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

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

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Abstract

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

Abrégé

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

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Introduction and Background

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

Family Communication and Dementia

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

Education and Training for the Care Partner

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

limitations and restrictions (for further discussion, see Byrne & Orange, 2005a; Clare, 2008).

Communication Strategies

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

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

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

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

TRACED (Training in Communication Enhancement for Dementia)

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

recognized and accepted theoretical frameworks which incorporate both of these dimensions. Specifically, TRACED is based on:

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

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

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

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

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

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

Table 1. Definitions and Examples of Compensatory Strategies

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

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

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

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

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

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

Questions that require retrieval of information from recent memory

Did you read the newspaper this morning?

Where did we go for a walk yesterday?

Questions that do not require retrieval of information from recent memory

Do you want to read the newspaper?

Where would you like to go for a walk?

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

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

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

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

Successful Repair of a Problem

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

Unsuccessful Repair of a Problem

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

Table 2. Definitions and Examples of Connecting Strategies

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

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

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

the dyad's interactional style, and as mentioned previously, takes into consideration family history, the context of communication, and the communicative needs and goals of the dyad, among other factors (Nolan, Ingram, & Watson, 2002; Purves & Phinney, see this issue; Schulz et al., 2003). In particular, the specific communication patterns and goals of the dyad are identified through interviews with each member of the dyad (see "Contextualizing Session" in Appendix A), on assessments of the language and communication abilities of the person with AD (e.g., Bayles & Tomoeda, 1993), and on trainers' analyses of their weekly conversations in training. Based on these data, dyad-specific demonstration and practice activities are developed and adapted to meet individual needs and to help care partners bring normally implicit communicative behaviours to explicit awareness so that they can be modified. The TRACED strategies that care partners do not employ routinely, but which could be used effectively, are emphasized in training activities (see Table 3 for examples of strategies in use, and Appendices A & B for an overview of TRACED activities and a sample training session). The education and skill-building goals of TRACED are: to increase

care partner's awareness of and appreciation for the program's philosophy and person- and context-specific approaches to communication, to advance care partner's knowledge using adult-based learning strategies, to modify expectations according to the dyad's context, and to facilitate changes in the care partner's behaviour (Perraud, Farran, Loukissa, & Paun, 2004). To accomplish these goals, we agree with Stevens and Burgio (2000) that "having caregivers accept full responsibility for communication with the person with AD is the most significant step in training" (p.63).

TRACED Pilot Study

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

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

Discussing a visit to the doctor

CP:	So we are going there tomorrow at 2:30. (*one idea sentence; provides information to remind date and time*)
PWD:	Is that at Dr. [name of doctor]'s?
CP:	Yes.
PWD:	Well, that will be nice, because I've called upon him as a patient.
CP:	As a patient, yes. (*Picking up on and reflecting back on spouse's comments*)
PWD:	Yes and he was very good.
CP:	Yes. What did you like about him? (*One idea open-ended question that gets at PWD's feelings rather than recall of specific episodic information*)
PWD:	The fact that he seemed sort of not just full of himself, but I think that he's not having difficulty with other people.
CP:	OK. Do you like him better than Mr. [name]? (*One idea yes/no question. Gives name to help PWD remember*)

Reminiscing about trip

CP:	What part of Australia did you really like the best? (*one idea open-ended question that doesn't require recall of specific episodic facts*)
PWD:	Coast.
CP:	The coast? That was the drive you mean? The drive that we took? (*one idea sentence that picks up and builds on "Coast"*)
PWD:	Yeah.
CP:	When we had the car? (*one idea question, continues to build on "The drive"; no abrupt topic shift*)
PWD:	Mmm hmm.
CP:	Yeah, we drove from Cairns to… Brisbane, I think. (*one idea sentence*)
PWD:	Yeah.
CP:	Yeah. Stops along the way. (*partnering in a way that includes PWD in story*)
PWD:	( )
CP:	Yeah. Nice country.
PWD:	((laughs)) Yeah.
CP:	You like it? (*one idea yes-no question that gets at PWD's feelings*)
PWD:	Oh yeah. ( )>
CP:	What'd you really like about it? (*one idea open-ended question that probes further about PWD's feelings*)
PWD:	The simplicity of the young--of the people.
CP:	I like the people too. I like the weather. (*one idea sentences; encourages and honors PWD by acknowledging and affirming his perspective*)
PWD:	Yeah.
CP:	Yeah. Nice country.

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

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

Results

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

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

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

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

Care Partners' comments in response to questions about:

Training Content

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

Training Forms

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

Care partner Log sheet to record strategy use between training sessions
- Care Partners reported mixed use and varied responses—some liked the idea of keeping a record, others didn't have the time

Information Sheet on Alzheimer's Disease
- "Very helpful, especially to link the problem with the behaviour"

Delivery

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

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

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

Future Directions

Although follow-up research is warranted to examine the efficacy of TRACED, we believe the phase one findings and revisions of the protocol provide a foundation for adapting the TRACED training and manual for use by community service providers who work with families (e.g., home health care workers; hospital-based geriatric counseling and education outreach staff; cf. Young, Manthorp, Howells, & Tullo, 2011). In adapting TRACED for health care professionals, and others in clinics and assessment units, the teaching strategies would be modified to build on participants' knowledge of the communication process as learned in most health care education programs. Some factors to consider in adapting the TRACED protocol for community settings are: 1) the duration of training (i.e., there may need to be shorter and/or fewer training

sessions to accommodate service provider time constraints); 2) the influence of the service provider's experience, personality, and training background on understanding and effectively delivering TRACED (e.g., the concepts and principles of TRACED may need to be elaborated on/simplified for persons who do not have background knowledge in these areas); and 3) methods to monitor efficiently and evaluate progress by the trainees (e.g., use of self-report and/or real-time observations). One approach to developing an adapted version of TRACED would be to consult with a variety of community service providers. This could take the form of focus group discussions, in order to identify their needs and constraints in implementing a program like TRACED. Actual training could then be implemented using a train-the-trainer approach so that key individuals from community agencies are trained how to train their staff (e.g., Fitzgerald et al., 2009).

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

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

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

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Appendix A: Overview of TRACED Activities

Contextualizing Session (Week 1).

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

Training One (Week 2).

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

Training Two (Week 3).

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

Training Three (Week 4).

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

Training Four (Week 5).

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

Booster Session (Week 6).

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

Appendix B: Sample TRACED Training Session 3

I. Opening the Session

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

II. Feedback from Care Partner

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

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

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

III. Review Content from Training Two

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

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

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

IV. Connecting Strategies Explained and Demonstrated

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

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

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

V. Practice using Connecting Strategies in Conversation with Family Member

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

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

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

VI. Feedback from Care Partner and Wrap Up

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

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

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