSR represents the Trouble Source and Repair coding. Italicized items were not observed in the video data.

<table>
<thead>
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<th>Effective</th>
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<tr>
<td>Repeat</td>
<td>Give more information</td>
<td>Ask to repeat</td>
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<tr>
<td>Try to figure out meaning</td>
<td>Simplify</td>
<td>Write</td>
</tr>
<tr>
<td>Ask questions</td>
<td>Rephrase</td>
<td>Pretend to understand</td>
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<tr>
<td>Fill in missing information</td>
<td>Ask for clarification</td>
<td>Ask for clarification</td>
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<tr>
<td>Go along w/ what s/he is saying</td>
<td>Ask to repeat</td>
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<td>&quot;I don't understand&quot;</td>
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<td>Go along w/ what s/he is saying</td>
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<td>Redirect</td>
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<td></td>
<td>Show what you mean</td>
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<th>Not helpful (1-3)</th>
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<td>Do things yourself</td>
<td>Louder</td>
<td>Continue talking</td>
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<td>Louder</td>
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Figure 2. Matched and mismatched appraisals of communication strategies by caregivers of persons with middle-stage AD. PCI-DAT represents the Perceptions of Conversation Index—Dementia of the Alzheimer’s Type; and TSR represents the Trouble Source and Repair coding. Italicized items were not observed in the video data.

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<th>Not helpful (1-3)</th>
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<tbody>
<tr>
<td>Repeat</td>
<td>Give more information</td>
<td>Ask to repeat</td>
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<tr>
<td>Try to figure out meaning</td>
<td>Simplify</td>
<td>Write</td>
</tr>
<tr>
<td>Ask questions</td>
<td>Rephrase</td>
<td>Pretend to understand</td>
</tr>
<tr>
<td>Fill in missing information</td>
<td>Ask for clarification</td>
<td>Ask for clarification</td>
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<tr>
<td>Go along w/ what s/he is saying</td>
<td>Ask to repeat</td>
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<tr>
<td>Redirect</td>
<td>Give choices</td>
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<tr>
<td></td>
<td>Gestures</td>
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<tr>
<td></td>
<td>&quot;I don't understand&quot;</td>
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<td></td>
<td>Go along w/ what s/he is saying</td>
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<td>Redirect</td>
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<td>Show what you mean</td>
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<tr>
<td>Do things yourself</td>
<td>Louder</td>
<td>Continue talking</td>
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<td>Louder</td>
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<td>Louder</td>
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<td>Louder</td>
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Figure 3. Matched and mismatched appraisals of communication strategies by caregivers of persons with late-stage AD. PCI-DAT represents the Perceptions of Conversation Index—Dementia of the Alzheimer’s Type; and TSR represents the Trouble Source and Repair coding. Italicized items were not observed in the video data.

and/or the literature. The columns include caregiver appraisals of communication strategies in the PCI-DAT. For descriptive purposes, the communication strategies were categorized in terms of those that were helpful, moderately helpful and not helpful using the labels from the PCI-DAT.

Among caregivers of persons with early-stage AD, matched appraisals were observed for 68% and mismatched appraisals were observed for 32% of the 22 communication strategies. Among caregivers of persons with middle-stage AD, matched appraisals were observed for 45% of communication strategies and mismatched appraisals were observed for 55% of the communication strategies. Among caregivers of persons with late-stage AD, matched appraisals were observed for 55% and mismatched appraisals were observed for 45% of the communication strategies. Moreover, most mismatched appraisals were for effective communication strategies that were appraised as ineffective. Chi-square tests were used to assess whether the proportion of matched versus mismatched appraisals was significantly different for each caregiver group. Using a one-tailed test, there were significant differences in the proportions of matched and mismatched appraisals for caregivers of persons with early AD ($\chi^2(1, N = 22) = 2.91, p < 0.05, \phi = 0.36$) but not for caregivers of persons with middle or late AD, who had the same chi square value ($\chi^2(1, N = 22) = 0.18, p > 0.05, \phi = 0.09$).

Discussion

This study examined family caregivers’ use and appraised helpfulness of effective communication strategies versus ineffective communication strategies in resolving communication breakdowns when conversing with a relative with AD as a function of disease severity. The
most frequently used communication strategies by family caregivers of individuals in all three clinical stages of AD in successful resolutions included strategies that have been documented in the literature to be effective. They include giving more information (Orange et al. 1996), verbatim and paraphrased repetition (Small et al. 1997, Wilson et al. 2012b), and simplifying sentences (Small et al. 2003). Conversely, across disease severity, unsuccessful resolutions of communication breakdowns frequently included the strategies of continue talking and tune out/ignore. Of note, the strategy of asking to repeat also was used frequently in unsuccessful resolutions by all three groups of caregivers. Asking to repeat is typically a good strategy to signal a misunderstanding because it makes clear that the person did not understand what was said as a result of not attending, poor comprehension, poor expression (e.g., slurred speech production, complex grammar, syntax or content, etc.) or some other reason (Orange et al. 1996). Caregivers in the current study were using these non-specific terms such as ‘huh?’ and ‘eh?’ to indicate a misunderstanding and to initiate a repair sequence, resulting in further communication breakdowns. Orange et al. (1996) noted similar findings, especially for family caregivers of persons with middle-stage AD. Our findings, in concert with Orange et al. (1996), suggest that caregivers need education and training on how to ask for specific types of clarification, given that clarification strategies found in this study led to further communication breakdowns.

This study is novel in its examination of strategy use as a function of disease severity. Caregivers of individuals of early-stage AD used a wider variety of communication strategies in successful resolutions of communication breakdowns (N = 13 strategies) compared with caregivers of individuals with middle-stage AD (N = 11 strategies) and late-stage AD (N = 8 strategies). However, this pattern of diversity of strategy use differed in unsuccessful resolutions. Caregivers of persons with late-stage AD used eight strategies compared with the six and two strategies used by caregivers of persons with early- and middle-stage AD, respectively. With disease progression, the complexity of conversation problems increases because language and communication deteriorate. Specifically, the language and communication patterns are more semantically empty, with fewer content units produced by persons with AD (Bayles and Kaszniak 1987). The changes in language make conversation more complex, resulting in family caregivers not knowing which communication strategies work better than others do, despite their increasing experience and exposure to the problems.

There are notable patterns among the PCI-DAT ratings within each caregiver group. For instance, caregivers of persons in early-stage AD had matched appraisals for many of the effective and ineffective communication strategies. In fact, all but one of the strategies (i.e., do things yourself) rated as most effective were indeed effective according to the video data and/or the existing literature. Compared with caregivers of persons in middle- and late-stage AD, caregivers of persons with early-stage AD had more matched appraisals over and above making matched appraisals by chance alone. This finding suggests that as the disease progresses, caregivers will need targeted education and training to use communication strategies that are helpful and to avoid or to discontinue using communication strategies that are unhelpful. Moreover, caregivers in all groups may need education and training on ways to engage their family member in tasks and interactions so that the caregivers do not always have to complete tasks on their own. Table 2 shows that the strategy of do things yourself was highly rated as helpful by all caregivers. Although this strategy is expedient in terms of task completion, expediency is yielded at the risk of disengagement, which can have serious mental health consequences for persons with dementia (Schreiner et al. 2005). Conversely, we found evidence that caregiver ratings are appropriately varied across AD stage to reflect differing communication impairments and needs. For example, caregivers of persons in late-stage AD rated highly the strategies of (1) go along with what s/he is saying and (2) show what you mean. These are helpful communication strategies, especially in later stages of AD when communication difficulties are more severe (Wilson et al. 2012b).

There were notable similarities and differences in the perceptions of unhelpful communication strategies among the three caregiver groups. Caregivers in all groups had matched appraisals for tune out/ignore and speak louder as unhelpful communication strategies. This might be because they are aware that these are face saving communication strategies, which aim to avoid embarrassing or humiliating their family member with AD. It is possible that caregivers want to maintain the personhood of their family member with AD. Caregivers of those in middle-stage AD were the only participants to appraise the strategy speak slowly as un-helpful. Their appraisal matched what has been documented empirically (Small et al. 1997, 2003, Tomoeda et al. 1990). It is possible that caregivers of persons in early- and late-stage AD were following clinical advice, such as speak slowly, from organizations like the Alzheimer’s Association. Finally, caregivers of those in middle- and late-stage AD also appraised the strategy continue talking as unhelpful. Their appraisal matched the video data, which showed continuing to talk was the most frequent strategy used by caregivers of those in late- and early-stage AD in unsuccessfully resolutions of communication breakdowns. To continue talking in the presence of a communication breakdown can threaten
the personhood of the family member with AD (Sabat 2002).

Although the findings are promising, there were many instances of mismatched appraisals of effective evidence-based communication strategies. It appears that caregivers are likely to rate repair initiators as ineffective (i.e., mismatched rating) despite the documented evidence of helpfulness (Orange et al. 1996, Ramanathan 1997, Watson et al. 1999). For example, the strategy ask to repeat was rated as unhelpful but the low rating could be due to caregivers’ use of the nonspecific terms such as ‘eh?’ and ‘huh?’ to request repetition. Similarly, it also is possible that asking to repeat by offering more cues would be helpful because the request does not rely solely on working memory system or processes. The strategy asking for clarification also was rated as unhelpful by caregivers of persons in early-stage AD, but especially by caregivers in late-stage AD, suggesting that the focus of communication in later stages of the disease might be to keep the conversation going at the expense of truly comprehending the person with AD. Other repair initiators that had mismatched appraisals by caregivers in the middle and late stages of AD include giving choices, saying ‘I don’t understand’, and asking questions. A possible interpretation of these findings is that caregivers of individuals in later stages of AD may not think their family member is able to respond to questions and various requests for clarification. These caregivers may feel that they need to do all the talking because their family member is not able to maintain a conversation.

In general, appraisals of communication strategies as either helpful when they are not helpful or unhelpful when they are helpful (i.e., mismatched appraisals) provide targeted opportunities for new learning among caregivers (Small et al. 2003). On the other hand, differences in ratings by AD stage reflect learning and coping with AD progression. For example, caregivers of those in early- and middle-stage AD rated pretend to understand as unhelpful but caregivers of those in late-stage AD rated it as moderately helpful. This finding may reflect a difference in strategy use by caregivers of persons in late-stage AD. These caregivers typically endorsed communication strategies that avoided conflict and may have supported personhood by allowing individuals with AD to express his/her needs. Consequently, education and training programs must target the evolving helpfulness (and devolving effectiveness) of communication strategies that occurs across the clinical stages of AD. Although this study makes a unique contribution in the literature by assessing caregivers’ use and appraisals of communication strategies across levels of disease severity, the findings are limited by a relatively small sample size and sample comprised primarily of spouse caregivers. Future research should include a larger and more varied sample of caregivers comprising both spouses and adults–children.

Conclusions

Findings show that one set of communication strategies is not sufficient to resolve myriad communication breakdowns across the progression of AD. Moreover, caregivers representing all three clinical stages of AD had matched appraisals of both effective and ineffective communication strategies, with caregivers of individuals with early-stage AD demonstrating a high proficiency of matching their appraisal of communication strategies to their documented helpfulness. Caregivers of individuals with middle and late clinical-stage AD showed lower proficiency of matching their appraisals of communication strategies, although their ratings did match a range of documented effective communication strategies. Future communication enhancement education and training programmes must include a wide range of empirically derived communication strategies that are targeted to the clinical stage of AD. In addition, such programmes must ensure that caregivers’ appraisals of the effectiveness of communication strategies match the evidence found in the scientific literature.

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**Caregiver appraisals of communication strategies**


**Appendix A: Resolution types (Orange et al. 1996)**

<table>
<thead>
<tr>
<th></th>
<th>Simple</th>
<th>Complex</th>
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<tbody>
<tr>
<td>Most successful</td>
<td>R1</td>
<td>//</td>
</tr>
<tr>
<td>Successful</td>
<td>R2</td>
<td>R3</td>
</tr>
<tr>
<td>Unsuccessful</td>
<td>R4</td>
<td>R5</td>
</tr>
</tbody>
</table>

- Simple: a single trouble source and use of one or more repair initiators and/or repairs.
- Complex: multiple trouble sources, repair initiators and/or repairs.
- Most successful: trouble source is repaired by one repair initiator and repair; conversation continues on same or similar topic.
- Successful: trouble source is repaired by more than one repair initiator and repair; conversation continues on same or similar topic.
- Unsuccessful: trouble source(s) not resolved by repair attempts; same topic may continue, change inappropriately, or conversation may terminate.

**References**


