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Development and Evaluation of a Nursing Psycho-educational Program focused on Communication for Family Caregivers in Early Alzheimer's Disease

par

Krystyna Klodnicka Kouri

Faculté des sciences infirmières

Thèse présentée à la Faculté des études supérieures
en vue de l'obtention du grade de
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Cette thèse intitulée:

Development and Evaluation of a Nursing Psycho-educational Program

focused on Communication

for Family Caregivers in Early Alzheimer's Disease

présentée par :

Krystyna Klodnicka Kouri

a été évaluée par un jury composé des personnes suivantes:

Hélène Lefebvre, Ph.D.
présidente-rapporteure

Francine Ducharme, Ph.D.
directrice de recherche

Lucie Richard, Ph.D.
membre du jury

Suzanne Ouellet, Ph.D.
examinatrice externe

Louise Getty, Ph.D.
représentante du doyen de la FES

ABSTRACT

In the early stage of Alzheimer's disease, a major area of concern for the family caregiver is that of communication with the family member. In response to this problem, a psycho-educational intervention focused on communication was developed for the family caregiver and tested within an experimental design. The theoretical framework for the study included the McGill Model of Nursing, Self-efficacy theory and Geragogy.

The study took place in a semi-urban region. The sample was recruited through memory clinics, a geriatric assessment unit and in the community. The inclusion criteria for participants were as follows: 1) being the principal caregiver of a family member or friend diagnosed with cognitive problems associated with the early stage of probable Alzheimer's disease, 2) aged 55 or older and 3) able to communicate in French or in English. The exclusion criteria targeted caregivers who 1) were participating, or had recently participated in an educational or support group and 2) who were unable to fulfill the role of learner, i.e., had cognitive limitations.

Fifty family caregivers were randomly assigned to an experimental group that received the program, or to a comparison group that was given an information flier on communication and memory. The intervention was conducted on a weekly basis over a five-week period to the experimental group and was conceived around fifty 'typical' activities-behaviours that frequently lead to communication difficulties for caregivers. Pre-post data were gathered on caregiver communication knowledge, perceptions of communication difficulties and degree of disturbance in regard to these difficulties, self-efficacy (related to communication skills), and communication skills. Measurement times were as follows for both groups: Time 1, one week prior to start of intervention; Time 2, one week after completion of intervention and Time 3, six weeks after completion of intervention.

The intervention resulted in statistically significant effects on three dependent variables: knowledge, degree of disturbance in regard to communication difficulties and self-efficacy. In comparison with individuals in the comparison group, participants who completed the program had become more knowledgeable and were less disturbed by communication difficulties at Time 2 and at Time 3. In regard to self-efficacy, the program resulted in significant effects at Time 3. No significant effects were observed in regard to the perceived presence of communication difficulties or in regard to communication skills.

Given that nurses are well placed in the health care system to facilitate learning opportunities for these persons, this communication program serves as a useful tool to better prepare these caregivers for their new role. Implications for nursing practice, education and research are proposed.

Key words: Caregiving, self-efficacy, Alzheimer's type dementia, geragogy, McGill Model, psycho-educational intervention

SOMMAIRE

Dans les premiers stades de la maladie d'Alzheimer, une préoccupation majeure pour le proche aidant concerne les difficultés de communication avec le parent malade. En réponse à ce problème, une intervention psycho-éducative, centrée sur la communication et basée sur le Modèle McGill, la théorie de l'efficacité personnelle et la gérontogogie a été développée et évaluée à l'aide d'un devis expérimental.

L'étude a été effectuée dans une région semi-urbaine. L'échantillon a été recruté via des cliniques de mémoire, une unité d'évaluation gériatrique et au sein de la communauté. Les critères d'inclusion des sujets étaient: 1) être l'aidant principal d'un parent-ami présentant un diagnostic de problèmes cognitifs associés au stade initial de la maladie d'Alzheimer, 2) être âgé de 55 ans ou plus et 3) être capable de communiquer en français ou en anglais. Les critères d'exclusion étaient : 1) de faire partie ou d'avoir récemment fait partie d'un groupe éducatif ou de soutien et 2) de présenter des difficultés cognitives limitant les possibilités d'apprentissage.

Cinquante proches aidants ont été assignés aléatoirement au groupe expérimental (programme psycho-éducatif) ou au groupe de comparaison (brochure d'information sur la communication et la mémoire). L'intervention expérimentale a été effectuée pendant cinq semaines à raison d'une rencontre par semaine et concernait cinquante activités ou comportements liés aux difficultés de communication. Des données ont été colligées sur les connaissances, la perception des aidants des difficultés de communication et leur degré de dérangement face à ces difficultés, l'efficacité personnelle et les habiletés de communication. Les temps de mesure ont été établis comme suit pour les deux groupes: Temps 1, une semaine avant le début de l'intervention; Temps 2, une semaine après l'intervention, et Temps 3, six semaines après l'intervention.

L'intervention a produit des effets statistiquement significatifs eu égard à trois des cinq variables dépendantes : les connaissances, le degré de dérangement face aux difficultés de communication et l'efficacité personnelle. Comparativement aux participants de groupe de comparaison, les sujets ayant complété le programme avaient davantage de connaissances et une perception moindre de dérangement face aux difficultés de communication aux temps 2 et 3. En ce qui concerne l'efficacité personnelle, un effet significatif du programme a été obtenu au T3. Aucun effet significatif n'a par ailleurs été observé sur les perceptions des difficultés de communication et les habiletés de communication des participants.

Ce programme psycho-éducatif est un outil novateur pour les infirmières, qui occupent une place stratégique dans le réseau de santé et qui doivent, dans une perspective de promotion de la santé, assurer la préparation de ces aidants afin qu'ils assument pleinement leur nouveau rôle. Des recommandations pour la pratique, la infirmière, la formation et la recherche sont proposées.

Mots clés : proche aidant, efficacité personnelle, intervention psycho-educative, programme de formation, démence, maladie de type Alzheimer, gérontogogie

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Knowing of Professor Ducharme's innovative and influential groundbreaking work in the field of family caregiving, I little expected that one day I would have the signal honour of being able to undertake doctoral studies under her supervision. The opportunity of working with a leader in her field proved to be more than an enriching experience. It was the occasion to appreciate at close hand the workings of a rigorous, dedicated and generous scientific mind. Demanding of herself, she expected no less of her students. Au cours de ma carrière d'infirmière exercée en bonne partie auprès d'une clientèle gériatrique, j'ai souvent eu l'occasion de consulter les travaux innovateurs de la Professeur Ducharme, portant sur les aidants naturels. Jamais n'aurais-je pû imaginer qu'un jour j'aurais l'honneur et le plaisir d'entreprendre des études de doctorat sous sa direction. L'opportunité de travailler avec une sommité de sa profession était plus qu'une expérience enrichissante, c'était l'occasion de voir à l'oeuvre une chercheure disciplinée, riguereuse et généreuse. Exigente envers elle-même, elle ne pouvait que demander autant de ses étudiants.

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Dedication

"They are able,

who think they are able."

Virgil

"A person who doubts himself

is like a man who would enlist the ranks of his enemies

and bear arms against himself.

He makes his failure certain

 by himself being the first person to be convinced of it."

attributed to **Alexandre Dumas**

(Ange Pitou)

Dedicated to my parents:

Zofia Misiag

and

Bronislaw Klodnicki

CHAPTER I

THE PROBLEM

Alzheimer's disease (AD), a dementia disorder that affects primarily older persons, is characterized by a progressive and generally irreversible cognitive deterioration, accompanied by extensive functional losses (Rockwood & MacKnight, 2001; Tranmer, Croxford & Coyte, 2003; Wilson, Beckett, Bennett, Albert & Evans, 1999). Given the projected two-fold increase in persons aged over 65, from 13% in 2001 to around 22% of the total population by 2031 (Health Canada, 2002), the number of persons afflicted with this disorder is also expected to double in this period, from 238,000 in 2001, to 509,000 in 2031 (Ibid). Moreover, in the elderly, the incidence of this disease increases progressively in an accelerated manner; from between 5 to 10% in those over 65, to around 20% in those over 80 (Canadian Study of Health and Aging Working Group, 1994; Jorm, in O'Brien, Ames & Burns, 2000). Considering that Alzheimer's disease represents two-thirds of all dementias (Canadian Study of Health and Aging Working Group, 1994), and is one of the most important determinants of institutionalization (Trottier, Martel, Houle et al., 2000), it is not surprising that this disease is portrayed as potentially one of the most costly public health problems of the next century (Kuhn & Mendes de Leon, 2001). Moreover, the long duration of AD, averaging eight to ten years, with some persons surviving up to twenty years (Mendez & Cummings, 2003; Thompson & Thompson, 2003), leaves caregivers with a very long time frame of caregiving challenges.

About one-half of individuals with Alzheimer's disease live in the community; most cared for by family caregivers (McDowell, Hill & Lindsay, 2001). The monetary costs of this care are well articulated. In a national workshop on research orientations of care for persons with AD (Chambers, Hendriks, Hall, et al., 2004), it was reported that average user hours of supplementary services for home-based elderly with dementia were almost double those of persons with either no cognitive impairment or those with cognitive impairment but no dementia (Shapiro & Tate, 1997, in Chambers et al., 2004). Moreover, the value of at-home dementia care represents about one-half of formal care costs (Hébert, 2000). Furthermore, it was put forth some 20 years ago, that if families were to withdraw their care at home, the need for care facilities would increase by about one-third (Commission d'Enquête sur la Santé et les Services Sociaux, 1987).

Dementia caregivers are especially vulnerable. In their seminal study, Ory, Yee, Tennstedt and Schultz (1999) reported that not only are these caregivers significantly *older* than non-dementia caregivers, but they provide care to persons significantly older than those cared for by non-dementia caregivers. Moreover, these caregivers also provide a significantly higher number of tasks (ADL's and IADL's), and significantly more hours of care than nondementia caregivers (Canadian Study of Health and Aging, 2002). In one recent study, it was reported that dementia caregivers provide, on average, 63 hours of care per month (Chambers et al., 2004).

These care providers are also at greater risk for *health* problems and are in poorer health than younger caregivers (Ory et al., 1999; Schulz & Martine, 2004). In a meta-analysis on the health of caregivers, Pinquart & Sörensen (2003) reported larger differences in physical health between dementia caregivers and noncaregivers than between heterogeneous samples of caregivers and noncaregivers. Dementia caregivers also report significantly higher burden and depression than non-dementia caregivers (Canadian Study of Health and Aging Working Group, 2002; Clyburn, Stones, Hadjistavropoulos & Tuokko, 2000). In one expansive study, at-home dementia caregivers reported that over time they experienced significant increases in depression and health problems. In contrast, after the family member was admitted to a care facility, significant decreases occurred over time on these variables (McDowell, Hill & Lindsay, 2001).

Even those in the *early* caregiving stage report a wide range of health problems (Kuhn, 1998; Morhardt, Sherrell, Groo, et al., 2003). Moreover, they also experience an adverse impact on social and leisure activities (Logiudice, Waltrowicz, Brown, et al., 1999; Seltzer & Li, 2000) and report feeling isolated from friends and networks (Morhardt, Sherrell & Groo, 2003). These *new* primarily *older* dementia care providers devote many hours caring for their family member – about 22 hours per week in the earlier stages of the disease, according to one early study (Canadian Study on Health and Aging Working Group, 1994). This caregiving portrait underlines a need for relevant interventions for caregivers, and moreover, underscores that such assistance should be available from the very *beginning* of their caregiving 'career'.

However, despite the proliferation of caregiving intervention studies, very few interventions of a psycho-educational nature have been developed for the *new* older caregiver in the dementia context, even though the need for such interventions is well articulated (Kuhn & Fulton, 2004; Kuhn, King & Fulton, 2005). To date, the great majority of caregiving interventions have targeted the mid to later phases of the disease (Hepburn, Tornatore, Center & Ostwald, 2001; Kuhn & Fulton, 2004; Ory, Yee, Tennstedt & Schultz, 2000; Whitlatch, Judge, Zarit & Femia, 2006), or have not specified the particular stage of the illness (Marriott, Donaldson, Tarrier, Burns et al., 2000; Quayhagen, Quayhagen, Corbeil, Hendrix et al., 2000). Moreover, the results of the caregiving intervention literature in this context generally are not encouraging (see meta-analysis, Sörensen, Pinquart, Habil & Duberstein, 2002; Zarit & Leitsch, 2001). In a systematic review of interventions for dementia caregivers, minimal significant outcomes were found (Peacock & Forbes, 2003), and few significant effects were identified in an expansive review (n = 73 studies) of nursing and non-nursing dementia caregiving intervention studies, in particular for global outcomes such as burden and depression (Acton & Winter, 2002).

One reason for these poor results may be related to the mode through which these interventions are delivered; i.e., an overwhelming preference exists for conducting interventions within a group versus individual approach, even though the greater benefits of the individualized approach are well articulated (Gitlin, Burgio, Mahoney, Burns et al., 2003). For example, even in early reported studies, caregivers of elderly parents made greater gains in psychological functioning and well being when they received individual counselling than when counselling was conducted in a group (Toseland, Rossiter, Peak & Smith, 1990; Toseland & Smith, 1990). In a later study, with an individually oriented nursing psycho-educational intervention, caregivers of older persons with primarily dementia diagnoses reported a statistically significant reduction in negative responses to the care recipients' problematic behaviours; which was not found in the comparison group (Gerdner, Buckwalter & Reed, 2002). Recently, in an expansive meta-analysis, interventions delivered via an individualized mode were more effective than those conducted in groups (Livingston, Johnston, Katona, Paton et al., 2005).

Another reason for poor outcomes in caregiving interventions may be related to the mismatch between intervention and outcome measure; that is, an inappropriate selection of outcome measures for the particular intervention. More particularly, outcome measures that are sensitive to change in the long term, such as psychological distress or burden, often are used inappropriately as proximal outcome measures for interventions unlikely to lead to change on these variables in the short term (Bourgeois, Schulz & Burgio, 1996; Zarit & Leitsch, 2001; Zarit & Femia, 2008).

Within the vast realm of potential intervention and outcome variables depicted in the literature, a psychological construct that is receiving increasing attention in the health care domain as a fundamental influential variable for both behaviour and thought is *self-efficacy*. Self-efficacy is concerned with the *belief* that one can perform a specific behaviour or task or modify one's thinking, rather than with the actual capacity to carry out the task. Self-efficacy also determines whether one will even attempt to perform a task, and how persistent one will be when difficulties are encountered (Bandura, 1986; 1997). The predictive attributes of self-efficacy in terms of *behavioural* outcomes are reported increasingly in the health related literature as well as in the aging related domain. In a review of self-efficacy and health behaviour, Hevey and colleagues found that self-efficacy was a fundamental variable in predicting health behaviours (see review, Hevey, Smith & McGee, 1998), and in their review, Martin & Sinden (2001) reported that exercise self-efficacy predicted older adults' adherence to exercise activity. More recently, Ducharme and her colleagues reported that in older husbands, self-efficacy predicted successful outcomes for self-perceived health (Ducharme, Lévesque, Zarit, Lachance et Giroux, 2007b).

Concomitantly, early evidence has suggested that dementia caregivers may be lacking in self-efficacy in regard to their caregiving abilities. In a grounded theory study, Szabo & Strang (1999) reported that a prevailing theme expressed by primarily older caregivers, was "*not believing* in their own *abilities* to manage as caregivers" (p.73). In their meta-analysis, Pinquart and Sörenson (2003) reported that caregivers had lower levels of self-efficacy than noncaregivers. Although presently there is a growing interest in self-efficacy in the caregiving literature (Ducharme et al., 2007a, 2007b; Etkin, 2006; Rabinowitz, 2006), at the time of conception of this study, self-efficacy had received little attention in regard to caregiving (DiBartolo, 2002).

While it is well substantiated that self-efficacy is a key determinant of successful performance or *behaviour*, perceptions of self capabilities for a particular behaviour-task are contingent upon having the relevant *knowledge* and *skills* for that task (Bandura, 1977; 1997). Knowledge and skills thus serve as antecedents, in part, to behaviour change. Once the individual has the requisite knowledge-skills base, the strength of his/her self-efficacy in regard to carrying out or applying particular skills or actions will determine the likelihood of success. Given this foundational role of knowledge and skills within the self-efficacy framework, it is noteworthy that dementia caregivers appear to lack both the necessary knowledge and skills to carry out their role. For example, in one early dated study ($n = 88$), the strongest area of dissatisfaction in *older* caregivers was in not being adequately prepared for providing care to their relatives at home (Haley, Clair & Saulsberry, 1992). In a subsequent survey study conducted with randomly selected older persons ($N = 527$), widespread misconceptions about AD were reported by these persons (Edwards, Cherry and Peterson, 2000). More recently, pre-intervention assessment of knowledge about AD revealed that caregivers were greatly lacking on this subject (Kuhn & Fulton, 2004).

In another study that explored caregiver needs in *early* Alzheimer's disease (AD), these care providers reported a lack of understanding of the disorder; and almost one-half stated that they knew nothing about AD at time of diagnosis (Kuhn, 1998). In particular, Kuhn (1998) reported that these *new* caregivers identified the *communication* domain as a principal preoccupation; a subject also identified as a major concern by dementia caregivers in the *initial* disease context in a much earlier investigation (Kinney & Stephens, 1989). Even more noteworthy, caregivers who had received *communication skills* training at a later time in their 'career', submitted that it would have been more useful to have learned these skills at an *earlier* time, as it would have helped them to resolve *communication* problems with the care receiver from the outset of the illness (Done & Thomas, 2001). This perspective was upheld in a recent randomized controlled trial wherein caregivers identified education about communication as one of the most important subjects (Martin-Cook, Davis, Hynan et al., 2005). However, in spite of the importance of this subject, little research has been conducted in response to the communication problems experienced by caregivers in the *early* dementia phase (Hendryx-Bedalov, 1999; Kuhn & Fulton, 2004).

Within the perspective of self-efficacy development, underpinned by a relevant knowledge base, several strategies have been shown to strengthen self-efficacy in regard to skills-tasks. These include successfully performing a task, observing others successfully model a task, being persuaded that one can perform a task, and receiving help-support to reduce fears or anxieties (Bandura, 1986; 1997). According to self-efficacy theory, when a learning program for new dementia caregivers is accompanied by such strategies, there is greater likelihood of success for implementing the newly learned skills. An approach that employs such educational and psychological dimensions is termed as being *psycho-educational* in nature.

Having identified the *communication* domain as being problematic for *early* stage dementia caregivers, and an area in which they lack knowledge and skills, it is noteworthy that an abundance of specific and well articulated *communication*-related 'behaviours' which typify the *early* dementia stage, with the potential of leading to communication difficulties, are well elucidated in the literature (Bayles, 2001; Caramelli, Mansur & Nitrini, 1998; Maxim & Bryan, in Bryan & Maxim, 2006; Reisberg, Ferris, de Leon & Crook, 1988; Rockwood & MacKnight, 2001). This data base greatly facilitates the conception of skills related learning strategies within a *self-efficacy* framework.

While a number of interventions have been developed to help caregivers deal with *communication* related difficulties in the overall dementia context (Barnes, 2006; Bayles & Tomoeda, 1995; Hopper, 2001; Kuhn, Fulton & Edelman, 2003; McCallion, Toseland & Freeman, 1999; Ripich, 1994; Tomoeda & Bayles, 1990), and more recently, for the early stage (Kuhn & Fulton, 2004), none were located that had used a communication-focused *self-efficacy* framework to guide a skills learning intervention for caregivers who were just starting in this role. Furthermore, no well-developed *measures* of self-efficacy in regard to the domain of communication skills were located.

Given the nature of the role of *self-efficacy* in psycho-educational interventions with a skills learning orientation, and considering that this construct has not been explored adequately in the dementia caregiving context in regard to *communication*, and that it has not been examined at all in relation to communication in the *early* dementia phase, (wherein communication related problems have been reported to be highly disturbing to caregivers), the study of self-efficacy in this context warrants further investigation. In response to these considerations, this study was concerned with developing and testing a nursing psycho-educational intervention focused on caregiver knowledge and skills acquisition and self-efficacy development in regard to caregiver communication skills.

Given that nurses play a key role in facilitating *learning* opportunities for families and individuals to help them to deal more effectively with their health related problems, a relevant nursing framework to guide this study, wherein *learning* plays a key role, is the McGill model (Allen, 1982). It is noteworthy that the underpinnings of the McGill model emanate largely from social learning theory, which also serves as the foundation for social cognitive theory upon which self-efficacy is founded. Learning serves as a 'bridge' between the principal concepts of the McGill model; and since the role of nursing in the model is to structure and 'tailor' appropriate learning situations for clients in collaborative partnerships, this perspective was coherent with the individualized nature of the intervention carried out in this study.

Purpose of the Study

The purpose of this study was two-fold: first, to develop a psycho-educational nursing intervention focused on communication for the caregiver of an individual with cognitive problems associated with the early stage of Alzheimer's disease; and second, to test the effects of this intervention on selected proximal dependent variables related to communication, that is, caregiver communication knowledge, extent of communication difficulties and degree of caregiver disturbance in regard to these difficulties, caregiver self-efficacy related to communication skills and caregiver communication skills.

CHAPTER II.

LITERATURE REVIEW
AND
THEORETICAL FRAMEWORK

This chapter addresses the empirical and theoretical foundations for the development and evaluation of a nursing intervention conceived for the dementia caregiver, focused on communication in early stage Alzheimer's disease (AD). The first section deals with the empirical evidence that underscores the principal dimensions of the intervention program and encompasses the current state of evidence on caregiving with a particular focus on communication in the early AD context. The second section addresses the theoretical perspective, and includes the nursing conceptual framework, i.e., the McGill Model, self-efficacy theory (underpinned by social cognitive theory) which guides the particular psycho-educational strategies of the intervention, and geragogy – the learning framework for the older learner, complemented by the pedagogical orientation of constructivism.

Literature Review

The review of the literature will address first, the current state of evidence in the scientific writings on caregiving. An overview of the context of early stage Alzheimer's disease follows, in conjunction with the needs and concerns of caregivers in relation to the communication dimension. In particular, the impact of such a dementia disorder on the care receiver's communication abilities and the repercussions of these limitations on the caregiver are addressed, and most especially on how the caregiver perceives these communication difficulties.

In this perspective, caregiver shortcomings related to knowledge, self-efficacy and skills pertinent to communication in this early stage of dementia are presented. Last, the caregiving literature in relation to the role of self-efficacy in communication, along with the measurement of this construct is examined.

Limitations of Caregiving Intervention Research

The vulnerable status of elderly family caregivers in the dementia context, along with a concomitant need for relevant interventions, was articulated in the first chapter. In particular, the paucity of interventions was underscored in relation to communication related difficulties and concerns of caregivers in the context of the *early* stage of a dementia disorder. In regard to the overall status of caregiving intervention research, Zarit & Leitsch (2001) have noted that while the number of studies concerned with such initiatives has been constantly on the rise, there has been minimal evidence of a related increase in the effectiveness of these initiatives. Moreover, they have underlined that caregiver interventions of a social and behavioural nature, while for the most part are well designed and conducted in a competent manner, tend to lead to only 'moderate' effects. The following meta-analyses and systematic reviews on caregiving attest to this viewpoint.

In one such meta-analysis, Acton & Kang (2001) reported that minimal effects of caregiver interventions were found in regard to burden. Similarly, Yin and colleagues, in a meta-analysis undertaken to assess the effectiveness of group and individual interventions on burden of caregivers of the frail elderly, reported that the evidence was 'inconclusive' (Yin, Zhou & Bashford, 2002). Moreover, they underscored the need for further research, most especially for experimental studies of large scale and high quality design to produce more definitive conclusions.

Other shortcomings of dementia-related interventions were found in a review of nursing and non-nursing caregiver intervention studies ($n = 73$) in the dementia context (Acton & Winter, 2002), wherein little supportive evidence was found to indicate that such programs lead to positive effects for the caregiver; and in particular in regard to global outcomes such as burden and depression (among others). Similarly, in a systematic review of interventions conceived to enhance the well being of dementia caregivers, few significant effects were found to result from these interventions (Peacock & Forbes, 2003).

In a recent expansive meta-analysis of dementia caregiving studies ($n = 127$), Pinquart and Sörensen (2006), were somewhat more encouraging although the authors cautionned the reader. They reported that interventions for dementia caregivers had, on average, 'small but meaningful' effects on reducing burden and depressive symptoms, and on increasing ability, knowledge and subjective well-being; and for a subset of interventions, reducing the risk for institutionalization. They also underlined, that given the small magnitude of change, the need still remained to improve the quality of interventions. In another recent systematic review focused on randomized trials, it was reported that no evidence was found for the effectiveness of interventions on a range of physical and psychological health outcomes with the exception of a 'tentative' positive impact on physical morbidity (Thompson, Spilsbury, Hall, Birks et al., 2007). In their large scale systematic review of psychological approaches in the management of neuropsychiatric symptoms of dementia ($n = 162$ studies - reduced from 1,632); in the nineteen studies focused on caregivers, Livingston and colleagues stated that they could only grade these caregiver interventions at a level 'D', (i.e., 'a level of evidence of 5 or troublingly inconsistent or inconclusive' (Livingston, Johnston, Katona, Paton et al., 2005).

While the aforementioned findings are disconcerting, there are indications in the literature that suggest that targeting the *earlier* stage of dementia may be related to certain benefits for the caregiver. Such findings are reported even in earlier studies. Farran and Keane-Hagarty (1994), in a quasi-experiment with caregivers ($n = 139$) assigned to educational support, support, and control groups, reported that greater benefits were found during the *early* stage of dementia; and in a review of psycho-social and behavioural interventions for AD patients and their families, Beck (1998) reported that in spite of a lack of rigorous testing, these interventions appeared to be more effective in the *early* (and middle) stages of dementia. In a randomized trial wherein family caregivers of individuals with *mild* cognitive impairment benefited from an intervention that included counselling and education, a significant improvement was found in the area of social interaction ($p < 0.01$) at 6 months, and at 12 months ($p < 0.05$) (Logiudice, et al., 1999).

Interventions with an *educational* focus appear to provide certain benefits to caregivers in the early AD context. *Early* stage dementia caregivers who were provided with group education and training (while their care receivers had 4 hours of weekly respite care), experienced a significant decrease in hostility, and improved communication and interaction with the care receiver (Quayhagen et al., 2000). Moreover, 90% of caregivers stated that the intervention program was of value. The outcomes of two other group educational interventions for relatives of persons in *early* stage AD included significantly increased caregiver knowledge about the disease, and slight improvements in caregiver reactions to patients' impairments (Kuhn & Mendes de Leon, 2001); and in a subsequent study, significant increases in knowledge about AD and significant decreases in the degree of caregiver upset were identified (Kuhn & Fulton, 2004). While a significant decrease in self-efficacy was also reported in the latter study, the format of the measure (a 5-point Likert scale) rendered this result suspect.

The results of another nurse-guided study wherein *early* stage dementia caregivers were provided with individualized support and advice, liaison and networking, and training and information (including information on the diagnosis, and 'learning to live with dementia'), a 'notable' improvement in psychological health was identified after six contacts. Most caregivers also stated that they valued having someone they trusted – i.e., the nurse, with whom to discuss problems, receive professional help, and to get information (Clark, Chaston & Clarke, 2003). Livingston and colleagues (2005), in their expansive review, reported that while they could only arrive at limited conclusions about these studies, certain types of psycho-educational programs focused on *teaching* caregivers how to change their interactions with persons with dementia (i.e., managing neuropsychiatric symptoms) were effective. Last, in a feasibility study that used a structured 'Early Diagnosis Dyadic Intervention' (EDDI) with 31 *early* stage dementia dyads, a number of favourable outcomes were identified, including increased knowledge about memory loss and appropriate services, and an overall satisfaction with the program (Whitlatch, Hudge, Zarit & Femia, 2006).

In summary, while this overview encompasses a great diversity of investigations (e.g., psychosocial, behavioural, educational, 'supportive', counselling, etc.), wherein the majority were conducted in groups, and while there are certain indications that dementia caregivers may be deriving some benefits from these initiatives in the *early* dementia stage of caregiving, only a few significant improvements are noted; i.e., reduced caregiver upset (Kuhn & Fulton, 2004); increased knowledge (Kuhn & Fulton, 2004; Kuhn & Mendes de Leon, 2001), and decreased hostility (Quayhagen et al., 2000). Other outcomes, while encouraging, are generally less definitive; i.e., improvements in distress (Clark, et al., 2003), slight improvements in caregiver reactions to patients' impairments (Kuhn & Mendes de Leon, 2001), improved communication and interaction between caregiver and care receiver (Quayhagen et al., 2000), and increased knowledge about memory loss and appropriate services (Whitlatch et al., 2006).

Potential Reasons for the Limited Effects of Caregiving Intervention Research

A number of possible reasons are offered for the limited effects of caregiving research. One such reason may be related to the nature of outcome measures and the degree to which outcomes bear a relationship to the type of the intervention or 'treatment' (Bourgeois, et al., 1996; Zarit & Femia, 2008). Outcome measures need to accurately reflect the focus of the intervention. For example, if the intervention is concerned with learning a skill, then outcome measures should address the impact of this learning, i.e., evaluation of the acquired skills. However, even when such relationships between intervention and outcome do exist, oftentimes measures are administered inappropriately from a timeline perspective; e.g., outcomes that tend *not* to be sensitive to change in the *short term*, such as depression or psychological distress, are all too often measured in terms of a short term or *proximal* outcome, rather than from the more appropriate *distal* perspective (Acton & Winter, 2002; Brodaty, Green & Koschera, 2003; Zarit & Leitsch, 2001).

To illustrate, while it is generally recognized that providing information to, or educating caregivers will likely help them to acquire a better understanding of the nature and implications of the disorder, and in turn assist them with certain caregiving tasks in the short term, there might be no short-term impact on such global outcomes as psychological distress or depression (Zarit & Leitsch, 2001; Bourgeois et al., 1996).

Another explanation for the overall poor outcomes in caregiving intervention research may be related to the *delivery mode* of these programs; that is, a *group* versus an *individualized* approach. As evidenced in the preceding discussion, by far the great majority of caregiving interventions are conducted in a group format. However, the benefits of the individualized approach are well articulated, as elucidated in the following three meta-analyses in the *general aging* literature.

In the first one, 28 psychotherapeutic treatments (n = 17 studies) for depressed, older individuals (n = 732, mean age = 68), revealed a higher mean effect size (d = .63) for *individual* therapies than for those delivered within a group format (z = 3.74, p = .00, n = 27) (Engels & Vermey, 1997). In another meta-analysis (n = 22 studies) of 'psychotherapeutic' and other psychosocial interventions for older persons, individual ones were more effective than those actualized in groups with respect to psychological well being (i.e., life satisfaction, self-esteem, happiness, loneliness) (Pinquart & Sörensen, 2001). In a third meta-analysis of community outreach programs for depressed elders, a larger participant dropout rate was reported in studies with a group approach (B = 0.36; SE = 0.06) than in those with an individualized focus (Cuijpers, 1998). In the *caregiving* literature, similar findings have been identified since some time. In an early dated meta-analytic review of 18 caregiver studies (with control groups) with diverse psycho-social interventions, greater reductions in anxiety, hostility, subjective burden, and other measures of negative affect were reported for interventions conducted in an individualized perspective, than when conducted in groups (Knight, Lutzky and Makofsky-Urban, 1993).

In a subsequent meta-analysis in regard to the effects of group and individual interventions on burden of caregivers of frail elderly, Yin and colleagues reported a higher effect size for individual interventions in comparison with group interventions (Yin, Zhou & Bashford, 2002). More recently, in a systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia (n = 162 studies, out of a potential 1,632 investigations that met the inclusion criteria for the review), it was found that 'psychoeducation intended to change caregivers' behaviour was found to be more effective when delivered in individual rather than group settings (Livingston et al., 2005).

The *nursing caregiving* literature upholds these findings. As already reported, Clark and colleagues (2003) carried out an individualized intervention (encompassing training, information-advice and support) with favourable results. In another nursing study, caregivers (n = 132) of older family members (principally with Alzheimer's disease), who received a psycho-educational intervention with an *individualized* care plan as the central component, reported a statistically significant reduction in adverse responses to the care recipients' problematic behaviours, whereas no such improvement was noted in the comparison group (Gerdner, et al., 2002).

In another earlier nurse-directed study (albeit with no comparison group), *individualized* problem-solving counselling to caregivers of cognitively impaired relatives was particularly helpful to caregivers with poor logical analysis coping skills. After one year, outcomes included improved psychosocial adjustment ($F(1,53)$ = 4.7; p = .035) and decreased psychological distress ($F(1,53)$ = 9.7; p = .003) (Roberts, Browne, Milne, Spooner et al., 1999). Last, albeit in a very early investigation, caregivers participating in a group intervention 'expressed a preference for an *individualized* approach'. That is, caregivers posited that the group intervention did not allow the time they needed at each meeting to ventilate and share their feelings, thus "some participants resented this and dropped out" (Priddy & Gallagher, 1984).

A number of reasons underscore the strengths of the *individualized* approach. First, the needs of the participant can be better identified in an approach that singles out the individual, allowing the intervention to be 'tailored' to his/her needs. The individualized approach also offers a higher degree of intensity because the intervention is directed at one individual at a time. Moreover, without the distracters of other persons, the participant is able to attend more fully to the program components. The individual also has more opportunities to ask questions, and to clarify and discuss issues with the professional. This one-on-one contact greatly increases the 'dosage' of the intervention, and therefore has the potential of reducing the number of meetings or contacts between the participant and professional-animator, in contrast with a group oriented strategy wherein the dosage is more 'diluted' for each individual, thus calling for a larger number of 'sessions'.

Alzheimer's disease: A Focus on the Early Stage

Alzheimer's disease (AD) is defined as a dementia syndrome that has a gradual onset and continuing cognitive decline (Maxim & Bryan, in Bryan & Maxim, 2006; Rockwood & MacKnight, 2001). The progressive impairments of this syndrome, accompanied by generally increasing care demands for the caregiver, are denoted by several phases (albeit with non-distinct boundaries and much inter-individual variability) (Kraemer, Tinklenberg & Yesavage, 1994; Maxim & Bryan, in Bryan & Maxim, 2006; Schwartz, 1990; Rockwood & MacKnight, 2001). These stages are referred to as early stage or mild dementia; mid stage or moderate dementia; and later stage or severe dementia (Morris, 1996; Reisberg & Ferris, 1988; Rockwood & MacKnight, 2001). Since the demands of the caregiving role can be expected to change with the evolution of the disease (Pearlin, 1992), and given that Alzheimer's disease is progressive in nature, the aims and contents of interventions also require adjustments to the changing needs of the caregiving context (Charlesworth, 2001; Pinquart and Sörensen, 2006).

Concomitantly, it must also be ascertained as to which interventions are most useful at particular stages of dementia (see systematic review, Peacock and Forbes, 2003; Bourgeois et al., 1996). Thus, an important aspect of caregiving interventions in AD is concerned with the 'timing' or the particular phase of the care receiver's dementia illness (Montgomery & Kosloski, 1994; Whitlatch et al., 2006).

Although the majority of dementia caregiving interventions to date have targeted either mid to later phases of the disease (Kuhn & Fulton, 2004; Kuhn, 1998; Ory et al.; 2000; Ostwald, Hepburn, Caron, Burns et al., 1999; Perren, Schmid & Wettstein, 2006; Whittlatch, Feinberg & Tuck, 2005), or the intervention has not focused on a particular stage of the illness (Belle, Burgio, Burns, Coon et al., 2006; Forbes, 1998; Quayhagen et al., 2000), interventions focused on the *early* caregiving stage have received little attention (Kuhn & Fulton, 2004). Among the *early* stage dementia intervention studies reported in the literature, the majority have targeted either the care receiver (i.e., the person with the disorder) (Goldsilver & Gruneir, 2001; Keady & Nolan, 1995a; 1995b; Trabert, 1996; Yale, 1999), or have included both the caregiver and care receiver (Chu, Edwards, Levin & Thomson, 2000; Clare, 2000, cited in Clare 2002a; 2002b; Cummings, 1996; Logsdon, McCurry & Teri, 2006; Moniz-Cook, Agar, Gibson, Win et al., 1998; Snyder, Quayhagen, Shepherd & Bower, 1995; Whitlatch et al., 2006; Zarit, Femia Watson, Rice-Oeschger et al., 2004). Few studies have focused primarily on the problems and concerns of the caregiver in the *earlier* stage of dementia (Hepburn, Tornatore, Center & Ostwald, 2001; Kuhn, 2003; Ory et al., 2000; Whitlatch et al., 2006).

The *early* stage of Alzheimer's disease – characterized by 'mild dementia' – is generally accorded a duration of about two years (Reisberg & Ferris, 1988); however oftentimes this 'initial' phase can last for a much longer time period (Mendez & Cummings, 2003). Considering that the evolution of this disorder can cover a time span of some 10 or more years (Thompson and Thompson, 2003), the *'early'* AD stage represents a significant portion of the overall illness trajectory.

Although there is great variability between persons in terms of symptomology in the initial stage (Maxim & Bryan, in Bryan & Maxim, 2006), nonetheless a great potential exists for the caregiver to be confronted with major challenges in the face of the changes being experienced by the family member in this early time of the disorder. For example, among the deficits that occur in the initial AD phase are included periodic and increasing memory limitations, and other cognitive deficits such as language disturbances, inability to recognize familiar things, or difficulty with activities requiring abstract thinking, problem solving or planning functions (American Psychiatric Association, 2000).

Communication: Early Stage Dementia Caregiving

Perceptions and Concerns of Early Stage Dementia Caregivers

An important concern for the dementia caregiver is related to communication; a problem area identified since many years (Barnes, 2006; Kuhn, 1998; Martin-Cook, Davis, Hynan & Weiner, 2005; Nolan, Ingram, & Watson, 2002; Small, Geldart & Gutman, 2000; Small, Kemper & Lyons, 1997; Small, Perry & Lewis, 2005; Orange, 2001; Santo Pietro, 1994). Even in early-dated publications, this domain has been highlighted as disturbing to the caregiver, i.e., communication breakdown between caregiver and family member was identified as highly problematic by Gilleard (1984). Subsequently, Cummings (1996) found that caregivers reported the dissolution of former communication patterns in the family member as especially disturbing. The need for education on this subject has also been well articulated (Barnes, 2006; Small, Geldart & Gutman, 2000; Small et al., 2005; Whitlatch et al., 2006). In a recent randomized controlled trial study of an Alzheimer caregiver supportive skills training program, caregivers identified education about communication as being among the most valued subjects of the multi-topic program (Martin-Cook et al., 2005).

In the *early* dementia context, while the literature is not abundant, concerns and difficulties experienced by these caregivers in relation to communication have been identified in a number of studies over the years. Some two decades ago, Kinney and Stephens (1989) reported that caregivers targeted this domain as an important concern, and in another older investigation, caregivers at all stages of the disease (including the early stage) identified communication as problematic, stating that communication problems adversely affected the quality of their relationship (Orange, 1991, in Small, Geldart & Gutman, 2000). In still another early dated study, Cummings and colleagues noted that communication related disturbances were accompanied by an emotive perspective, i.e., caregivers said that they were disturbed when their family member ignored their feelings, didn't appreciate their help, and when the family member didn't try hard enough at particular tasks – occasions with a high likelihood of leading to major communication difficulties (Cummings, Pettersen-Hazen, Harrison & Van Tuyl, 1993).

In an early exploratory study focused on the primary domains of communicative function, Orange (1991) reported that communication problems identified by early stage caregivers were related to their family members having trouble finishing sentences, putting thoughts into words, not initiating conversations, displaying lengthy hesitations in speech, and introducing statements that were unrelated to the conversation. Subsequently, Cummings (1996) reported that early stage dementia caregivers were disturbed because their family members were not able to interact with them 'as before'. In another exploratory study conceived to determine the needs of caregivers in the early dementia context, caregivers were disturbed by their family member's communication related difficulties such as language problems, memory-related deficits (e.g., forgetfulness, misplacing things and repetitiveness speech), and problems related to concentration and disorientation, (Kuhn, 1998). Cummings and her colleagues reported that spouse caregivers in early stage dementia were disturbed by the increased silence and decreased responsiveness of their family members and spoke of their painful adjustment to these deficits; this viewpoint being related to the affective perspective (Cummings, Long, Peterson-Hazan & Harrison, 1998).

Kuhn (2003a) illustrated a number of communication difficulties experienced by caregivers (and care receivers) in the early AD stage. In one situation, the caregiver stated that he felt bewildered with his wife's inability to recognize problems with memory, judgement and language. He tried to 'make her remember things' and 'often pointed out errors in her logic'. This would result in a hostile reaction on the part of the care receiver and the relationship began to deteriorate.

In summary, these early stage caregivers were disturbed by a diverse range of communication related limitations in their family members, many of which were accompanied by affective changes and emotional lability in the care receiver.

*Caregiver Knowledge and Skills related to Communication in **Early** Stage Dementia*

It is well articulated in the dementia literature that a lack of knowledge and skills represents a major concern for caregivers (Ayalon & Arean, 2004; Kuhn, King & Fulton, 2005; Werner, 2001). In an older dementia study, caregivers said that their most important need was for education about the disorder (Fortinsky & Hathaway, 1990). In an exploratory study in the *early* dementia context, caregivers stated that the lack of knowledge about the relevant dementia disorder was most upsetting for them (Boise, Morgan, Kaye & Camicioli, 1999). Montgomery and Koslowski (1994) reported that caregivers in the *earlier* (versus later) AD phase expressed a greater need for information about a wide range of dementia related subjects. It has also been posited that in order for *new* caregivers to be able to deal with their concerns relevant to Alzheimer's disease, they must first accept the illness in terms of the diagnosis and prognosis. However, in order to do so they must be *knowledgeable* about and *understand* the progressive and degenerative nature of the disorder, and how it affects the care receiver in terms of such *communication* related dimensions as memory, judgement and insight, and the emotive or affective aspect (Cummings et al., 1998; Kuhn, 2003b; Lindgren, 1993; Small et al., 2000).

A lack of caregiver knowledge and skills about *communication* related areas (often depicted as *learning needs*), has been identified in several investigations in the *early* dementia context, and more recently by Kuhn and Fulton (2004). In an early dated exploratory study, Orange (1991) reported that early stage caregivers *lacked understanding* about why the family member was not communicating as before. In a later study, early stage dementia caregivers *sought out advice* on *how* to deal with communication difficulties (i.e., knowhow-skills) related to the cognitive deficits of their family member (Hill, O'Brien, Morant & Levy, 1995). Subsequently, Kuhn (1998) reported that caregivers desired *to learn* about the interpersonal aspects of the disease, and especially about *communication techniques* (i.e., skills), and *how* to develop an empathetic approach with their family member. Arguelles, Loewenstein, Eisdorfer & Arguelles (2001) reported that caregivers ($n = 128$) exhibited an apparent lack of knowledge when they overestimated the performance of their family members for such activities as telling time, counting money, etc.; these misperceptions having the potential to result in communication problems.

A particularly relevant point of view was put forth by caregivers who had received communication skills training at a later time in their 'career', and who reported that it would have been more useful to have *learned* these skills at an *earlier* time, as it would have helped them to resolve communication problems with the care receiver at the outset of assuming this role (i.e., in the early stages of the illness) (Done & Thomas, 2001). A similar perspective was reported by Cahill and Shapiro (1997) in which caregivers of dementia patients stated that they would have cared for their family member in a different manner had they been *better informed*. Furthermore, in the 'mild to moderate' dementia context, a positive correlation was identified between caregivers' *knowledge* of dementia and their perceptions of caregiving competence (Graham, Ballard & Sham, 1997a; 1997b). Last, caregivers were 'surprised' at the communication related difficulties that their family members were experiencing, and did not realize that these difficulties were related to their cognitive limitations (Small & Perry, 2005).

Despite the critical role of *communication* in the *early* dementia caregiving context, minimal research has been conducted in response to the communication related difficulties experienced by caregivers at this time in the disorder (Hendryx-Bedalov, 1999; Kuhn 2003b; Kuhn, Fulton & Edelman, 2003; Whitlatch et al., 2006). In order to ground the communication related concerns and perceptions of caregivers of individuals with early stage Alzheimer's within an evidence-based perspective, a more detailed examination of the research literature is submitted henceforth. In turn, these scientific findings provide a more solid foundation upon which to formulate an evidence-based intervention program in response to the communication related challenges with which the early caregiver is faced.

*Communication: Problematic Areas in **Early Stage** Alzheimer's disease*

The communication domain in early Alzheimer's disease (AD) is depicted by problems of verbal and nonverbal *comprehension*, language *production* (oral and written) – including conversational abilities (Bayles, 2001; Small et al., 2005), as well as problems related to the *emotive* or *affective* dimension (e.g., anosognosia) (Clare, 2002a; 2002b; Derouesne, Thibault, Lagha-Pierucci, Baudoin et al., 1999). In large part, these difficulties result from the effects of AD on the cognitive domains of memory, attention and perception, and from the related behavioural changes (Caramelli, Mansur & Nitrini, 1998; Maxim & Bryan, in Bryan & Maxim, 2006; Sabat, 2006; Small et al., 2005).

Thus, this literature review will focus first on how *memory* and *attentional* deficits affect communication abilities, these being the first notable impairments in early Alzheimer's disease (Albert, 1996; Caramelli, et al., 1998; De Vreese, Neri, Fioravante, Belloi et al., 2001; Hopper, Bayles & Kim, 2001; Maxim & Bryan, in Bryan & Maxim, 2006), and subsequently the domain of verbal and nonverbal communication will be examined, while recognizing the overlaps that exist between all these areas.

Memory

Memory impairment is frequently the presenting and prominent symptom in Alzheimer's disease (Bayles, 2003). Memory systems are generally categorized as *declarative, nondeclarative* and *working* memory (Bayles, 2001). Declarative and nondeclarative memory systems conjointly make up what is typically referred to as *long term* memory (Frank, 1994), whereas working memory (a sort of short-term memory system which includes executive functions and systems concerned with visual functioning and language acquisition), operates in the *immediate* present (Baddeley, 1989, cited in Bayles, 2001).

Declarative Memory

Declarative or explicit memory encompasses consciously learned, fact-based (rather than action-based) knowledge (Tulving, 1972, 1983, cited in Azuma & Bayles, 1997). Declarative memory, concerned with remembering the 'what' or 'who' (e.g., the name of one's piano teacher at an early age or what one ate this morning), is more affected in the early AD stage (especially for recent events) than nondeclarative memory; the latter concerned with remembering 'how' to do something (e.g., how to read or how to play the piano) (Costa, Williams, Albert, Butters, Folstein, et al., 1996).

The three forms of declarative memory include *episodic* memory (memory for events and periods of time in our lives), *semantic* memory (memory for facts about our world), and *lexical* memory (memory for words and the rules for their use) (Bayles, 2001); lexical memory oftentimes being included within the domain of semantic memory (see review, Nebes, 1989).

Episodic memory, a type of declarative memory that deals with the acquisition of new or recent information, is an autobiographical record of unique events in an individual's experiences in relation to a particular spatial-temporal context (a specific time and place of a person's life) (Bayles, 1991, 2001; Kindell & Griffiths, in Bryan & Maxim, 2006; see review Nebes, 1989). Typically, individuals in early AD begin to have difficulties in learning new information and retaining it for more than short periods of time (Bayles, 2001; Duchek, Cheney, Ferraro et al., 1991, cited in Costa, et al., 1996). The *first* and most pervasive episodic memory related problem to emerge in individuals with AD is the *forgetting* of recent personal events (Albert, 1996; Bayles, 1991; 2001); also identified as the most frequently reported *first* problem in two earlier *nursing* studies focused on the early AD stage (Keady & Nolan, 1995a; 1995b; La Rue, Watson & Plotkin, 1993).

In a later *nursing* study, Clare (2002a; 2002b), documented early episodic memory loss of an individual who didn't know why he was attending a hospital clinic, and thought that the new medication for his disorder was a 'previous' drug. Repetitive speech – also a key indicator of early episodic memory deficits (Bayles, Tomoeda, Kaszniak, Stern et al., 1985; Miller & Hague, 1975), and presenting important communication difficulties for family caregivers in early AD (Quayhagen & Quayhagen, 1988) was identified by caregivers in 63% of individuals with mild to moderate AD, albeit in an early dated study (Ulatowska, Allard, Donnell et al., 1988).

Episodic memory deficits presenting communication difficulties were well elucidated by caregivers (n = 88) who reported (at the first memory clinic visit) that *over one-half* of their family members with probable AD had problems with remembering where they had placed things, forgot to button or zip their clothing, and did not remember to do errands thus needed a written list. About one-third did not remember the day of the month and about one-quarter forgot to pay bills, record cheques and attend to other similar activities. Some 21 months later, these caregivers reported additional difficulties for remembering the days of the week, dates and appointments (Derouesne et al., 1999).

However, recognition memory is better preserved in *early* AD than free recall. In one large-scale cross-sectional study, persons with 'mild' AD (n = 244) had a specific deficit of free recall of recently acquired information, not identified in non-demented elderly controls (Vliet, Manley, Target et al., 2003). In another study, individuals in early stage dementia performed significantly better on confrontation naming tests (recognition tests) than on generative naming tests (recall tests) (Frank, 1994; Bayles, 2003). Last, as a practical example of this deficit, caregivers reported that 'retrieval' (i.e., free recall) of previously known telephone numbers was problematic for over 50 per cent of their family members with early stage AD (Derouesne et al., 1999).

Helpful strategies for these problems, wherein the individual can *recognize* what he is trying to *find* or *remember*, include providing contextual support such as pictorial-physical cues or written information (e.g., lists, reminder boards, note-books, diaries, day-by-day calendars) (Bayles & Tomoeda, 1993; Bourgeois & Mason, 1996; Hopper, Bayles & Tomoeda, 1998). Verbal 'recognition' strategies reported as highly successful by caregivers of spouses with earlier stage AD include repeating messages using the same wording, and paraphrasing repeated messages (the latter somewhat less effective than the first) (Small & Gutman, 2002; Small, Kemper & Lyons, 1996). A slowed rate of speech was not found to be helpful (Small et al., 1996). Another approach is to work within the span capacity of the individual (Bayles, 2003); such as transmitting *one* message at a time, using *short* and *simple* sentences, questions or 'commands' and using 'yes/no' rather than open-ended questions – affirmed as helpful by early stage caregivers (Small & Gutman, 2002; Small, Gutman, Makela & Hillhouse, 2003; Small & Perry, 2005).

On the positive side, individuals in the early AD stage generally have a very good memory for past 'personal' events, or life experiences that occurred at an earlier time in their lives, even though at times they may be uncertain about the chronology of these events (Clare, 2002a; 2002b). The fact that these 'older' memories are generally intact is an important area of knowledge for the caregiver, who is then better placed to guide conversations around subjects meaningful to the family member with early stage AD.

Semantic memory, which includes general knowledge about the world, facts and schema (Bayles, Tomoeda & Trosset, 1990), is the *second* area of declarative memory wherein problems occur in the early AD stage (albeit to a much lesser degree than in episodic memory) (Bayles & Kaszniak, 1987; and Becker & Lopez, 1992, cited in Azuma & Bayles, 1997; see meta-analusis, Henry, Crawford & Phillips, 2004; see review, Moreno-Martinez & Laws, 2007). It is posited that information in semantic memory is organized conceptually without reference to the time and context in which it was acquired (see review Nebes, 1989). Persons with *semantic memory* problems have an 'impoverished vocabulary' (Kertesz, 1994), wherein they provide less information about concepts, and fewer descriptors about objects than normal adults (Bayles, 2003), or produce fewer attributes of specific items in a category (Chertkov & Bub, 1990; Martin & Fedio, 1983, cited in Caramelli et al., 1998).

This 'loss' of information about specific objects and their 'names' results in a decreased ability to recall names of even common objects (Arango-Lasprilla, Cuetos, Valencia, Uribe et al., 2007; Bayles, 2003; see meta-analysis, Laws, Adlington, Gale, Morena-Martinez et al., 2007; see review Nebes, 1989). In one report, the most frequent and earliest communication related concern identified by caregivers was the difficulties that family members had in trying to 'find' the right word (Bayles & Tomoeda, 1991). Problems are more frequent for remembering less familiar or less frequently used words, or words with multiple, subtle or vague meanings (Frank, 1994; see review, Hart, 1988; in Chobor & Brown, 1990). Helpful strategies identified by early AD caregivers include encouraging the person to describe the word for which they are looking and providing the individual with cues (Small & Gutman, 2002).

The *third* area of declarative memory, lexical memory, is concerned with memory for words, i.e., names of 'objects' and rules for their use (a 'lexicon'). In *early* AD, *lexical* memory essentially remains unaffected, and speech is grammatically correct (see review Nebes, 1989). To illustrate, in a study with *early* and *mid*-stage AD contexts, all caregivers reported that family members had no difficulties in forming sentences (Orange, 1991).

Nondeclarative Memory

Nondeclarative (implicit) memory, concerned with remembering the *'how to'* perspective, is non-fact, non-volitional memory, thus is not open to introspection (Ritchie, Touchon, Ledeser et al., 1997). This memory area deals with the automatic acquisition of verbal and non-verbal knowledge or skills and encompasses knowledge of processes or procedures of various actions. *Procedural* memory, wherein one remembers *how to do* something, is one type of nondeclarative memory. This knowledge can be learned to such a high degree that certain actions (or 'procedures'), such as writing, golfing, or bicycling are performed automatically, in the absence of conscious recollection of the content or circumstances in which learning took place (Albert, 1996; De Vreese et al., 2001; Salmon, Heindel & Butters, 1991). This subject area is important for caregivers as knowledge about procedural memory would allow them to guide communication around those activities associated with the particular procedural memory strengths of their care receiver.

Nondeclarative memory is also depicted in the *habits* (taking a bath in the evening), and *associations* (stopping at a red light) that people develop over a lifetime (Bayles, 2001). In sum, since the *nondeclarative* memory system is generally well preserved until moderate to later AD (De Vreese et al., 2001; Salmon et al., 1991; Hopper et al., 2001; Rogers, Holm, Burgio, Hsu et al., 2000), it depicts a memory area about which the caregiver needs to become knowledgeable in order to maximize communication potential.

Working Memory

Working memory has a major impact on communication in early AD. Generally depicted as a short duration, limited capacity, multi-component system; working memory englobes storage and processing capabilities, and has three components; the central executive and two subsystems (the visuospatial sketchpad – a visual subcomponent and the articulatory/phonological loop – a verbal subcomponent (Baddeley & Hitch, 1974; Baddeley, 1986, cited in Rochon, Waters & Caplan, 2000).

Working memory makes it possible to temporarily hold several pieces of information *at the same time* in an inter-related manner *in the present* (Baddeley, 1999). With the central executive function at its core, working memory is concerned with goal directed behaviour (problem-solving, long-term planning, etc.), and concept formation, judgement and comprehension (Albert, 1996).

Executive function abilities decline significantly in early AD (Albert, 1996; Grady, Haxby, Horwitz et al., 1988; Lafleche & Albert, 1995; Morris, 1996; see review, Perry & Hodges, 1999) and are purported to be related to certain difficulties experienced by individuals in this stage in *activities of daily living* (Patterson, Mack, Geldmacher & Whitehouse, 1996, cited in Perry & Hodges, 1999) and *instrumental activities of daily living* (Small et al., 2000), in turn giving rise to communication problems between caregiver and care receiver (Arguelles et al., 2001; Small, et al., 2000). For example, caregivers of persons with mild to moderate AD symptoms reported *communication* problems in regard to using the telephone (60%); preparing meals, locating items, planning agendas and using the bathroom (40%); and in dressing, eating and taking medication (20% to 30%) (Small et al., 2000).

The magnitude of this problem in early AD is depicted in several other studies. At the first memory clinic visit, over *one-half* of individuals with probable Alzheimer's disease (*n* = 88) had difficulties manipulating buttons/zippers and putting a key in a lock, and *one-third* experienced problems in sewing, mending, etc. (Derouesne et al., 1999). After 21 months, additional problems were identified in manipulating tools and scissors (Ibid).

In another study, not only did individuals with mild AD (MMSE > 22) experience difficulties on psychological tests wherein tasks required concurrent manipulation of information (problems not identified in control subjects), but caregivers reported that these same persons also had difficulties with well-learned everyday tasks that required simultaneous manipulation of information (e.g., preparing meals, balancing a check book) (Lafleche & Albert, 1995).

Last, in another study, individuals with mild dementia (n = 35; MMSE scores = 21 to 25) had difficulties with dressing (almost 60%), using the telephone, doing laundry and taking medication (40% to 50%), and activities of daily living (e.g., bathing, toileting, feeding) (30%) (Haley, Wadley, West & Bestzel, 1994). An effective communication strategy for dealing with such problems reported by caregivers (in mild to moderate dementia contexts) is to use prompts or cues via the mode of *one instruction at a time* (Small & Gutman, 2002).

Executive functions are also related to difficulties in making comparisons and judgements, wherein incorrect evaluations of one's own memory functioning can lead to a sense of *unawareness* (or *anosognosia*) (Clare, 2002a; 2002b; Derouesne et al., 1999). This problem occurs in up to 75% of individuals with early AD, albeit only occasionally in the majority of these persons (Derouesne et al., 1999; Migliorelli, Teson, Sabe, Petracca et al., 1995). For example, the individual may not be able to recognize a problem when it is happening, or anticipate that a problem will occur in a given situation, or distinguish real events from imaginary ones (Clare, 2002a; 2002b). In one case study, difficulties in making judgements about the temporal context of events were depicted in an individual with early dementia who linked events from different time periods in a way that was logical to him, but did not represent reality (Clare, 2002a; 2002b). Such limitations can lead to misunderstandings in communication when the caregiver lacks the knowledge or skills to deal with the problem.

Another type of problem related to executive function deficits which gives rise to communication difficulties in early AD is concerned with difficulties related to orientation to place, i.e., that of the individual with AD 'getting lost'. This problem was reported in two nursing studies; both by caregivers who observed this their family members getting lost (La Rue et al., 1993) and by individuals with dementia who had increasing problems in following simple instructions in driving (Keady & Nolan, 1995a; 1995b).

Attention

The second area of impairment that appears in early AD is attention. Attention bears a relationship to executive function in that a certain degree of attention is required in all problem-solving aspects of executive functions (see review Perry & Hodges, 1999). *Sustained attention* – the ability to focus attention over longer time periods – is generally well retained in *early* AD (Bayles & Tomoeda, 1994; see review Perry & Hodges, 1999; Perry, Watson & Hodges, 2000), making it possible for the affected person to converse (Bayles & Tomoeda, 1994), thus reflects an area of strength in terms of communication potential.

However, problems in *divided* attention (sharing of attention when one focuses on *more than one* 'activity' at a time), occur with a high degree of frequency in *early* AD (Lines, Dawson, Preston, et al., 1991; Perry et al., 2000) and become even greater with *selective* attention deficits, i.e., the ability to focus on something while simultaneously ignoring other stimuli (Perry et al., 2000), and the ability to switch attention ('shifting sets') between two or more activities (Hopper et al., 2001; see review, Perry & Hodges, 1999; Perry, et al., 2000). In the early dementia nursing literature, both *caregivers* (La Rue et al., 1993), and *individuals* with dementia (Keady & Nolan, 1995a; 1995b), report 'inattention' problems, likely being related to difficulties with *divided* and/or *selective* attention.

Attention related problems were noted in *early* AD individuals who had difficulties following even 'simple' conversations with few individuals (in videos of different sized groups). This problem increased as the number of 'video participants' grew, and was even further exacerbated when persons moved around (Alberoni, Baddeley, Della Sala et al., 1992). In another study, one-third of caregivers reported that family members (with mild to moderate AD), experienced communication problems when watching television (Small et al., 2000).

Helpful strategies include having fewer conversational participants, (ideally a one-on-one context wherein conversational partners remain stationary), with adherence to similar principles in the presence of a passive medium such as the television (Alberoni et al., 1992). Caregivers of earlier stage AD spouses reported that effective communication strategies included the elimination of distractions (radio, TV), approaching their spouse from the front, and establishing and maintaining eye contact (Small & Gutman, 2002).

Language Related Problems

The evidence concerning communication in *early* stage Alzheimer's disease from the perspective of language comprehension and language production complements the preceding literature review on memory and attention. *Language comprehension* encompasses auditory and reading skills, whereas *language production* is concerned with oral (conversational) and writing skills (Caramelli et al., 1998). In the nursing literature, language problems have been identified in the *early* stage of dementia by both caregivers (La Rue et al., 1995), and by persons with dementia (Keady & Nolan, 1995a; 1995b).

Language comprehension

In general, *reading comprehension* is well preserved in early AD (Bayles, Tomoeda & Trosset, 1992), although some individuals experience periodic difficulties (see review Hart, 1988), as evidenced in one study where 20% of caregivers reported that family members with mild to moderate AD had *reading* difficulties (Small et al., 2000). *Auditory* comprehension skills remain fairly intact in early AD as long as material is well structured, easy-to-understand and 'concrete', although it can be forgotten quickly (Kempler, 1991; Kempler, Almor & MacDonald, 1998). Listening comprehension tends to become increasingly impaired for more abstract or complex sentences that include inferences, comparisons or causal relationships (Appel, Kertesz & Fisman, 1982; Code & Lodge, 1987, in Kempler, 1991; Cummings, Benson, Hill & Read, 1995, in Caramelli et al., 1998; Kempler, Van Lanker & Read, 1988, in Kempler, 1991).

Another auditory problem for these individuals is *sensitivity to sound,* due to a decreased ability to filter out extraneous noise (Powell, Hale & Bayer, 1995). A significantly higher sensitivity to sound was reported in individuals with dementia (albeit in different stages) (n = 76), than was identified in a similar sized control group (Powell et al., 1995). Since attention related deficits are also affected by noise (Vliet et al., 2003), the importance of attending to this influence is underscored. The person with auditory comprehension difficulties in regard to queries finds it easier to answer verbal questions of a 'two-choice' and 'yes-no' type (Bayles & Tomoeda, 1993). Other strategies that early AD caregivers find effective are using short, simple sentences and questions/commands, and a moderate speed of speech (Small & Gutman, 2002).

When *oral* and *written* information transmission modes are compared in early to mid-stage AD patients, the *oral* mode works well for comprehending less complex communication exchanges (e.g., responding to 'Yes-No' questions, a 'command' or a straightforward request), and sometimes this mode is even better than the written or combined oral-written approach. However, for sharing longer messages, or when the individual must provide information, both the *written* and the *combined* (written *and* oral) modes are *superior* to the oral mode alone (Obler, Obermann, Samuels & Albert, 1999).

Language Production

<u>*Verbal*</u> and <u>*written*</u> language production encompasses the five areas of the semiotic framework; i.e., *phonology* – sounds of language without reference to meaning; *morphology* – parts of words and words (the smallest units of *meaningful* linguistic signalling); *syntax* – structure of phrases and sentences; *semantics* – knowledge and organization of meaning; and *pragmatics* – use of contextually appropriate language (Hendryx-Bedalov, 1999; Kempler, 1991). It is in the conversational context that problems in some of these areas become apparent in early AD.

In terms of verbal expression in *phonology* and *morphology*, generally no difficulties are experienced herein until the very late AD stage (Bayles, 1994, cited in Caramelli et al., 1998; Collette, VanderLinden, Bechet et al., 1997, cited in Emery, 2000; Kertesz, 1994, cited in Emery, 2000). However, *phonological* errors do occur on occasion in *written expression* (to be discussed forthwith). In *syntax* (sentence structure) problems in expressive language are minimal as long as sentence structure is not complex (Costa et al., 1996; Hopper et al., 2001). Thus, individuals speak correctly grammatically and can detect and correct syntactic errors in sentences (Bayles, 1982; Kempler, Curtiss & Jackson, 1987, cited in Caramelli et al., 1998).

Language production problems in early AD are concerned principally with *semantics* (*lexicon* knowledge) and *pragmatics* (contextually appropriate language) (Kempler, 1991). In the semantics domain, language production generally remains intact when it depends on *non-declarative* (*implicit*) memory such as over learned and 'automatic' speech, (e.g., stereotypical social expressions – hello, thanks) (Hopper et al., 2001; Sabat, 2006). Problems in language production are characterized by *word-finding* difficulties (e.g., substituting words with others with similar meaning –'clock' for 'watch' or an inability to remember the word). Errors occur in *word production*, e.g., using an incorrect word, or less often – producing the wrong syllable or substituting a word that sounds like the intended word, e.g., 'bun' for 'pen'; *naming* or *name-finding* problems (being unable to assign the correct name to something, or to name a common object, e.g., car, but able to name its parts – tires, steering wheel).

Occasional *stammering* and *broken speech* can occur, such as using round-about explanations or gestures instead of words, or *circumlocutions* (i.e., ability to describe the function of something but not know its name); and (Reisberg et al., 1988; Rockwood & MacKnight, 2001). Because of a decreased functional vocabulary (due to semantic memory deficits), less common or less frequently used words are left out of one's vocabulary, resulting in a paucity of speech. Less meaningful or more generic words/expressions (such as 'these', 'stuff', 'things', 'is that so?') are frequently used to replace the correct word(s) (see review, Nebes, 1989).

Because of a loosening of associative links between words, and between words and ideas, an overlap of neighbouring terms also occurs frequently (e.g., the person might say 'the over iron is heating', instead of saying 'the iron is overheating' (Reisberg et al., 1988; Rockwood & MacKnight, 2001).

Pragmatics is concerned with the use of contextually appropriate language (Kempler, 1991), and problems herein become most apparent in the *conversational* context in early AD. First, on the positive side, and in favourable conditions, the person is generally able to adhere to the conventions of conversations (e.g., taking turns, and keeping and relinquishing his/her turn) (Orange & Purves, 1996; Ripich, Vertes, Whitehouse, Fulton et al., 1991). The person can still answer open-ended questions and in general can contribute meaningfully to conversations. As mentioned earlier, over learned communicative acts such as social conventions (e.g., 'how are you doing', 'I'm doing well', etc.) remain well preserved in this stage (Fromm & Holland, 1989, in Caramelli et al., 1998). However, since *optimal* conversational abilities require intact memory, attention and perception, all these affected in early stage AD, discourse is characterized by a certain amount of *repetitiveness*, a general *poverty* of *vocabulary* and range of expression, and an *omission* of relevant *details*. There is also an increase in circuitous or *circumlocutory* speech; however, caregivers of earlier AD spouses report that it is helpful to encourage circumlocution when the individual has difficulties to express him/herself (Small & Gutman, 2002). Persons also tend to have an *increased response time, pause* more frequently and generally *take more time* in conversing (Chobor & Brown, 1990). Effective strategies include giving the person more time to reply and not interrupt (Small & Gutman, 2002).

Vague speech or *irrelevant comments* are also made at times (Orange & Purves, 1996; Ripich et al., 1991), for which a useful approach is to have the family member describe the word(s) they are looking for or to 'talk around' the subject (Small & Gutman, 2002). At times, conversations may tend to be focused on the person (with AD) him-herself, i.e., the individual may give the impression of being egocentric (Chobor & Brown, 1990; Hendryx-Bedalov, 2000; Kempler, 1991; Orange & Purves, 1996; Ripich et al., 1991).

As conversations become increasingly complex and abstract, it becomes even more difficult for the person with early AD to follow a conversation (Hendryx-Bendalov, 2000); and more so when combined with conditions of increased noise (e.g., simultaneous input from the media (TV, radio), live conversations, etc.). The difficulties depicted in the preceding paragraphs then become even more exaggerated; for example, increased problems in introducing/changing topics during a conversation (Mentis, Briggs-Whittaker & Gramigna, 1995, cited in Caramelli et al., 1998).

In sum, with increasing complexity in the discourse context, it becomes more and more difficult for the person to integrate cognitive and linguistic components (Caramelli et al., 1998). To further underline the significance of communication problems in conversation, when caregivers (in the mild to moderate AD context) were asked to identify the activity at home that was *most* affected by communication problems, over 80% identified communication problems related to *conversation* with their family member (Small et al., 2000).

Problems with *written language production,* i.e., difficulties with spelling and the mechanics of writing (d*ysgraphia* or *agraphia*) are infrequent in early AD (see review, Neils-Strunjas, Groves-Wright, Mashima & Harnish, 2007). While there is no predictable pattern, when problems do occur, the most common ones are in *spelling* exception words (*surface dysgraphia* or *lexical agraphia),* e.g., errors in the spelling of words with unpredictable or sound-to-spelling correspondences (e.g., cough – spelled 'cawf' or yacht – spelled 'yat'), and by a tendency to produce phonologically plausible spelling errors (e.g., tomb – TOOM, crane – CRAIN). Non-phonological errors (errors in spelling of regular words) are less frequent.

Difficulties in the mechanics of writing (*graphomotor* impairment) also occur occasionally in early AD (see review, Graham, 2000), in particular with spontaneous writing (Kempler, 1991); one of the earliest reported problems being concerned with letter writing (Bayles & Tomoeda, 1991).

Another – infrequent – early AD *writing* problem is *perseveration*, the incorrect continuation or recurrence of a response. In particular, problems are noted with *continuous perseveration* (Caccappolo-Van Vliet, Miozzo, Marder & Stern, 2003; Neil-Strunjas, Shuren, Roeltgen & Brown, 1998, cited in Caccappolo et al., 2003), i.e., the incorrect prolongation or repetition of letters (e.g., lam*p* – lam*ppp*) (Caccappolo-van Vliet et al., 2003). While individuals have demonstrated continuous perseveration in incorrect repetition of *written* letters, no such deficit is noted in oral spelling or in graphic or motor tasks (Caccappolo et al., 2003). When the caregiver is knowledgeable about the possibility of such difficulties, the potential for miscommunication with the family member can be reduced.

Other Communication Related Problems

Several other early AD deficits that give rise to communication related problems, thus represent a key knowledge need for the caregiver, are submitted herein. Certain ones influence communication more directly, while others have a less direct effect. One early stage deficit more directly linked to the communication domain is *confusion* (Bryden Boden, 2002). In the nursing literature, confusion is reported as problematic by both caregivers of persons with *early* dementia (La Rue et al., 1993), and by persons in the *early* stage of dementia (Keady & Nolan, 1995a; 1995b).

Another type of AD deficit that also directly influences communication in early AD is termed as *passive behaviour*, and is purported to be distinct from depression (Colling, 1999). In a review of fifteen studies, Colling (1999) offers a descriptive analysis of 'passive behaviours', and while these occur less frequently in the early AD stage, they are nonetheless reported to be troubling for caregivers. Among the numerous descriptors for these behaviours in the literature, many of which are articulated by caregivers, are included: apathy, withdrawal, indifference, lack of responsiveness, blunting of emotions, decreased or lack of spontaneity, diminished emotional responsiveness, listlessness, lifelessness, decreased enthusiasm, lack of goal directed behaviour, disinterest, flat affect, reclusiveness, 'loss of interest', decreased openness, and the person being less cheerful (Colling, 1999).

AD related deficits that are less directly linked to communication in the early AD stage, however which also hold the potential for communication misunderstandings, are related to *lower energy levels* along with *psychomotor slowing* and an overall *reduction in physical activity* (not due to physical causes); which in some individuals can be profound, even at this 'mild' stage. While the slowing dimension can characterize all aspects of functioning, including staying in bed for extended periods of time, it is usually most noticeable in regard to *gait* (Rockwood & MacKnight, 2001). If the caregiver is not aware of this phenomenon, and holds the perception that the family member should not remain in bed, or should be able to go faster, communication problems can result.

Emotive or *affective* changes are also found in the person with early stage AD, which can lead to a myriad of communication related problems. A great deal of variability exists between individuals; and among the 'symptoms' described in the literature are included anger, frustration, anxiety, sadness, irritability, agitation, insensitivity, 'instability', 'immaturity', decreased kindness and generosity, 'self-centredness', and decreased levels of affection, cheerfulness and reasonability, to give a few examples (Clare, 2002a; 2002b; Costa et al., 1996; Colling, 1999; Rockwood & MacKnight, 2001; Snyder et al., 1995; Visser, 2000; Wilkinson, 2002).

In the next section, a promising approach for responding to the aforementioned communication related difficulties in the early dementia context will be examined, an approach that has received little attention in the caregiving literature. In particular, we are referring to strategies guided by a *self-efficacy* orientation.

Self-efficacy: A Promising Variable in Behaviour Change

Having identified that dementia caregivers lack the necessary knowledge and skills to carry out their role (Ayalon & Arean, 2004; Kuhn, King & Fulton, 2005; Werner, 2001), and in particular in regard to the *communication* domain in the *early* 'dementia' stage (Kuhn, 1998; Kuhn & Fulton, 2004), interventions with a goal to augment knowledge and skills in this area are deemed necessary. However, when the purpose of an intervention is to facilitate a change in thinking or in behaviour, such as, for example, to acquire a *communication* skill that will be carried out or actualized in the caregiving setting, there is no assurance that strategies to facilitate knowledge acquisition alone will necessarily result in modifying thinking and action(s) (Bandura, 1997). Indeed, in a systematic review of interventions designed to enhance the well being of caregivers of people with dementia, while *education* interventions were rated as strong, they were found to be insufficient to improve overall caregiver psychological well being (Peacock & Forbes, 2003).

Self-efficacy theory postulates that even if one has the requisite knowledge and skills, if one does *not believe* that one can actually apply or transform this know-how into effective action or behaviours, then one will be less likely to succeed (Bandura, 1997). Thus, while an important antecedent to behaviour is having the requisite knowledge and skills, it is the strength of the individual's self-efficacy in regard to carrying out the particular skills-behaviours that will determine the likelihood of success. In the scientific literature, there is ample evidence to support the influential role of self-efficacy in regard to behavioural change. More particularly, self-efficacy has been shown to influence a wide range of relevant outcomes in a significant manner; e.g., health behaviour (see review, Hevey, Smith & McGee, 1998); parental competence, (see review, Jones & Prinz, 2005); writing (see review, Pajares, 2003); academic performance (Bandura, Barbaranelli, Caprava & Pastorelli, 1996; see meta-analysis Multon, Brown & Lent, 1991); exercise (Bandura, 1986; Konradi & Anglin, 2003; see meta-analysis, Marshall & Biddle, 2001; see review Sallis & Owen, 1999), sports performance (see meta-analysis, Stajkovic & Luthans, 1998); teacher self-efficacy (see review Soto & Goetz, 1998; Tollerud, 1990) and in the field of psychology and counselling (Larsen & Daniels, 1998).

Predictive attributes of self-efficacy are also being reported with increasing frequency in the *health* and *aging* related domains. In the *health* area, higher self-efficacy predicted increased mobility, and decreased pain and functional disability in persons with arthritis (Keefe, Smith, Buffington, Gibson et al., 2002; see review, Marks, 2001). Self-efficacy was also found to predict health behaviours (see review, Hevey, Smith & McGee, 1998), and in the field of substance abuse, self-efficacy predicted which individuals were susceptible to relapse (see review, O'Leary, 1985). In three *nursing* studies, self-efficacy was a significant predictor of diet and exercise behaviours (Clarke & Dodge, 1999); activity levels after cardiac surgery (Gortner & Jenkins, 1990); and physical, social and leisure functional status post coronary artery bypass surgery (Allen, Becker & Swank, 1990). More recently, self-efficacy was found to predict weight control behaviour and weight change (Linde, Rothman, Baldwin & Jeffery, 2006).

In the *elderly* population, self-efficacy predicted physical activity in elders with osteoarthritis (Rejeski, Craven, Ettinger, McFarlane et al., 1996), and in a longitudinal *nursing* study on exercise in older adults, self-efficacy expectations indirectly influenced the upkeep of regular exercise (Resnick, 2004). In other studies with older persons, self-efficacy predicted increased adherence to exercise after a structured exercise program (McAuley, Lox & Duncan, 1993); greater improvements in exercise in older individuals versus younger adults (McAuley, Shaffer & Rudolph, 1995), and successful outcomes for self-perceived health in older male caregivers (Ducharme et al, 2007b). In the frail elderly, falls self-efficacy predicted physical functioning (Stretton, Latham, Carter et al., 2006).

In correlational research, in a *nurse*-directed study, increases in post-stroke self-care self-efficacy (at six months post-CVA) were strongly correlated with quality of life measures, functional independence and depression (Robinson-Smith, Johnston & Allen, 2000). In regard to caregiving self-efficacy, in one early study higher self-efficacy was related to higher caregiver coping ability (Schulz, Biegel, Morycz & Visitainer, 1989). More recently, Ducharme and colleagues reported that self-efficacy was associated with psychological distress (Ducharme, Levesque, Lachance, Gangbe-Marcellin, Zarit et al., 2007a).

Measurement of Self-efficacy

The core tenet of self-efficacy is that it is a task or behaviour specific perception of capability in relation to a particular context and behavioural domain (Bandura, 1986; 1997). In order to ensure that self-efficacy scales are conceived in such a way that they are specific to the particular domain of functioning, the activity domain must be clearly defined, and a conceptual analysis of its various facets conducted, including the types of capabilities that are relevant to the domain, and the various situations in which these capabilities might be applied (Bandura, 1997).

From an overall theoretical measurement perspective, self-efficacy measurement is situated within the criterion-referenced measurement domain (Waltz, Strickland & Lenz, 1991), having as its main feature the use of an interpretive frame of reference based on a specified domain (rather than on a particular group or population) (Popham, 1978, cited in Waltz et al., 1991). Criterion-referenced measures are used to determine an object's (i.e., person's) domain status (the domain being the content area or variable that is the focus of measurement), in regard to a specific property or attribute (e.g., *self-efficacy*), or performance standard (e.g., skills, behaviours) (Waltz et al., 1991). An important dimension of criterion-referenced measurement is that the distinguishing characteristics that serve as the criterion or «standard» for measurement of the subject's domain status must be clearly identified and explicated in regard to the nature of the domain (Waltz et al., 1991). In terms of this discussion, a criterion-referenced measure (i.e., *self-efficacy*) in a specified domain (i.e., *communication in early stage Alzheimer's disease*), is used to ascertain an object's status (e.g., *level, strength, generality*) (Waltz et al., 1991).

These dimensions of *level, strength* and *generality* represent the parameters of self-efficacy measurement (Bandura, 1977; 1997). The *level* of self-efficacy refers to the person's expected performance attainments in relation to the requirements of the task. For example, one may have high efficacy perceptions for walking one mile on a flat surface, and lower efficacy beliefs for walking one mile uphill or on a very hot day.

Strength refers to the person's confidence that he/she **can** perform at a **given level,** or how strongly he/she believes that he/she is capable of performing an action. A person might be very confident to perform at a low level, but less confident to perform at a higher level. Moreover, the level and strength of efficacy expectations for a particular behaviour determines whether or not the behaviour will be *initiated*, how much *effort* will be expended, and how long the individual will *persevere* in relation to obstacles that may be present.

Efficacy expectations also differ in *generality*, this being the number of domains of functioning in which the individual judges him-herself to be efficacious. The degree to which activities resemble each other, the modalities through which capabilities are demonstrated (behavioural, cognitive or affective), the characteristics of the situation, and the attributes of the person to whom the actions-behaviours are directed, all these can influence efficacy beliefs.

In the measurement of self-efficacy, the individual is presented with a list of tasks, typically with increasing gradations of difficulty, and subsequently asked which tasks he/she believes he/she can perform. For each task that the individual believes he/she can perform, the strength of perceived efficacy is rated on a 100-point scale ranging from high uncertainty, through intermediate levels of certainty, to full certainty. Questions must be termed in such a way that they seek out answers about a maximal, rather than a habitual performance; and should be formulated in some kind of hierarchical order of difficulty (Bandura, 1997). Because efficacy beliefs are task-specific, **every domain** requires a **different** self-efficacy measure.

Self-efficacy Measures for the Dementia Caregiving Context

Several self-efficacy measures have been developed recently for the dementia context (Fortinsky, Kercher & Burant, 2002; Gallant & Connell, 1998; Gottlieb & Rooney, 2003; Haley, Roth, Coleton, Ford et al., 1996; Steffen, McKibbon, Zeiss, Gallagher-Thompson & Bandura, 2002; Zeiss, Gallagher-Thompson, Lovett, Rose et al., 1999). However, *none* of these instruments specifically target the *early* phase of dementia caregiving. While the majority of these measures include, to varying degrees, *items* related to the *communication* perspective (e.g., Fortinsky et al., 2002; Gottlieb & Rooney, 2003; Haley et al., 1996; Steffen et al. 2002), not one of these measures is focused on the communication domain.

Given that self-efficacy measurement requires a 'state' (versus 'trait') orientation, it is imperative that such an instrument be focused on the particular domain and context, i.e., the communication domain in early dementia. The following overview includes five dementia caregiving self-efficacy measures, with a particular emphasis on the *communication* related aspect.

The *Caregiver Self-Care Self-efficacy scale* (Zeiss et al., 1999) served as the foundation for the *Revised Scale for Caregiving Self-efficacy* (Steffen et al., 2002), the latter measure being the **first** one addressed in this discussion. This *'revised'* self-efficacy scale encompasses three subscales; of which two subscales include items relevant to the *communication* dimension. The first subscale, *Self-efficacy scale for responding to disruptive patient behaviours* encompasses beliefs about dealing with difficulties related to the care receiver's *forgetfulness* and *repetitive speech*, and also beliefs about *responding effectively* (calmly and without anger) to challenging comments from the care receiver. The second relevant subscale, the *Self-efficacy scale for controlling upsetting thoughts,* deals with an *emotive* communication-related dimension, and encompasses beliefs about *controlling one's thoughts* about the unpleasant aspects of caregiving, potential future problems, and what is missing in the caregiver's life.

In terms of internal reliability and construct validity, this instrument performs 'very consistently' (p.83) (Steffen et al., 2002). Moreover, given the similar findings concerning internal consistency and factor structure of these self-efficacy subscales in two different samples, the generalizability of these findings is also underlined (Steffen et al., 2002). As well, this measure respects the 10-point scale range deemed necessary for measuring self-efficacy.

The **second** dementia caregiving self-efficacy scale, the *RIS Eldercare Self-Efficacy Scale*, is made up of three subscales, underscored by domains which, (according to the authors), represent the "three central challenges universally experienced by caregivers, thus represent the most salient domains for the measurement of self-efficacy beliefs" (Gottlieb & Rooney, 2003, p.97). One subscale, the *Relational self-efficacy scale,* is concerned with the domain of maintaining a co-operative and harmonious relationship with the care receiver, thus encompasses a *communication* perspective. It includes three items, i.e., beliefs about minimizing or avoiding conflicts with relative; obtaining the relative's cooperation, and enjoying time with the relative. The wording of the items is fairly general, with specificity lower than what is required for self-efficacy measures.

A second subscale, the *Instrumental self-efficacy subscale* (3 items), is essentially concerned with instrumental and non-instrumental activities of daily living, and while it is not focused on the communication perspective, it addresses a domain that has been shown to be related to communication problems. While supportive information is provided in regard to internal consistency and construct validity for these subscales, in order to affirm that the subscales are truly representative of the caregiving domains identified in this study, additional validation work is required. Moreover, given the limited range of items in each scale, and the lack of specificity in the wording of the items, it is questionable whether self-efficacy is actually being measured. Furthermore, while the 5-point Likert-type scale in this measure is generally judged acceptable, the ideal range for a self-efficacy measure is a 10-point scale (Bandura, 2001).

A **third** dementia caregiving scale is underscored by two caregiving domains identified as 'key' for the older family dementia caregiver; that is, 'managing relatives symptoms' (e.g., wandering, behaviour problems, incontinence); and 'finding and using community support services' (e.g., respite care, paid in-home care, day care) (Fortinsky et al., 2002). Only the first domain, upon which the *Symptom management self-efficacy scale* (5 items) is founded, includes *communication* related items ($n = 2$). One item is concerned with 'beliefs about handling problems related to the care recipient's *memory loss*' (albeit this wording is less specific than the items concerned with *forgetfulness* and *repetitiveness* elucidated in Steffen et al.'s (2002) tool). A second item, 'beliefs about dealing with the frustrations of caring for one's relative', is also relevant for the *communication* domain. It was confirmed that this subscale represents a distinct domain, and that the internal consistency was 'adequate' (Cronbach's $\alpha = 0.77$). In terms of validity, while these authors did consult the scientific literature to identify the caregiving domain that underpins this scale, no further validation work was conducted to ensure that this is a 'key' domain for dementia caregiving. An important feature of this measure is that it has a 10-point scale with appropriate wording for scale items.

A **fourth** dementia caregiving self-efficacy measure, developed by Haley et al. (1996), encompasses three subscales founded on the domains of: activities of daily living (ADL's), instrumental activities of daily living (IADL's), and memory and behavioural problems. While the relationship between communication related problems and ADLs/IADLs has been well elucidated, only the third subscale, *Self-efficacy for behavioural and memory problems*, appears to be concerned with a *communication* aspect, given that it includes a '*memory*' dimension. A critical weakness of this measure is that it is conceived with a 3-point scale (rather than the recommended 10-point scale) (Bandura, 1997), thus greatly lacks in precision.

Last, a **fifth** self-efficacy scale conceived for dementia caregivers was founded upon two domains: first, the caregiving needs of the care recipient (1 item), and second, the needs of the caregiver in terms of health (1 item) (Gallant & Connell, 1998). However, neither domain is focused on the *communication* dimension.

While the first four scales address, to varying degrees, the *communication* domain as it pertains to the caregiver and care receiver, because this domain has not been explored in depth, the range of communication items in all of these studies is low. Moreover, with the exception of Zeiss et al's (1999) measure, for the most part, these items are worded in general, rather than specific terms (the latter required for self-efficacy measurement). As has been elucidated in the literature review in the preceding section, the communication domain for early stage dementia, and in particular, Alzheimer's disease, includes a large and diverse number of communication subjects that can serve to underpin relevant self-efficacy measures.

Self-efficacy and Caregiving Studies

While the conjoint study of self-efficacy and caregiving has not received much attention in the past (DiBartolo, 2002; Dorfman, Holmes & Berlin, 1996), in recent years, more researchers have displayed an interest in this subject (Ducharme et al., 2007a; 2007b; Etkin, 2006; Gallagher-Thompson, Gray, Tang-Paulette, Pu-Chun-Yu et al., 2007; Gant, Steffen & Lauderdale, 2007; Gilliam & Steffen, 2006; Gitlin, Reever, Dennis, Mathieu et al., 2006; Rabinowitz, 2005).

Concomitantly, there are indications that caregivers are lacking in self-efficacy in regard to varied caregiving activities. Early dated findings that support this perspective are reported in a grounded theory study of *dementia caregiving*, wherein a prevailing theme was that caregivers did "*not believe* in their own abilities to manage" (as caregivers) (p.73) (Szabo and Strang, 1999). While the particular caregiving tasks linked to these reduced beliefs in abilities are not elucidated, these perceptions reflected a lowered sense of self-efficacy for caregiving activities. In a meta-analysis conducted by Pinquart & Sörensen (2003), caregivers were found to have significantly lower levels of self-efficacy in regard to diverse domains, than non-caregivers. More recently, Ducharme and her colleagues reported that male spouse caregivers reported lower levels of self-efficacy (and at the same time exhibited higher psychological distress) (Ducharme et al., 2007a).

In the following studies, post intervention increases in caregiver self-efficacy (in relation to several domains), indicated that these self-beliefs had been lower prior to the interventions. First, further to a skills training program, significant increases in self-efficacy related to managing agitation were reported in a community based older-aged dementia caregivers, in comparison with a control group (Huang et al., 2003). In another study, enhanced self-efficacy for managing troublesome behaviours (albeit not statistically significant) was identified further to an educational intervention (Gitlin et al., 2001). In a third study, after participating in a psycho-educational program, caregivers of family members with dementia disorders and other chronic disease problems reported higher levels of self-efficacy related to 'maintaining pleasant events' and 'solving caregiver problems' (Lovett and Gallagher, 2003).

Communication Self-efficacy and Caregiving

As depicted in an earlier discussion, several caregiving self-efficacy measures have been developed for the dementia context (albeit none for the *early* caregiving stage), and a few of these have incorporated items relevant to the communication domain. While cognizant of the limitations of the majority of these instruments, a number of these measures have been tested in diverse settings with certain encouraging, albeit cautioned results. In the **first** investigation, the *Revised Scale for Caregiving self-efficacy,* comprised of three subscales: 1) *SE-obtaining respite;* 2) *SE-controlling upsetting thoughts*; and 3) *SE-responding to disruptive behaviours* of care recipient (Zeiss et al., 1999; Steffen et al., 2002), was tested with two independent samples of older caregivers, primarily in the '*mid* stage' dementia context. Among the most noteworthy outcomes were significant negative relationships between self-efficacy concerning the communication domain of '*dealing with disruptive behaviours*' on the one hand, and 1) *anger* (on the Speilberger's Trait Anger scale), (1st sample: r ($n = 169$) = -0.41, $p < 0.001$, and 2nd sample: r ($n = 145$) = -0.45, $p < 0.001$); 2) *depression* (on the Beck Depression Inventory) (1st sample: r (n = 169) = -0.31, $p < 0.001$; and 2nd sample: r ($n = 145$) = -0.34, $p < 0.001$), and 3) *anxiety* levels (1st sample: r ($n = 169$) = -0.53, $p < 0.001$; and 2nd sample: r ($n = 145$) = -0.20, $p < 0.05$), on the other.

In a **second** study, *The Family Caregivers' self-efficacy scale for managing dementia* with two subscales: 1) beliefs about *managing relatives' symptoms*, and 2) beliefs about *finding and using community support services*, was examined by Fortinsky and his colleagues (2002). In a multivariate regression model, it was found that caregivers who reported a higher level of self-efficacy in the communication related domain of *symptom management,* reported significantly fewer depressive symptoms (n = 191, β = -0.17, $p<0.05$), and significantly fewer physical health symptoms (n = 191, β = -0.16, $p<0.05$). These findings however, must be treated with caution given the validity limitations of these self-efficacy measures.

In a **third** study, validation work was conducted on the *RIS Eldercare Self-efficacy Scale* for dementia caregivers with three self-efficacy perspectives: *instrumental self-efficacy* (for personal care tasks); *self-soothing self-efficacy* (for maintaining caregiver well-being); and *relational self-efficacy* (with a strong *communication* perspective on maintaining a harmonious relationship between caregiver and care receiver) (Gottlieb & Rooney, 2003). A relevant outcome of validation testing was that the communication related *relational self-efficacy* scale, proved to be highly and inversely associated with the amount of upset that caregivers experienced in response to memory and behavioural problems (r (n = 134) = -0.27, $p<0.01$). That is, the lower the level of relational self-efficacy, the greater was the caregiver's upset in regard to the memory and behavioural problems concerning their care receiver. Moreover, *relational self-efficacy* was significantly associated with the caregivers' mental health and vitality, i.e., caregivers with higher levels of *relational self-efficacy* had better general health (r (n = 134) = 0.35, p <0.001); better physical functioning (r (n = 134) = 0.38, p <0.001); fewer role limitations due to physical health problems (r (n = 134) = 0.20, p <0.01); better social functioning, (r (n = 134) = 0.25, $p<0.01$); less bodily pain (r (n = 134) = 0.18, $p<0.05$); better mental health (r (n = 134) = 0.28, p <0.001); and better vitality (r (n = 134) = 0.29, $p<0.001$).

One must however, treat these findings with caution. While supportive information was provided in regard to internal consistency and construct validity for this measure, additional validation work is needed to affirm that these self-efficacy sub-scales are truly representative of the three respective caregiving domains.

In a **fourth** study, Haley and his colleagues (1996) measured self-efficacy in regard to three domains: *self-efficacy* for managing *activities of daily living* (ADL's), and *instrumental activities of daily living* (IADL's), and self-efficacy for managing *behavioural and memory problems*. In regard to the latter measure, a significant relationship was reported between low levels of caregiver *self-efficacy to manage memory and behavioural problems* and higher levels of caregiver depression ($r = -.40$, $p < 0.01$). However, while these results must be treated with a certain degree of caution, given that a limiting 3-point scale format was used, this relationship offers support for construct validity of this measure.

In these four studies wherein self-efficacy measures were partially underscored by communication related domains of a diverse nature, while being cognizant of the limitations in validity, reliability and scale format in the majority of these measures, significant correlations were reported between depressive symptomology and each of the respective communication related self-efficacy measures.

Even though the influential role of self-efficacy is well substantiated in the literature in a large number of diverse areas, self-efficacy has not yet been studied in regard to the communication related problem areas that have been identified in the early AD caregiving context. Given that nurses fulfill a major role in caring for individuals and families in the dementia context and moreover are well placed in the health care system to facilitate caregiver-learning opportunities, the self-efficacy framework offers a particularly relevant and potentially effective orientation to augment knowledge and relevant skills.

Theoretical Framework

This section addresses the theoretical perspective of this study, and includes the nursing conceptual framework, i.e., the McGill Model, self-efficacy theory (underpinned by social cognitive theory), which guides the particular psycho-educational strategies of the intervention and geragogy – the learning framework for the older learner (complemented by the pedagogical orientation of constructivism),

Nursing Conceptual Framework: The McGill Model

The McGill Model, conceived by Moyra Allen and nurse colleagues at McGill University, provides overall direction to this investigation (Allen, 1977; Gottlieb & Rowat, 1987; Gottlieb & Ezer, 1997; Gottlieb & Feeley, with Cindy Dalton, 2006). A complemental role for nursing is central in this model, wherein nursing care, knowledge and skills 'complement' that of other professionals; and the role of nursing is 'expanded' into the family's unmet, health-related areas of need (Allen, 1977). This global depiction of nursing encompasses the four generally accepted meta-paradigm concepts of nursing (Fawcett, 1983; 1984): 1) the human being, 2) health, 3) environment, and 4) nursing. Within the organizing framework of the model: 'family – health – learning – collaboration', nursing is focused on health promotion within the family unit through a *collaborative learning* process between the person and the nurse (Kravitz & Frey, 1989).

The conception of nursing care delivery – elaborated in the initial model as *'situation-responsive' nursing* (Allen, 1977, 1982) – is subsumed within a broader view of the 'nurse-person relationship', termed as a *collaborative partnership* (Gottlieb & Feeley, with Dalton, 2006). In 'situation-responsive' nursing, Allen (1977) submits that skills (relevant to perception, assessment, planning and practice), are derived from the nurse's ability to be *responsive* to the family in a wide range of situations. In the present study, the nurse is responsive to helping the caregiver to live with the family member's long-term condition of dementia.

Moreover, based on the premise that people *learn* to become 'situation-responsive to life events (Glass, 1997), the role of *nursing* is to structure and tailor appropriate learning situations which provide clients (i.e., persons) with pertinent health information and opportunities to discuss and share, as well as to test appropriate action plans (Kravitz & Frey, 1989), these elements being reflected in the intervention program in this study.

The *collaborative partnership* model articulated by Gottlieb and her colleagues (2006), offers a broader view of the 'nurse-person relationship'. This *collaborative partnership*, which is considered to be central to nursing practice, is defined as 'the pursuit of person-centred goals through a dynamic process that requires the active participation and agreement of all partners' (p. 8). Thus, the nature of the relationship is one of partnership and the way of working together is collaborative. The key features of a *collaborative partnership* include the sharing of power and expertise, the pursuit of mutually agreed-upon, person-centred goals and the creation of a dynamic process wherein the active participation and agreement of all partners is a requisite element of the relationship (Gottlieb et al., 2006).

In the McGill Model, the *person* – as the central focus of care (Gottlieb et al., 2006) and as an active participant in care (Allen, 1982), is viewed from a family perspective (Allen, 1986; cited in Laforet-Fliesser & Ford Gilboe, 1996), this notion melding well with the 'family' caregiving orientation in this study. Being endowed with potential strengths and resources, the person is an active problem-solver with the capacity to *learn* (Gottlieb & Rowat, 1987). Viewed as an *equal partner*, the person is deemed to be the primary source of information. In this study, information related to the communication-related difficulties that he/she had been experiencing with the family member was sought from the person (i.e., caregiver). Moreover, as an active, valued *partner* who shares responsibility for his/her care, the person plays a key role in setting goals and finding solutions that are best for him/her (Gottlieb & Feeley, with Dalton, 2006). In this investigation, primary consideration was given to the learning-related goals of the *partner* (i.e., participant) and to the identification of the most appropriate solutions (i.e., communication strategies) for his/her context.

Within this nurse-person partnership, the *nurse* is a facilitator who encourages the person: to share his/her perceptions and expertise, to participate in joint decision-making, and to develop his/her autonomy, i.e., the ability to be self-directed, and self-efficacy (the latter concept serving to guide the particular pedagogical strategies in this study). The nurse, who is knowledgeable about the person's illness, i.e., related to communication and dementia disorders in the present study, helps the person to use his/her strengths and resources 'more fully' (Gottlieb & Feeley, with Dalton, 2006).

Health is viewed as separate from illness, rather than as part of a health-illness continuum (Allen, 1981; 1983; Gottlieb & Rowat, 1987). In the collaborative partnership, the focus is on the person's ability to be well, to experience a high quality of life and to live in a meaningful way (Gottlieb et al., 2006). In this study, it was hypothesized that the person would learn to communicate more effectively and be less disturbed when faced with communication difficulties; this being conducive to a higher quality of life. Health is also depicted as a dynamic process; best *learned* through active involvement, likened, in part, to mastery experiences in the self-efficacy model; and to personal discovery that develops over time (Gottlieb & Rowat, 1987), a viewpoint similar to the notion of self-efficacy development over the lifespan (Bandura, 1994).

The expansive physical *environment* for nursing practice includes diverse *milieux*, including the home and formal care settings (Allen, 1982), thus lending itself to the community focus in this study. This environment – which includes the person-family and nurse, is denoted as the social context for *learning* (Kravitz & Frey, 1989). This perspective emanates from Bandura and Walter's (1963) Social learning theory, which subsequently served as the foundation for Bandura's (1977, 1986) social cognitive theory from which self-efficacy theory evolved.

In the McGill model, *learning* is focused on helping individuals/families to develop their potential for health through an active *learning process* (Gottlieb & Rowat, 1987), wherein the person plays a key role in 'finding solutions' (Gottlieb & Feeley, 2006). This perspective melds well with the teaching-learning dimensions of self-efficacy and geragogy-constructivism.

As a bridge between concepts in the McGill Model, learning is evidenced in *health* – as a *learning process*; in the *environment* – as a *learning context*; and in *individuals* and *families* (i.e., persons) – as endowed with the *capacity* and the *desire* to *learn* (Kravitz & Frey, 1989). Moreover, the degree of involvement of the individual (in the *learning process*), being contingent upon his/her physical, psychological and social status (Gottlieb & Rowat, 1987), is likened to the reciprocal inter-relationships between efficacy perceptions and psychological (i.e., cognitive and affective), physiological and social (contextual) dimensions. Furthermore, the stronger the individual's efficacy beliefs in regard to a particular learning task, the more likely it is that *learning* will take place.

<center>*Self-efficacy in Social Cognitive Theory*</center>

Self-efficacy theory is situated within a family of present-day social cognitive models of personality (Cervone, 2000). With origins in social learning theory, social cognitivism is concerned with *learning* that is "embedded in social networks" wherein "environmental influences are mediated through cognitive processes" (Bandura, 1997). From a historical perspective, according to Pajares (2002), early references to the notion of self-efficacy are ascribed to such ancient thinkers as Virgil (a Roman poet), who stated that "they are able, who think they are able"; and to the renowned French author, Alexandre Dumas, who wrote that "when people doubt themselves they make their own failure certain by themselves being the first to be convinced of it" (Pajares, 2002, p.8). More recently, Robert White (1959) proposed the term "effectance" to describe the notion of human motivation being related to an individual's perceptions of competence in bringing about change, conceptualizing effectance motivation as "feelings of efficacy" (p.321). Around the same time, Bandura, in his early work on "social cognitivism", conceptualized observational learning as being mediated through perceptual and cognitive processes (Bandura & Walters, 1963). This work later served as the basis for Bandura's (1977) self-efficacy theory that encompasses the notions of self-beliefs. A decade later, Bandura (1986) further explicated self-efficacy within a theory of human social cognition with an even stronger cognitive-based orientation.

At the heart of Bandura's Social Cognitive Theory (Bandura, 1977, 1986, 1997) lies the notion of a *triadic reciprocal causation model* characterized by ongoing interactions between, and among, the three variables of the model: the person's behaviours, the characteristics of the individual (cognitive, affective and biological), and the surrounding environment or social context (Bandura, 1977, 1997). An important feature of social cognitive theory is that it is rooted in the notion of *human agency*. As "agents", humans are characterized by the capacity to exercise control over their thoughts, feelings and actions; that is, to carry out acts intentionally (Bandura, 2001). A central agentic capability is *self-efficacy*.

Self-efficacy is defined as people's judgments of their capabilities to organize and execute courses of action required to attain designated types of performances. Thus, self-efficacy is concerned **not** with the skills one has; rather it is concerned with the **judgments** of what one **can do** with whatever skills one possesses (Bandura, 1986). In other words, an individual with a high degree of self-efficacy feels confident that he or she can exercise control over his/her behaviour and motivation, as well as over environmental demands.

A relevant *nursing* definition of self-efficacy (which emanates from a concept analysis of this construct), is offered by Berarducci and Lengacher (1998) who define self-efficacy as "an individual's *belief* that he or she has the competence to perform a necessary behaviour to attain a particular goal in order to promote physical, psychological or social well-being" (p.63).

Self-efficacy is characterized by important *contextual* and *developmental* dimensions. In terms of contextual factors, it is first concerned with beliefs about capabilities of performing *specific* behaviours or tasks in *particular* situations (Bandura, 1977; 1999). Thus, an individual cannot be characterized as having 'high' or 'low' self-efficacy without referring to both the specific behaviour, and the circumstance with which the efficacy judgment is associated.

The second contextual dimension relates to the *situational challenge* of the task. More particularly, self-efficacy plays a key role in influencing the likelihood of performing behaviours in two types of situations: when *new* behaviours are *learned*, or when *established* behaviours are *challenged* (Mendes de Leon, Seeman, Baker, Richardson & Tinetti, 1996). In contrast, when the performance of behaviours is more or less routine, then self-efficacy is thought to be less important (Bandura, 1989; McAuley, 1993). In addition, self-efficacy has a *developmental* perspective in that it evolves over the lifespan of the individual in terms of its strength and character (Bandura, 1994).

Efficacy beliefs are dynamic, and are appraised and constructed (developed) from cognitive appraisal of four principal information sources (modes of influence): 1) *enactive mastery experiences,* or learning through personal experience; 2) *vicarious experiences,* or learning through observing others 'model' behaviours; 3) *verbal persuasion* and related types of social influences that one possesses particular capabilities; and 4) *physiologic and affective states* wherein high arousal can be debilitating for performance (Bandura, 1997).

The **first** and most powerful source of efficacy perceptions is *performance accomplishment*, in that people *learn* best from their own experiences (Bandura, 1977; 1997). Successive mastery over tasks, and especially over those of increasing complexity, helps one to refine and build skills, which in turn leads to increased self-efficacy. At the same time, failure in the *early* development of a new skill is more likely to decrease perceived self-efficacy than failure after a well-established belief in the skill has been developed. When people have strong self-efficacy beliefs they tend to attribute failure to the circumstances, poor effort on their part, or the use of poor strategies (Bandura, 1986).

The **second** source of self-efficacy 'information' – *vicarious experience (modeling)* – is concerned with *learning* that occurs through observing others successfully perform, or 'model' challenging activities. Model *competence* carries the *most weight* in influencing efficacy perceptions. When people have a great deal to *learn*, they turn to *proficient models* for knowledge, skills and effective strategies" (Bandura, 1997).

Therefore, given the large amount of caregiver learning in this study, the nurse – as a competent and knowledgeable 'model' – was well placed to help influence the caregiver's perceptions of self-efficacy. A second, albeit less powerful model, is one's peer (i.e., a person similar to oneself in age, gender, etc.), who demonstrates successful performance on a task. When it is evident that the model is displaying an *effort,* especially when carrying out a difficult or fearful task, this will have a greater influence on the individual's self-efficacy than when the task appears to be carried out without much effort (Bandura, 1997). Models can also take the form of video or written ('story') representations.

Verbal (or social) persuasion (i.e., instructive feedback) constitutes a **third** means of strengthening people's beliefs that they posses the capabilities to carry out desired activities or attain their goals. When one is successful in (verbally) persuading another person that he/she possesses the capabilities to *learn* and master a given task, that person is more likely to mobilize greater effort and sustain it (Bandura, 1997). Persuasory influences can be guided by the following three 'sources': *framing, knowledgeableness* and *credibility,* and the *degree of appraisal disparity.*

First, the way in which persuasory influences and performance feedback are *framed* can affect the appraisal of personal efficacy (Bandura, 1997). People are generally more motivated to *avoid* potential *losses in the present,* than to secure potential future gains. Moreover, when feedback is framed in terms of *gains,* (i.e., the persuader underlines *achieved progress* from point of departure), the likelihood of self-efficacy development is greater than when feedback is framed in terms of shortfalls; even if it is objectively equivalent (Bandura, 1997). Second, in regard to *knowledgeableness* and *credibility,* the more believable the source of information (i.e., the persuader) about one's capabilities, the more likely are judgments of personal efficacy to change and to be held strongly. People tend to trust evaluations of their capabilities by those who are themselves skilled in the activity, or possess a rich fund of knowledge (Bandura, 1997). Thus, nurses, endowed with knowledge and expertise, are well situated to influence their clients' self-efficacy.

Third, in terms of *appraisal disparity*, social appraisals vary in how discrepant they are from people's own beliefs about their capabilities. Depending on what individuals are told, this information may be minimally, moderately, or markedly different from how they view themselves. Social appraisals that differ markedly from judgments of their current capabilities may be considered believable for the distant future but not in the short term. The *optimal level* of *disparity* therefore, will be much *lower* for a *proximate level* of *functioning* than for future functioning. Thus, persuasory efficacy appraisals tend to be most believable when they are only moderately beyond what individuals can do at the time.

The *optimal level* of *disparity* also varies depending on whether deficient performances reflect basic *skills deficits* or *ineffectual use* of pre-existing *skills*. When individuals have the knowledge or skills, but are not using them effectively, performance improvements can be realized when individuals are convinced that they have what it takes to succeed. However, when individuals do not have the requisite knowledge and skills, such as foreseen in the caregivers in this study, social persuasion *alone* cannot compensate for skill development. Social persuasion thus serves as a useful adjunct to more powerful efficacy-promoting influences of *mastery* and *modeling*.

The **fourth** source of efficacy perceptions is concerned with the *somatic* (*physiologic*) and *affective states* that influence performance. Because high levels of aversive arousal can debilitate performance, when people are tense and viscerally agitated in stressful or taxing situations, they are less likely to expect success than when they are not experiencing such arousal (Bandura, 1994; 1997). It is underlined however that it is not the 'objective' strength of emotional and physical reactions to challenging situations that is important, but rather the way in which these reactions are perceived. People who have a high sense of self-efficacy are more likely to view their state of affective arousal (up to a point) as energizing, thus being a facilitator of performance, whereas those who doubt their capabilities will view even low levels of arousal as debilitating.

While recognizing the variability of perceptions and subsequent interpretations of physiological and emotive arousal levels in different individuals, generally, *individual perceptions* that reflect moderate arousal levels heighten attentiveness and facilitate skill or task actualization, whereas perceptions of higher arousal tend to have the opposite effect. Mood also influences people's judgements of their personal efficacy, i.e., positive mood enhances perceptions of self-efficacy, whereas despondent mood decreases it. Thus, the fourth way of strengthening efficacy perceptions is to reduce people's anxieties and fears in order to ameliorate their negative emotional proclivities and misinterpretations of physical states (Bandura, 1994; 1997).

Interventions which integrate the three self-efficacy strengthening strategies which were described previously, that is, benefiting from opportunities for mastery experiences, validating one's capability through comparisons with others (modeling), and receiving favourable appraisals from knowledgeable others (verbal persuasion), all will tend to lower arousal levels, thus lead to higher efficacy perceptions. Other strategies that help to reduce the anxieties and 'fears' of people include the use of visual imagery, 'physiological' strategies such as relaxation exercises and an empathetic approach, among others.

Geragogy and Constructivism: The Pedagogical Framework

Geragogy (John, 1988; Lebel, 1978) or *Geragogics* (Mieskes, 1970, 1971) is a pedagogical framework that provides an aging-related learning perspective. Even though *geragogy* is a relatively new discipline in terms of a pedagogical approach to the older learner, it is rooted in a long history that spans at least the last two millennia (see review, Zych, 1992). In the mid 1950's, Hans Mieskes (1970, 1971), a German pedagogue and gerontologist, coined the expression *geragogik (sic geragogics)*, in reference to the pedagogy of older persons.

Other pedagogues drew from this conception to inform educational theory for older learners, arguing for the need to develop the science and art of education for older persons; i.e., 'geragogy', as distinct from 'andragogy', and 'pedagogy' – in reference to the younger learner (Battersby, 1987; Lebel, 1978; Zych, 1992). Peterson (1983) put forth that the geragogical orientation should be relevant to those activities which enable older individuals to gain further control over their lives; and Moody (1987) stated that such an approach should help older persons to meet their particular, numerous needs; become more self-reliant and self-sufficient; and acquire relevant skills so as to reduce their level of dependency. Glendenning (1992) argued that the role of learning (in geragogy) is to augment control for the elder, and that the older individual must learn how to deal with the transitions and changes associated with later life and realize his/her full developmental potential.

Martha Tyler John (1988), focused on the *frail* elderly, and articulated a theoretical viewpoint centered on the sector of the older population with *health-related needs*. She elucidated in more depth on some of the important dimensions that need to be considered in the teaching-learning 'health' context, namely: cognition (e.g., memory, motivation, logical thinking and problem-solving); physical and behavioural concerns (e.g., sensory limitations, muscle and bone loss, circulatory impairments, etc.); as well as socio-emotional needs.

In summary, there is consensus among these pedagogues that older persons as a group, in terms of overall needs, have a learning orientation that is particular to them. This is largely related to where elders are situated on the developmental continuum; that is, in the later phase of life. Moreover, it is underscored that a certain proportion of this population (i.e., those individuals who are *'frail'* and/or are faced with *health-related* problems), have learning needs of a particular nature. In terms of this study, not only were the older individuals themselves likely to be in a precarious state of health, but they were also providing care to others with major health problems, i.e., a dementia disorder. Thus, the pedagogical orientation of geragogy served as an appropriate adjunct to both the McGill Model and Self-efficacy theory.

A complementary perspective to geragogy is the **constructivist** pedagogical orientation, having at its central core a *'learner' driven* approach (i.e., one which has evolved through theoretical notions developed around the *learner*, rather than around the pedagogue (Windschitl, 2002)). A central tenet of this philosophical approach is that the pedagogue must acquire indepth knowledge of the learner at both *individual* and *group* levels (Borg & Gall, 1989; Donald, 2000; Loewenberg Ball & Cohen, 1999).

The *group* perspective is reflected in the *"historical period"* of the individual (Borg and Gall, 1989), and encompasses cohort differences reflected in different worldviews and different approaches to learning (Donald, 2000). Given the wide spectrum of the aging population (ranging in age from the mid 50's up to the 90's), it is not inconceivable that several different cohorts are depicted in this vast population group. Examples of *cohort*-specific knowledge include the learner's *culture, language, community* and *family* (the family dimension also integral to the McGill model), and the learner's familiarity with different instructional-learning styles (e.g., expository versus discovery learning), or knowledge about current-day technology (e.g., audio-video tools, informatics) (Donald, 2000; Loewenberg Ball & Cohen, 1999).

At the *individual* level, the *age* of the learner is identified as a highly relevant physical characteristic for the pedagogue (Donald, 2000; Loewenberg & Cohen, 1999). However, given that older learners not only come from a wide range of educational backgrounds, but also have experienced a diversity of learning experiences in their lifetimes, an area of particular importance is the *learner's knowledge base* (Donald, 2000; Loewenberg Ball and Cohen; 1999). One notable example is that older learners (vs. younger learners) tend to be disadvantaged by *poor literacy* skills (see review, Tooth, Clark & Mckenna, 2000). Moreover, being knowledgeable about relevant psychological attributes of the learner is affirmed as important by several authors (Donald, 2000; Loewenberg Ball & Cohen, 1999). More specifically, Loewenberg Ball and Cohen, (1999) state that the pedagogue must consider the intentions, ideas and *beliefs* of the learner. Relevant to this study is the *belief* in one's capability, that is, *self-efficacy* (Bandura, 1987; 1997).

In summary, the theoretical framework for this study encompasses the McGill Model as the overall nursing conceptual orientation, self-efficacy as the framework for the specific learning strategies retained in the psycho-educational program, and geragogy as the elder-oriented pedagogical perspective. Underscored by this literature review, the purpose of this study was to develop and test a psycho-educational intervention focused on communication, inspired by a learning orientation emanating from geragogy and self-efficacy theory, and guided by the McGill Model of Nursing.

CHAPTER III

METHODS

This chapter is concerned with the methodology of the study and includes the research design, research hypotheses, setting and sample, description of independent variable (intervention) and data collection tools for dependent variables, procedures for recruitment and data collection, data analysis and ethical aspects.

Design

An *experimental design* with pre- and post-tests and random assignment to intervention and comparison groups was retained (Campbell & Stanley, 1963; Cook & Campbell, 1979) to test the effects of the communication-focused intervention on five dependent variables.

Research Hypotheses

Guided by the theoretical and empirical literature, the hypotheses for this study were the following. Compared with participants of a comparison group, participants in the experimental condition, that is, the 'psycho-educational' intervention group:

H I) would have a significant increase in knowledge about communication in relation to cognitive limitations;

H II) would perceive significantly fewer communication-related problems associated with the family member's cognitive limitations;

H III) would perceive a significantly lower degree of disturbance in regard to communication-related problems associated with the family member's cognitive limitations;

H IV) would perceive a significantly higher degree of self-efficacy in regard to communication skills associated with the family member's cognitive limitations;

H V) would report a significantly higher use of effective communication skills with their family member.

Setting and Subjects

The study took place in an urban – rural region with a population of around 150,000. The sample was recruited through memory clinics, a geriatric assessment unit and in the community. The *inclusion* criteria for participants were as follows: 1) being the principal caregiver of a family member or friend diagnosed with cognitive problems associated with the early stage of probable Alzheimer's disease (MMSE score: 20 to 28), 2) aged 55 or older and 3) able to communicate in French or in English. The *exclusion criteria* targeted caregivers who were participating, or had recently participated in an educational or support group or similar forum, or who were unable to assume the role of learner (e.g., had cognitive limitations).

Procedure for Recruitment

Sample

At the conception phase of the study, the size of the sample was set at 50 participants per group, as substantiated by the following rationale. According to Polit and Beck (2004), the best estimate of a population parameter of effect size (ES) is obtained from a meta-analysis in which an estimated population ES is calculated through the use of statistical values of all studies included in the analysis. When the present study was first conceived (in 2004), a meta-analysis for self-efficacy and academic performance was located wherein an effect size of .58 was reported for post-treatment effects (Multon, Brown & Lent, 1991). Guided by these findings, a medium expected ES of .5 was proposed. Based on this ES, and significance level of .05 (one-directional *t*-test), with a power greater than 80%, a sample size of 100 (*n* = 50 per group) was set initially (Cohen, 1988).

With respect to the final determination of sample size, Cohen's table indicates that for a power of 80% and alpha of 5%, sample sizes ranging from 20 to 50 per group would permit the detection of medium $(d = .5)$ to large $(d = .8)$ effect sizes. In the early stage of the study, access to potential participants was adversely affected due to the unforeseen reduced operations of the memory clinic in one large university health care setting Thus, after eighteen months of recruitment, it was decided to conclude the data collection phase with 25 subjects in each group, this sample size being situated within the desired range of 20 to 50 per group for the related range of medium to large effect sizes.

In total, 57 caregivers accepted to participate in the study. Participants were randomly assigned to one of two groups: a nursing psycho-educational intervention group, or a comparison group where they received a printed information flier on 'Memory and Communication' (College of Family Physicians of Canada, 1999). Of these 57 individuals, seven either did not take part, or did not complete the study. Four persons withdrew before starting the study because their family member had died or was ill, two could not participate because of personal reasons, and one withdrew after completing the first series of questionnaires, (i.e., could not return for Time 2 and Time 3 sessions).

In the dropout group, three persons had been assigned to the intervention group and four had been assigned to the comparison group. Altogether, fifty participants completed the entire study, with twenty-five in each group. A summary of the sampling process for participants is presented in Figure 1.
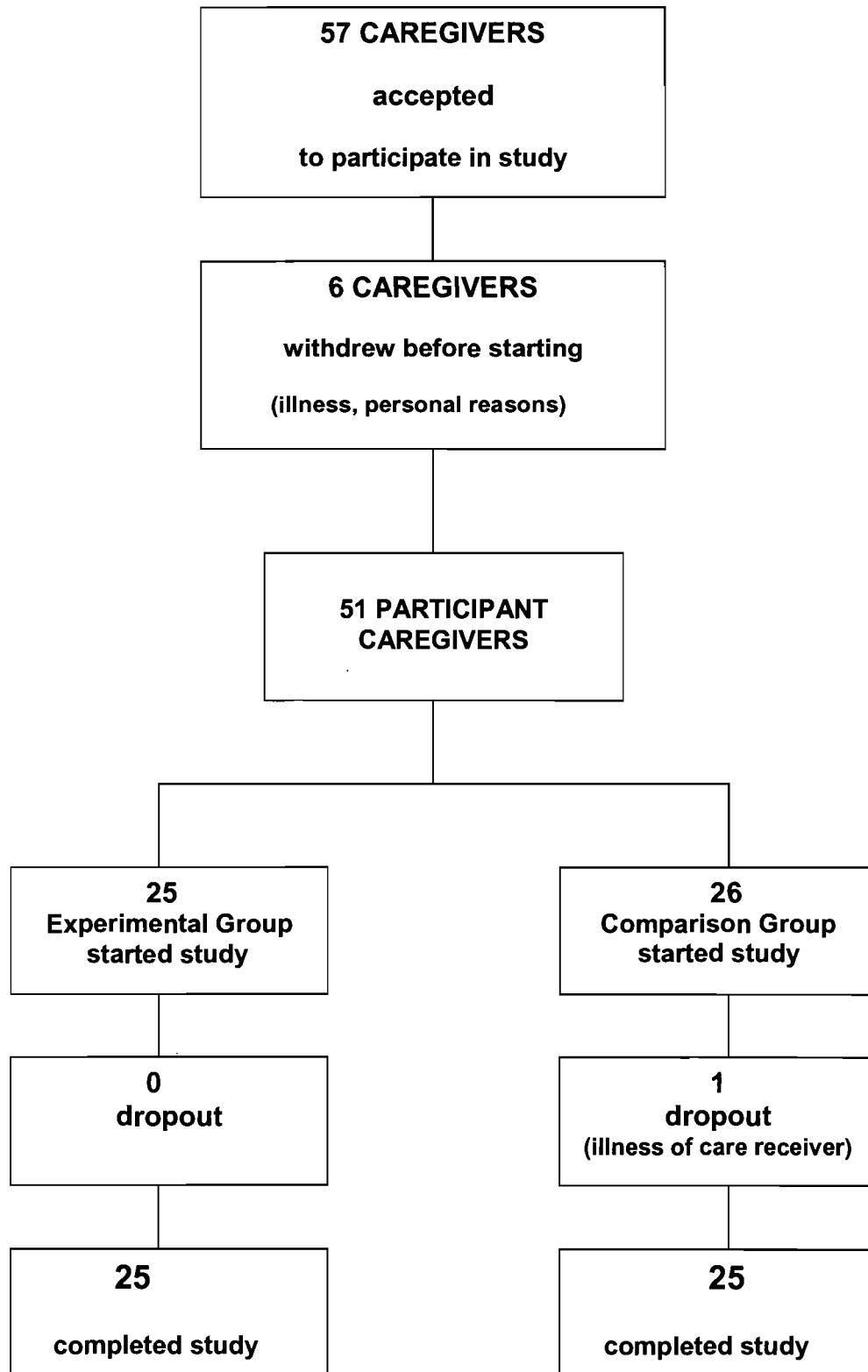
Figure 1. Summary of Sampling process

Recruitment Modalities

In the preparatory phase of the project, from October to December 2005, collaborative relationships were established with key professionals, i.e., physicians, nurses and psychologists associated with memory clinics and geriatric units at two university affiliated care facilities. These experts helped to identify the modalities through which the sample could be recruited and gave suggestions for improving the feasibility of the study. Contacts were also made with relevant groups and organizations in the community. Two *principal* recruitment modes were retained for this study. In the *first* one, the researcher provided printed information about the study to professionals at relevant health care facilities. The professional then shared this information with prospective participants (caregivers) and/or patients (care receivers). The nurse researcher conducted the follow-up with these individuals, usually by telephone. At the facility, prospective participants were also identified through retrospective verification of files of their care receivers (patients) who had been treated at the care establishment within the past year. The researcher made contact with potential participants by communicating with those patients who met the relevant criteria, and requested their support to gain access to their respective caregivers. In the *second* recruitment mode, the project was presented to the community, i.e., at educational events, to physicians and to community organizations where potential participants were present (e.g., Alzheimer's Society, Senior's groups, Retiree clubs, etc.). Individuals who expressed an interest were contacted *in situ* or by telephone.

For each individual who was interested in the study, the researcher met with him/her for about one-half hour to provide more details about the project, including information about the nature of questionnaires, the oral question, the randomization procedure and for those in the comparison group, the possibility of receiving the program at a later date (after Time 3 measures) – if they so desired. They were also told that they could make their decision to participate (or not) at a later time. Most persons decided to participate in the study at this meeting, while several did so at a later date, usually within a week of the meeting (see Recruitment Guidelines in Appendix A).

Once the individual accepted to participate, he/she was *randomly assigned* to the experimental or comparison group. The randomization process was determined by statistical procedure, i.e., coin toss. Letters were sent to participants confirming their participation, the intervention mode to which they had been assigned, along with the date and place of the first meeting (see Letters to Participants in Appendix B).

Description of the Independent Variable – Intervention

A Psycho-educational Nursing Intervention focused on Communication
for the Caregiver of an Individual with Cognitive Problems associated with early AD

This psycho-educational intervention, guided by the McGill Model of Nursing, and conceived within a pedagogical framework for the older learner (i.e., geragogy), encompasses an individualized, learner-driven (i.e., constructivist) orientation. Within this learning perspective, the four self-efficacy strengthening strategies (i.e., skills mastery, modeling, persuasion and reducing aversive emotional arousal) were integrated into the program (see Summary of Program in Appendix C).

Modalities of 'Individualized' Intervention Program

The experimental intervention consisted of five (1½ - 2 hour) individualized sessions, held at weekly intervals. The rationale for retaining five sessions emanates from a meta-analysis of caregiving studies wherein the strength (dosage) of an intervention was considered to be 'moderate' for 3 – 5 sessions, and 'medium-high' for 6 – 10 sessions (Brodaty, Green & Koschera, 2003). Given that the great majority of these interventions were conceived in a group mode, by extrapolation, a moderate dosage of 'five' sessions from a *group* perspective assumes a higher degree of intensity when conducted at the *individual* level. For this reason, the five-session, more intense, individualized format was adopted. At each session, the participant was provided with a paper copy of the module that would be reviewed at the subsequent meeting. Thus, at the end of the five sessions each participant had a complete copy of the program in his/her possession.

Content and Structure of the Psycho-educational Program

The content domain of the program was drawn – in part – from the clinical practice of the researcher. Having observed numerous instances of communication difficulties between family members and their next-of-kin with cognitive problems, the nurse-researcher was prompted to study this field in more depth. An evidence-based program founded upon empirical data from the scientific literature in nursing, medicine, neuropsychology and speech language pathology that targeted the communication domain relevant to cognitive problems associated with early Alzheimer's disease was developed. The five modules (components) of the program were formulated around five communication subject areas.

The program was conceived at a grade five to six level of comprehension and a larger print size was retained to facilitate reading. The program was developed in **both** *French* and in *English*.

The content areas of the **five** modules (subject areas) are as follows:

The *first* module, entitled *'Memories are Important – What do we do Today?'* is concerned primarily with the communication related areas that are 'preserved' in this early stage of dementia. Its focus is on maximizing the communication potential of the affected person, and addresses the ways in which these strengths can be exploited in regard to response time, contextual cues, verbal validation, and so forth.

The *second* module (*'Remembering and forgetting: Where did I put my keys?'*), deals primarily with short term memory limitations which lead to communication difficulties related to forgetfulness and repetitive speech, which are experienced by all persons in this stage, and encompasses such topics as loosing things, forgetting to accomplish or complete tasks, not remembering what one had heard/read and orientation difficulties. Long-term memory strengths are also integrated into the module.

The **third** module (*'Why doesn't he – she listen? How can I get his – her attention?'*), deals with physical environment aspects and attention-concentration deficits that contribute to communication problems and includes the role of environmental influences or distracters (e.g., noise, social events, crowds, and similar contexts).

The **fourth** module (*'Caring for my family member'*), is concerned with communication issues in regard to 'everyday care' areas, (i.e., activities of daily living and instrumental activities of daily living), and encompasses such areas as judgement, reasoning and visual-spatial and executive functions.

The **fifth** module (*'Emotions and my family member: What can I do?'*) deals with the communication difficulties related to the emotive – affective domain and addresses such problems as mood variability, unawareness and sadness, confusion in relation to the emotive component, among other subjects. This module also serves as an overview for the first four modules albeit from an emotions perspective (see Summary of Program in Appendix C).

Validation of Content of Program

Two geriatricians and a head nurse of a geriatric evaluation unit at a university institute of geriatrics reviewed the program. There was a general consensus in regard to both the comprehensiveness of the program (i.e., it covered the subject domain in a complete manner), and the appropriateness of the comprehension level in relation to the age of the prospective participants.

In addition, a nurse who had filled the role of principal caregiver of her mother (diagnosed with Alzheimer's disease) over the past few years also reviewed the program. She made useful comments about its contents, and concurred that its overall content was relevant, easy to understand and comprehensive (i.e., encompassed the key subject areas).

Pre-test of Program

The program was *pre-tested* with two caregivers who had cared for or were caring for family members with 'moderate' stage Alzheimer's disease. Different modules were tested with each of the two caregivers. A number of minor refinements were made to all five modules subsequent to this trial. The complete program was *pre-tested* with one family member of an individual with cognitive problems and no further adjustments were proposed.

Consistency of Intervention

Each of the five **modules** was conceived around a similar format, ensuring the administration of the intervention in a consistent manner at each session. The format of *each module* commenced with a brief overview of the ten **topics** covered in the preceding module (exception – first module). This was followed by an overview of the ten *new* topics (of the current session), permitting the participant to identify those topics that were more important or relevant for him/her, (i.e., subjects that reflected his/her most urgent learning needs). These 'more pertinent' topics were addressed in greater depth at the beginning of each session. Then, the remaining (less pertinent) topics were dealt with in a synthesized manner until all ten topics had been covered.

Each **topic** also followed a specific format. It commenced with a definition of the topic, followed by a review of the learning objectives for the topic and then a review of four 'models' (short stories or scenarios that depicted situations relevant to that topic). Two models represented 'better' communication strategies and two models represented 'inadequate' communication strategies.

Following the review of the models, a discussion took place in regard to the participant's particular context and potential strategies to address the caregiver's communication concerns were then identified. Practice exercises in regard to communication problems were subsequently conducted in relation to the need(s) of the participant (see Summary of Program in Appendix C).

Monitoring of Intervention

In order to ensure conformity of the intervention throughout the study and to keep track of the communication-related strategies that the participants were implementing (with a particular focus on those relevant to the case scenario questions), a checklist was completed for each participant. This tool allowed the nurse researcher to monitor the program from session to session to ensure that all components were covered in a consistent manner for each individual (see Intervention Monitoring Checklist in Appendix D).

Information 'Flier' for Comparison Group

Content and Modalities of Information 'Flier'

The comparison group also received a treatment, as deemed appropriate for this design (Brink & Wood, 1998). In this group, participants were provided with printed material on the subject of *memory problems*, adapted from the document entitled 'Memory Loss with Aging' (for the person with memory problems), published in both English and French by the College of Family Physicians of Canada (1996) (see Information Flier in Appendix E).

It was posited that offering a helpful approach to both groups would lead to a greater likelihood of obtaining a favourable response from potential participants, given that all prospective participants would know that upon acceptance, i.e., at the outset, they would benefit in some way. Moreover, prior to randomization, participants were informed that members of the comparison group would also be offered an abridged program, at a future time (after the Time 3 measures). In sum, when *both* groups are deemed to receive a benefit, this feature strengthens the overall design.

Description of Data Collection Tools

The instruments used to measure the key variables in the study are described in this section. The dependent variables were: caregiver knowledge, caregiver perceptions of communication difficulties and the degree of caregiver perceived disturbance in relation to said difficulties, caregiver communication self-efficacy and caregiver communication skills. The following strategies were retained to evaluate these variables.

General Considerations for Measures

Four *quantitative* measures and one *qualitative* tool were used to evaluate the dependent variables (see Table 1 for Summary of Measurement Instruments). All measures are founded upon the scientific literature in nursing, medicine, neuropsychology and speech language pathology relevant to the communication domain concerned with cognitive problems associated with early AD. Given the unavailability of relevant tools in the literature, the researcher conceived certain measures. The measures were formulated at a grade six level of comprehension, with a larger print format to render better visibility for the older participant. In order to minimize distractions for the participant, only one to four (maximum) questions were placed on a single (questionnaire) page. All measures were developed in ***English*** and in ***French***. Additional information about the measures, along with general instructions about their administration, is provided in Appendix F.

Validation

The measures were submitted to experts in the field (i.e., a nurse, physician, neuropsychologist and speech language therapist) for evaluation. Using an assessment grid, these experts judged the items in the measures to be both representative of the 'cognitive problems' domain associated with early stage AD, as well as comprehensive (i.e., covered the complete spectrum of the domain). They also confirmed that the items were easy to comprehend and that the tools were appropriate for the potential users (i.e., older individuals) (see Assessment Grid for Experts in Appendix G).

Table 1

Summary of Measurement Instruments

Name of Measure	Number of Items - Questions	Response Format	Cronbach's alpha (α)
Questionnaire on Caregiver Knowledge	50 items	Three (3) responses: *True – False – Don't Know*	0.91
Questionnaire on Communication Difficulties perceived by the Caregiver and	50 items	Five (5) responses: *Never – Not very often – Sometimes – Quite often – All the time*	0.92
Degree of Disturbance perceived by Caregiver in regard to these Difficulties	50 items	Five (5) responses: *Not at all – A little – Moderatley – Very much – Extremely*	____
Caregiver Self-efficacy scale for Communication Skills	50 items	Visual analogue scale: 0 to 100 mm.	0.96
Communication Skills Questionnaire	50 items	Six (6) responses: *Does not apply On occasion Less than one-half of the time About one-half of the time Most of the time All of the time*	0.94
Case Scenarios - Open Questions	Three case scenarios	Unstructured response (Verbatum or Written)	NA

NA: Not applicable

Translation of Instruments

Measures were initially formulated in English, and then translated into French. Verification of the English-to-French translation was conducted using Brislin's (1970) forward-backward method. Brislin's methods are widely used and are generally acclaimed to ensure 'semantic equivalence' in the translated product (Burns & Grove, 2001; Polit & Beck, 2004).

Pre-tests

All measures were *pre-tested* with family members (*n* = 2) of two individuals with cognitive problems associated with the moderate stage of Alzheimer's disease. Both care providers confirmed that the measures were easy to understand and to complete and that all items (questions) were relevant to the caregiving context of the study.

Description of Quantitative Data Collection Tools

Four 'quantitative' measures were used to evaluate the five domains (modules) of the intervention program. The *first* part of *each* measure evaluates the communication related subjects relevant to 'preserved' cognitive functioning in the person with memory; the *second* part is largely centred on the communication problem of 'forgetfulness'; the *third* one deals primarily with communication problems related to attention – concentration deficits; the *fourth* one is linked to communication problems in conjunction with activities of daily living and instrumental activities (related to difficulties in such areas as reasoning, judgement and visual-spatial and executive functioning); and the *fifth* one addresses the 'emotive' or 'affective' communication related aspects and – in part – serves as a review of the majority of subjects addressed in the first four modules of the program.

While each measure is formulated around the same five subject domains, *each instrument* is conceived around a particular concept. To further explicate, the wording of the items (topics) in the particular tool depicts the central concept of that measure. More specifically, items in the *Knowledge* questionnaire are presented in terms of being knowledgeable about the particular communication-related subjects in the early AD context. In the questionnaire concerned with *Communication difficulties* and *Degree of disturbance related to these difficulties*, items are couched first, in terms of the specific communication difficulties experienced by the caregiver and second, in regard to the degree to which these difficulties are perceived as disturbing by the caregiver. In the *Self-efficacy* Scale, items are worded from a perspective of perceived capability or *belief* in one's ability to carry out a task-skill. In the *Skills* Questionnaire, items are phrased in terms of actually carrying out the task-skill, i.e., the act of doing something.

Furthermore, not only are the five content areas repeated throughout the four questionnaires, but also the essence of *each item* is repeated from one questionnaire to another. The direct relationship that exists between *any particular items* throughout all four measures is illustrated as follows. For example, item 7 in the third content area of each questionnaire deals with the influence of noise on communication. In the measure concerned with *knowledge*, this item is linked to participant's knowledge about the effect of noise upon communication. In the questionnaire on *communication difficulties* and *degree of disturbance* perceived by caregiver, the caregiver identifies whether 'noise' in relation to communication is a problematic variable for him/her. If the answer is affirmative, the participant evaluates the degree to which the noise variable is problematic for him/her. In the *self-efficacy* scale, the caregiver evaluates his/her level of confidence in regard to dealing with the noise related communication concern, and in the *skills* questionnaire the caregiver indicates how he/she actually responds to, or deals with the noise related communication subject. These measures are described in more detail in the next section. The internal consistency of the *degree of disturbance* measure could not be determined because too many of the responses 'did not apply'. For the other measures, internal consistency was calculated with the data gathered in the study and resulted in Cronbach's α ranging from 0.91 to 0.96.

'Caregiver Knowledge about Communication' Questionnaire

Knowledge was measured with a 50-item questionnaire, structured in a closed question format, appropriate for gathering factual (versus attitudinal) data (Polit & Beck, 2004). Respondents chose one of three possible answers; *true, false* or *don't know,* (e.g., 'the person with memory problems always remembers where he/she has put his/her keys'; response choices: *true, false* or *don't know*). The latter response option is retained when a respondent may be undecided or has minimal knowledge about a subject (Polit and Beck, 2004). The correct responses were computed – in relation to a potential maximum score of 50 (for the *total* measure), and a potential maximum score of 10 (for *individual* modules). The internal consistency reliability coefficient was 0.91 for this measure.

'Questionnaire on Communication Difficulties with the Person with Cognitive Problems as Perceived by the Caregiver and the Degree of Perceived Caregiver Disturbance in regard to these Difficulties.'

The measurement *perspective* of this measure is based on a questionnaire format developed by Teri, Truax, Logsdon, Uomoto et al.. (1992). Teri's instrument (albeit not focused on the early stage) was conceived to evaluate first, the *frequency* with which caregivers perceive *problematic behaviours* in patients with dementia, and second, *caregiver reactions* to these behaviours. A key finding in their study was that the frequency of a patient's behaviour was not necessarily related to greater (stronger) caregiver reaction (Teri et al., 1992). Given that no tool has been developed to measure these two aspects in regard to communication problems relevant to cognitive problems associated with the *early* phase of AD, Teri et al's tool was adapted to address this subject. This questionnaire is composed of two dimensions; *first,* communication difficulties encountered with the person who has cognitive problems associated with early AD as perceived by the caregiver and *second,* the degree to which the caregiver is disturbed by these difficulties.

The *first* part of each question encompasses perceived communication difficulties (e.g., My family member finds it *difficult to understand* when others use words like 'it', 'they', or 'that'). It is structured in a multiple-choice format with *five* graded alternatives (Polit and Beck, 2004), in a Likert scale format (ranging from (0) *Never occurred* to (4) *Occurs daily or more often*), this being the same format as in Teri et al's (1992) measure wherein the caregiver identifies the frequency of occurrence of problematic behaviours in the person with dementia. The *second* part of each question deals with the degree to which the caregiver is disturbed by communication difficulties (e.g., *It disturbs me* when my family member finds it *difficult to understand* words like 'it', 'they', or 'that'). The *four* graded alternative responses (ranging from (0) *not at all* to (4) *extremely*) are the same as in Teri et al.'s (1992) measure, wherein the caregiver evaluates the degree to which individual behaviours currently bother or upset the caregiver. For each of the two parts of these questions, item scores varied between 0 and 4. The means of these scores – ranging from 0 to 4 – were calculated for the *total* measure (50 items), and for *individual* modules (10 items per module).

This questionnaire has several strengths. First, it has *a priori* content validity given that it is founded upon the scientific literature. Its strengths were also confirmed by experts, who deemed the tool to be representative of the cognitive problems domain associated with early stage AD, as well as comprehensive, i.e., it covered the complete spectrum of the domain. A second strength is that it is based on a validated tool, the 'Revised Memory and Behaviour Problems Checklist' (RMBPC) (Teri et al., 1992). Teri tested this measure with caregivers (n = 201) of individuals primarily in the early and moderate stages of dementia, this sample representing a somewhat lower level of cognitive functioning than that of the care receivers in the present study.

The 'degree of caregiver upset' in Teri et al.'s tool was measured in relation to the patient's behaviour in the *present*, as was done as well in the tool conceived for this study. In addition, each of the seven memory problems that had been identified in Teri et al's tool were included among the much larger range of cognitive-related communication problems encompassed by the measure in this study.

Another strength of Teri's measure is the overall scale reliability of the RMBPC, with alphas of .84 for patient behaviour and .90 for caregiver reaction. Concurrent and discriminant validity were confirmed through comparison of RMBPC scores with well-established indexes of cognitive impairment, caregiver burden and depression (Teri et al., 1992). In this study a Cronbach's α 0.92 was reported for the first part of this measure i.e., the presence of *communicaton difficulties* (although not calculated for *degree of disturbance* because of too many '*does not apply*' responses).

Caregiver Self-efficacy Scale in regard to Communication Skills

The 'Caregiver Self-efficacy Scale for Communication Skills', is comprised of 50 items distributed among five sub-scales (ten items per scale) and evaluates the participant's level of self-efficacy for communication skills in relation to cognitive problems associated with early AD within the five subject areas retained for the program.

Self-efficacy scales are unipolar, and range from '0' to a maximum strength (Bandura, 2001). The level (strength) of the efficacy belief is typically indicated on a '0' to '100' point scale; the scale format ranging from '0' (*cannot do* or *not at all confident*), to the highest level of perceived efficacy of 100 (*certain can do* or *completely confident*) (Bandura, 1977, 1997). The wording of items reflects judgements of capability, thus items are phrased in terms of '*I am confident that I can do*' (Bandura, 1997). The single judgement format wherein both judgements of *capability* and *strength* are integrated into a single item within a one-scale format is the most common measurement method (Bandura, 1997; Maibach & Murphy, 1995; Lee & Bobko, 1994), and was retained in this study. The measurement approach to self-efficacy lends itself to magnitude scaling, in particular, the utilization of an analogue scale (Gift, 1989). A measure is obtained by asking the person to place a vertical mark through the line to reflect the strength (intensity) of the stimulus (i.e., the strength of efficacy beliefs). A horizontal scale was retained for this study, and the value of the 'stimulus' was obtained by measuring the distance between the left end ('0') of the line and the mark made by the participant, (maximum distance or score) being '100').

Another strength of Teri's measure is reflected in the overall scale reliability of the RMBPC - reported as good, with alphas of .84 for patient behaviour and .90 for caregiver reaction. Concurrent and discriminant validity were confirmed through comparison of RMBPC scores with well-established indexes of cognitive impairment, caregiver burden and depression (Teri et al., 1992). A Cronbach's α 0.92 was reported for this measure.

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Given that the specific items in this communication self-efficacy scale were drawn from the evidence-based literature relevant to the person with cognitive problems associated with early AD, it is purported that they represent this domain and thus possess *face validity* – a critical dimension of self-efficacy scales (Bandura, 2001). The internal consistency reliability coefficient of 0.96 was reported for this study.

The participant evaluates his/her perceptions of self-efficacy in regard to specific communication difficulties that he/she may encounter (e.g., 'If my family member has difficulties to remember something that I have told him/her, *I am confident* that I can help him/her to remember by WRITING a reminder note). Bandura (2001) recommends that self-efficacy perceptions should be recorded privately, thus a paper-pencil format was retained. However, considering that the interview format has been found to be clearer and easier to use by *older* individuals (Zeiss et al., 1999), and given that Telch, Bandura, Vinciguerra et al. (1982) reported that face-to-face reporting for self-efficacy did not differ systematically from a confidential self-report format, the interview format was also made available to participants (although none chose to use it). In the computation process, first responses to each item were measured, and then added to render a total score. Mean scores were then calculated for the *total* measure (50 items), and for *individual* modules (10 items per module). Mean scores can range from 0 to 100.

Caregiver Communication Skills Questionnaire

The 50-item Caregiver Communication Skills Questionnaire is conceived as a Likert scale with a multiple choice, graded alternative format. This questionnaire provides information in regard to both *intensity* and the *direction of opinion* of the respondent (Polit and Beck, 2004). The response format requires first, a determination by the caregiver whether the item was *relevant* for the caregiver's *current context* (e.g., When my family member/friend seems to be 'lost', (that is, he/she does not know where he/she is, even in his/her own home), I tell him/her where he/she is, and talk about familiar things.')

For non-relevant items, the respondent replies (0) *does not apply*, and for the relevant items the caregiver chooses (out of five alternatives), the one that best describes the extent to which he/she actually carries out the appropriate skills in regard to the identified communication difficulties; that is, from (5) *all of the time*, to (1) *on occasion*. The means of valid item scores (potential range from 0 to 5) were calculated for the *total* measure (50 items), and for *individual* modules (10 items per module). Scores of '0' were considered valid if a response other than '0' had been indicated on at least one of the measurement times. If the respondent answered '0' (*does not apply*) at all three measurement times, this was not included in the calculations. A Cronbach's α 0.94 was reported for this measure.

Qualitative Data Collection Tool

Case Scenario Questions

The qualitative strategy encompassed three *case scenarios* with open questions, depicting some of the most frequently encountered communication related problem situations in the caregiving context of the individual with cognitive problems associated with early AD (see Appendix F) The rationale for including this qualitative strategy was to help ascertain through another perspective whether the participant had acquired the relevant knowledge and communication skills, and to determine whether the learned skills were being put into practice. Integrating qualitative and quantitative data in a single study is a form of triangulation, the goal being to validate outcomes via two perspectives. In the present study, the qualitative outcomes served to validate the results of three topics in two of the four quantitative measures, i.e., *caregiver* knowledge and *caregiver* communication skills.

This strategy gave participants an opportunity to express themselves freely and provided insight through an alternate perspective on how these caregivers were dealing, or would likely deal with frequently encountered communication related situations. The *first* case scenario was concerned with the subject area of 'forgetting', a *second* one dealt with 'naming' and 'word finding' difficulties and a *third* scenario addressed the communication problems that can result when the affected individual encounters difficulties with activities of daily living and instrumental activities of daily living.

Sociodemographic Questionnaire

A questionnaire was developed to gather sociodemographic information about caregivers and also their care receivers. Information about the *caregiver* included: age, gender, education, living arrangements, present employment status, relationship to person with cognitive problems, duration of caregiving and care provided to the care receiver, formal assistance and/or services, nature of perceived support from the caregiver's social network, and perceived state of health (as defined in the *'Enquête sociale et de santé'* ('Health and Social Survey'), Québec, 1998).

Information about the care receiver (family member) with cognitive problems included age, gender, and length of time with cognitive problems, whether the care receiver had received a diagnosis from a doctor and time since diagnosis, and if other professionals had been consulted (see Sociodemographic questionnaire in Appendix H).

Procedure for Data Collection

Data were collected over twenty months, from February 2006 to September 2007, inclusive. Three research assistants (two nurses and a social worker) collected pre and post intervention data. They received a six-hour structured training program wherein they learned about the modalities of the research project, as well as how to remain impartial and avoid leading the participants to answer in any particular direction. Mock sessions were conducted in regard to completion of measures. Research assistants were blind to treatment or comparison group assignments. The nurse researcher met with both research assistants and participants after Time 1 measures were administered to the first three participants. These meetings permitted the researcher to verify if participants had difficulties to complete the questionnaires and to ensure that the correct sequence had been followed for administration of measures. It also provided an opportunity to respond to their preoccupations.

The majority of participants in the two groups came to a central location (at a health care facility) for both the administration of measures and the intervention sessions. The meeting room was quiet, well lit and furnished with comfortable and appropriate furnishings (i.e., tables, chairs, display-writing board, etc.). In a few instances, usually because of the participant's physical limitations, the measures and program were carried out at the participant's home. Most participants completed the measures at all three measurement times with the same research assistant.

After completing the Sociodemographic questionnaire and signing the Consent form, the *first* measure presented to participants at each of the measurement times was the 'Case scenario – Open question'. The research assistant read the case scenario and question aloud and the participant followed on his/her own sheet. Participants had the option of either writing their answers or giving them orally. With the exception of one person who wrote out her answers at all three measurement times, the responses of the other participants were taped.

The rationale for this sequence was to avoid any possibility for the quantitative measures (which followed) to serve as helpful 'cues' to participants when responding to the open questions. To control for the effects of learning or recall of questions submitted at the preceding measurement time(s), a different scenario was presented at each measurement time.

Second, the remaining four paper questionnaires were administered through an interview self-report format. The research assistant read each question aloud at the first session (Time 1), however for subsequent meetings (Times 2 and 3), participants had the choice of either having the research assistant read each question aloud (with the participant following on his/her own copy), or to read the questions silently to him-herself. All participants wrote their own replies on the questionnaires. To reduce the likelihood of missed responses, the research assistants verified the responses to the questions (in the four questionnaires) immediately after completion before participants left the meeting.

The 'Knowledge' questionnaire was the **first** of the four quantitative measures to be administered (after the case scenarios). The two-part Questionnaire on 'Communication Difficulties with the Person with Cognitive Problems as Perceived by the Caregiver and the Degree of Perceived Caregiver Disturbance in regard to these Difficulties' was the **second** quantitative measure to be administered in the study. The **third** and **fourth** quantitative measures that were administered were the Self-efficacy questionnaire and the Communication Skills questionnaire. The rationale for this sequence is that knowledge is the antecedent of self-efficacy, and self-efficacy is the antecedent of action or behaviour (i.e., communication skills).

Once Time 1 measures had been conducted, Time 2 measures were scheduled seven weeks later. In the experimental group, this coincided with one week after completion of the program (intervention). The rationale for Time 2 measures was to determine the short-term effects of the program. Time 3 measures were scheduled five weeks after Time 2. In the experimental group, this coincided with six weeks after completion of the program (intervention). The rationale for Time 3 measures was to determine if there were longer-term effects of the program. The data collection schedule (timeframe of administration of measures) is depicted in Figure 2.

The program (intervention) was administered by the investigator to the Experimental group and commenced one week after Time 1 measures. Weekly meetings took place with the participant until all five modules had been covered. At each meeting the participant was provided with a copy of the module document that would be covered at the subsequent session. The information flier was distributed to participants in the Comparison Group after completing the Time 1 questionnaires.

In terms of participation in the program, all participants in the Experimental group completed the five modules, and most participants did so within the five-week period for most participants. Two individuals completed Modules 4 and 5 on the same day, however additional time was accorded to make this possible. In a few cases, it was necessary to extend the one-week period between sessions.

Groups	Measurement Times		
	T1	T2	T3
Intervention Group	O X	O	O
Comparison Group	O	O	O

X = INTERVENTION   **O = OBSERVATION** (measurement time)

T1: 1 week pre intervention

T2: 1 week post intervention

T3: 6 weeks post intervention

Figure 2. **Overview of Data Collection Schedule**

Data Analysis Plan

Sociodemographic variables for participants and care recipients were examined and analyzed, and a descriptive profile of the sample was developed. Descriptive statistics were calculated to determine if there were significant differences between experimental and comparison groups. The Student *t*-test and the Chi-Square statistics were used, as relevant to categorical and continuous variables. Analyses of covariance (ANCOVA) (Group X Time) were conducted to test the research hypotheses. Two assumptions of statistical procedure were examined: first, homogeneity of variance-covariance matrices and second, sphericity. The normality of distribution assumption was verified for all dependent variables. No deviations were identified at the alpha level of 0.05.

In addition to the assumption of normal distribution, the analysis of covariance (ANCOVA) included the assumption of homogeneity of regression curve. This assumption was respected for all Total scores and Module scores, with the exception of Self-efficacy. Examination of outliers revealed one aberrant value (for one participant) for the self-efficacy variable. However, even with the removal of this participant's scores, the assumption of homogeneity of regression curve was not respected, thus for this variable it was decided to proceed to analysis of variance (ANOVA). Given that exploratory analyses had been carried out on the modules, it was decided to apply the Bonferroni correction. Only results that were significant at $p < .01$ were retained.

Analysis of Case Scenario Questions

Two research assistants transcribed the tape recordings verbatim. Data were then analyzed using the template analysis style (Polit & Beck, 2004). A template (analysis guide) was developed, to which the narrative data was applied. A preliminary, rudimentary template was conceived respecting the nature of the data that was being sought out, as relevant to communication knowledge and skills. This initial template was revised as more data was gathered and analyzed. The final organization and management of data obtained from the template analysis encompassed a categorization scheme wherein data were coded according to three categories or themes, i.e., emotive, behavioural and 'other'.

One category of response was termed 'emotive', that is, the caregiver verbal response included such comments as: remain calm, be patient, reassure one's loved one, and not make an issue or a big deal of the problem. A second category of response was termed 'behavioural-verbal' and encompassed responses such as: informing the family member that he/she would: '*help* him/her with a word he/she was unable to say (i.e., help to 'find' or identify the word), *help* him/her find a lost item or *help* him/her with dressing; or '*distract*' the person if item cannot be found or if the word cannot be identified.

The third category of response encompassed the <u>other</u> types of responses, and included primarily environmental components, e.g., 'organizing' or 'maintaining' the physical environment', 'doing' something for the person or organizing 'things' to make it easier for the individual (e.g., preparing clothes in advance or rendering better visibility of environmental components), to facilitate communication.

The data was then compiled by frequencies, followed by Chi Square analyses. Examples of communication strategies provided by participants in the experimental group during the learning sessions were recorded and served to further illustrate the learning that had taken place in regard to the three subject areas addressed in the case scenario questions.

Ethical Considerations and Consent

Approval for the research project was obtained from the Research and Ethics Committee of the Institut universitaire de gériatrie de Sherbrooke affiliated with the Université de Sherbrooke on June 17, 2005 (to June 2006). Due to the supplementary time required to complete the project, additional approvals were obtained from the Committee on June 19, 2006 (approved extension date: June 2007), and June 23, 2007 (approved extension date: June 2008) (see Research and Ethics documents in Appendix J).

The following dimensions were addressed in the consent form: information about the nature of the project and the process for participation, benefits and risks of participation, how confidentiality would be assured in regard to information (including storage and disposal of completed questionnaires and audiotapes), and conditions of participation in the project. The consent form was provided to the participant prior to the first meeting with the research assistant thus allowing the participant to become familiar with its contents. At the first meeting with the participant, the research assistant reviewed the consent form and answered questions before obtaining the participant's signature. A second copy of the consent form was provided to the participant (see Consent form in Appendix I).

A number of initiatives were put into place to protect confidentiality of data and the identity of participants. All questionnaires, record forms, audiotapes and any other material related to specific participants was identified by code numbers. A record book of codes with names of participants was maintained by nurse researcher and kept in locked filing cabinet to which only she had access. Audiotapes and questionnaires were turned over to the nurse researcher immediately after the research assistant met with participant, and then locked in a filing cabinet. These materials will be destroyed five years after the final analyses have been completed.

Since both groups had access to potentially helpful 'interventions', from an ethical perspective it is posited that neither group was 'disadvantaged' in the study. Furthermore, participants were informed that if they were assigned to the comparison group, they would still be offered the program – albeit after the administration of the third session of measures (T3). Moreover, given that both care facilities identified for this study serve bilingual clients (English and French), and since the intervention was offered in both languages, it was accessible to the large majority of qualified users of the respective establishments. If, in the course of the study, the participant and/or his/her care receiver required health care, the individual(s) was referred to the appropriate professional.

CHAPTER IV

RESULTS

This chapter is divided into four sections: 1) descriptive characteristics of the sample, 2) descriptive characteristics of the care recipients, 3) results of hypotheses testing and 4) results of the data related to the case scenario questions.

Descriptive Characteristics of the Sample

An overview of the sample is presented in Table 2. Group equivalence was assessed using chi-square tests for categorical variables and two-tailed t-tests for continuous variables. The two groups, i.e., experimental and comparison, were equivalent on all variables except age. Participants in the experimental group were significantly younger ($\bar{x}$ = 59.12; SD = 8.56) than those in the comparison group ($\bar{x}$ = 64.8, SD = 10.5): (t_{48}=2,095, p = 0.041) (two-tailed t-test).

Participants (n = 50) were Caucasian, predominantly female (n = 41), the majority aged over 55 years (n = 41), and primarily family members (n = 44) of the person with cognitive problems, i.e., 26 children and 18 spouses. A larger proportion (n = 29) lived apart from the family member. In regard to education, almost all had completed secondary school (n = 48) and all were able to read fluently. Chi-square analyses were performed using three categories of education levels (i.e., participants with primary and secondary education levels, participants with collegial education and those educated at the university level). No significant differences were identified between the experimental and comparison groups.

Most participants (n = 43) judged their health to be *good* or at a higher level (i.e., *very good* or *excellent*), and most individuals (n = 42) reported having received an average or a *great deal* amount of support.

Table 2

Characteristics of the Sample (n = 50)

	Sample (*n* = 50)	**Experimental** Group (*n* = 25)	**Comparison** Group (*n* =25)
Age			
Range	39 – 81 .	40 – 77	39 – 81
Mean ($\bar{x}$)	61.96	59.12*	64.8*
SD	9.91	8.56	10.50

* (p < 0.05) (two-tailed t-test)

	Frequency (%)	**Frequency (%)**	**Frequency (%)**
Sex			
Female:	41 (82%)	20 (80%)	21 (84%)
Male:	9 (18%)	5 (20%)	4 (16%)
Ethnicity			
Caucasian	50 (100%)	25 (50%)	25 (50%)
Education			
Primary	2 (4%)	0 (0%)	2 (8%)
Secondary	12 (24%)	4 (16%)	8 (32%)
College	15 (30%)	7 (28%)	8 (32%)
University	21 (42%)	14 (56%)	7 (28%)
Occupation			
Employed (FT)	9 (18%)	6 (24%)	3 (12%)
Employed (PT)	10 (20%)	5 (20%)	5 (20%)
Homemaker	5 (10%)	3 (12%)	2 (8%)
Retired	26 (52%)	11 (44%)	15 (60%)

FT: Full time; PT: Part time

Continued...

Table 2

	Sample Frequency (%)	Experimental Group Frequency (%)	Comparison Group Frequency (%)
Language of Participants			
French	27 (54%)	12 (48%)	15 (60%)
English	23 (46%)	13 (52%)	10 (40%)
Relationship to care receiver			
Married/civil	18 (36%)	7 (28%)	11 (44%)
Son-daughter	26 (52%)	15 (60%)	11 (44%)
Other relation	3 (6%)	0 (0%)	3 (12%)
Friend	3 (6%)	3 (12%)	0 (0%)
Living arrangements			
Co-habits	21 (42%)	10 (40%)	11 (44%)
Lives apart	29 (58%)	15 (60%)	14 (56%)
Health			
Excellent	8 (16%)	3 (12%)	5 (20%)
Very good	19 (38%)	9 (36%)	10 (40%)
Good	16 (32%)	8 (32%)	8 (32%)
Average	7 (14%)	5 (20%)	2 (8%)
Poor	0 (0%)	0 (0%)	0 (0%)
Perceived support			
Great deal	20 (40%)	6 (24%)	14 (76%)
Average	22 (44%)	16 (64%)	6 (24%)
Small	7 (14%)	3 (12%)	4 (16%)
No support	1 (2%)	0 (0%)	1 (4%)

A large number of participants (n = 30) had benefited from external services, the largest category being nursing care services. Almost all participants provided assistance and/or care to their family members (n = 48), and the nature of this care-assistance was similar in both groups (see Table 3).

Table 3

Services Received and Assistance Provided to Care Receivers (n = 50)

	Sample Frequency (%)	Experimental Group Frequency (%)	Comparison Group Frequency (%)
Services received			
Received	30 (60%)	15 (60%)	15 (60%)
Type of services			
Transport	9 (18%)	6 (24%)	3 (12%)
Housekeeping	5 (10%)	2 (8%)	3 (12%)
Meals	9 (18%)	3 (12%)	6 (24%)
Nursing	19 (38%)	11 (44%)	8 (32%)
Custodial/Daycare	7 (14%)	2 (8%)	5 (20%)
Foot care	10 (20%)	4 (16%)	6 (24%)
Assistance - Care provided by caregiver (rank order - frequency)			
Budgeting	35 (70%)	17 (76%)	18 (72%)
Medications	34 (68%)	18 (72%)	16 (64%)
Paying bills	29 (58%)	15 (60%)	14 (56%)
Shopping	27 (54%)	16 (64%)	11 (44%)
Errands	23 (46%)	14 (56%)	9 (36%)
Dress-feed-wash	19 (38%)	10 (40%)	9 (36%)
Driving	16 (32%)	8 (32%)	8 (32%)
Walking	14 (28%)	7 (28%)	7 (28%)
Housekeeping	14 (28%)	10 (40%)	4 (16%)
Telephone	13 (36%)	8 (32%)	5 (20%)
Cooking	11 (22%)	6 (24%)	5 (20%)
Laundry	11 (22%)	6 (24%)	5 (20%)
Toileting	5 (10%)	2 (8%)	3 (12%)

Descriptive Characteristics of Care Receivers

An overview of the care receivers' characteristics is presented in Table 4. Group equivalence was assessed using chi-square for categorical variables and two-tailed t-tests for continuous variables. The two care receiver groups were equivalent on all variables.

Care receivers ($n = 50$) were Caucasian, predominantly female ($n = 32$), ranging in age from 58 to 91. Their mean age was 79.1. A slightly larger number of care receivers lived apart from their caregiver ($n = 29$) and almost all were related in some way to their caregivers ($n = 48$).

These care receivers had been diagnosed with cognitive problems associated with early stage Alzheimer's disease (AD) ($n = 48$) or with a mixed dementia with an early stage AD component ($n = 2$). Folstein scores ranged from 20 to 28 (mean = 25.14; $SD = 2.22$) (Folstein, Folstein & McHugh, 1975; Snyder et al., 1995; Kuhn, 1998) and met the criteria of NINCDS-ADRDA for probable Alzheimer's disease, or had been diagnosed with probable Alzheimer's disease according to the DSM-4 criteria (American Psychiatric Association, 2000). The two groups were similar in terms of cognitive status as determined by MMSE scores. Thirty-three (64%) care recipients had experienced 'memory problems' for more than 2 years and fifteen (30%) had displayed this problem over the preceding one to two years, according to their caregivers. Two individuals reported having experienced memory problems only within the preceding year.

With respect to 'Time since Diagnosis', almost one-half ($n = 24$) had been diagnosed more than one year ago and the remaining fifty-two per cent ($n = 26$) had received their diagnosis within the past year.

Table 4

Characteristics of Care Receivers (n = 50)

	Total (*n* = 50)	Experimental Group (*n* = 25)	Comparison Group (*n* =25)
Age			
Range	58 – 93	58 – 93	60 – 91
Mean ($\bar{x}$)	79.1	78.64	79.56
SD	9.05	10.16	7.98
	Frequency (%)	**Frequency (%)**	**Frequency (%)**
Age Distribution			
55 – 64	4 (8%)	3 (12%)	1 (4%)
65 – 74	9 (18%)	5 (20%)	4 (16%)
75 – 84	22 (44%)	9 (36%)	13 (42%)
< 85	15 (30%)	8 (24%)	7 (28%)
Sex			
Female	32 (64%)	16 (64%)	16 (64%)
Male	18 (36%)	9 (36%)	9 (36%)
Ethnicity			
Caucasian	50 (100%)	25 (50%)	25 (50%)
Living Arrangements in regard to Caregiver			
Lives with	21 (42%)	10 (40%)	11 (44%)
Lives apart	29 (58%)	15 (60%)	14 (56%)
Relationship to Caregiver			
Parent	27 (54%)	16 (64%)	11 (44%)
Married/civil	18 (36%)	7 (28%)	11 (44%)
Other relation	3 (6%)	0 (0%)	3 (12%)
Friend	2 (4%)	2 (8%)	0 (0%)

Continued...

Table 4

Characteristics of Care Receivers (n = 50)

	Total (*n* = 50)	Experimental Group (*n* = 25)	Comparison Group (*n* =25)
Duration of memory problems			
< 1 year	2 (4%)	2 (8%)	0 (0%)
1 – 2 years	15 (30%)	7 (28%)	8 (32%)
> 2 years	33 (64%)	16 (64%)	17 (68%)
Time since diagnosis			
< 1 year	24 (48%)	13 (52%)	11 (44%)
> 1 year	26 (52%)	12 (48%)	14 (56%)
MMSE Score (Folstein)			
Mean ($\overline{x}$) score:	25.14	25.04	25.24
SD	2.22	1.97	2.49
Diagnosis			
Probable AD	48 (96%)	23 (92%)	25 (100%)
Mixed dementia	2 (4%)	2 (8%)	0 (0%)
Consulted professionals			
Yes	9 (18%)	6 (24%)	3 (12%)
No	41 (82%)	19 (76%)	22 (88%)
Professionals consulted			
Psychologist	1 (2%)	1 (4%)	0 (0%)
Nurse	0 (0%)	0 (0%)	0 (0%)
Social Worker	3 (6%)	2 (8%)	1 (4%)
Other (Dr.)	5 (10%)	3 (12%)	2 (8%)

Results of Hypotheses Testing

As described in Chapter 3, after verifying the requisite assumptions, the principal analytic strategy for hypotheses testing was the Analyses of covariance (ANCOVA) with the pre-test scores as covariates. Age was not retained as a covariate even though significant differences in age had been identified between the two groups (i.e., $\bar{x}$ = 59.12 for experimental group and 64.8 for comparison group (t_{48} = 2,095, p = 0.041) (two-tailed t-test), given that there is no empirical evidence or theoretical underpinnings to support this age difference as an influencing variable on the outcome measures.

Repeated analysis of variance (ANOVA) was carried out on one dependent variable (i.e., self-efficacy), as the assumption of homogeneity of regression curve was not upheld for this variable. As previously mentioned, given that numerous tests were carried out to explore the effects of the individual modules, the Bonferroni correction was applied. Only the results with a significance level of p < .01 were considered as significant for the modules.

Effect of Intervention on Knowledge

In Hypothesis I, it was postulated that individuals participating in the experimental group (psycho-educational program), would have a significant increase in *knowledge* about communication related to cognitive limitations, in comparison to individuals in the comparison group. An analysis of covariance, with pretest as covariate, was conducted on the total score of the *Knowledge* questionnaire and showed a statistically significant covariate effect ($F(1,47)$ = 33.98, p < 0.001).

After controlling for the effect of pre-test scores, the total scores of the two groups were significantly different ($F(1,47) = 13.84$, $p < 0.001$). Moreover, twenty-three percent (23%) of the variance was explained by the Group effect. There was also a significant Time effect between Post-test (Time 2) and Follow-up (Time 3) ($F(1,47) = 6.40$, $p < 0.05$). Results for the total score, and for the five modules of the knowledge variable are reported in Table 5.

In conclusion, Hypothesis I was supported. The experimental group exhibited overall significant differences in *Knowledge* scores at Post-test (Time 2) and Follow-up (Time 3) and a significant Time effect between Post-test (Time 2) and Follow-up (Time 3). Significant differences were also reported for certain modules.

Table 5

Results of ANCOVA : Knowledge (n = 50)

Variables	Experimental Group (n = 25)			Comparison Group (n = 25)			F				Partial eta squared (group)
	Pre-test	Post-test	Follow-up	Pre-test	Post-test	Follow-up	Covariatle	Group X Time	Time	Group	
Total score											
M	29.12	38.96	39.96	33.44	35.88	34.24	33.98 ***	0.546	6.409 *	13.845 ***	0.23
SD	9.42	7.65	7.48	9.95	9.86	10.17					
Adjusted M	-	40.43	40.83	-	34.41	33.37					
Module 1											
M	5.92	8.40	8.52	6.68	7.48	6.92	10.393**	1.534	0.771	21.014***	0.31
SD	1.93	1.41	1.29	1.86	1.66	1.41					
Adjusted M	-	8.53	8.60	-	7.35	6.84					
Module 2											
M	6.64	8.36	8.36	7.64	8.00	7.56	36.568***	0.497	1.022	9.739 **	0.172
SD	1.87	1.60	1.82	1.82	1.94	2.08					
Adjusted M	-	8.71	8.63	-	7.65	7.29					
Module 3											
M	5.08	7.56	7.60	6.36	6.72	6.52	33.702***	0.010	1.280	11.488***	0.196
SD	2.40	2.02	1.91	2.86	2.56	2.80					
Adjusted M	-	7.94	7.89	-	6.34	6.23					
Module 4											
M	4.72	6.64	7.24	5.80	6.12	5.80	27.774**	0.864	4.146*	8.798**	0.158
SD	2.72	2.31	2.11	2.58	2.85	2.84					
Adjusted M	-	6.99	7.45	-	5.77	5.59					
Module 5											
M	6.76	7.68	7.92	6.96	7.60	7.48	19.079**	0.472	1.345	0.453	0.01
SD	2.40	2.32	2.00	2.64	2.27	2.71					
Adjusted M											

*$p < 0.05$,   **$p < 0.01$,   ***$p < 0.001$

After Bonferroni correction, only results at $p < .01$ are considered significant for the tests on the modules.

Effect of Intervention on Communication Difficulties

In Hypothesis II, it was postulated that individuals participating in the experimental group (psycho-educational program), would perceive significantly fewer *communication difficulties* associated with the family member's cognitive limitations, than individuals who participated in the comparison group.

In regard to the total score of the variable, the ANCOVA showed a statistically significant covariate effect ($F(1,47) = 69.05$, $p < 0.001$). However, neither the Group X Time interaction, nor Time or Group effects reached a significance level. Results for the total scores and for the modules are reported in Table 6. In conclusion, Hypothesis II was not supported.

Table 6
Results of ANCOVA : Communication difficulties (n = 50)

Variables	Experimental Group (n = 25)			Comparison Group (n = 25)			F				Partial eta squared (group)
	Pre-test	Post-test	Follow-up	Pre-test	Post-test	Follow-up	Covariate	Group X Time	Time	Group	
Total score											
M	1.65	1.74	1.86	1.65	1.70	1.68	69.057***	2.208	0.039	1.152	0.024
SD	0.57	0.55	0.54	0.61	0.59	0.57					
Adjusted M	-	1.74	1.86	-	1.70	1.68					
Module 1											
M	1.66	1.92	1.86	1.41	1.64	1.6	29.313***	0.005	0.032	0.716	0.015
SD	0.57	0.77	0.70	0.76	0.79	0.70					
Adjusted M	-	1.84	1.79	-	1.72	1.64					
Module 2											
M	2.05	1.96	2.06	1.98	1.91	1.83	69.871***	1.439	0.057	0.345	0.007
SD	0.89	0.84	0.89	0.92	0.95	0.93					
Adjusted M	-	1.94	2.03	-	1.93	1.85					
Module 3											
M	1.74	2.02	2.16	1.86	2.01	2.04	52.420***	0.533	1.901	0.752	0.016
SD	0.91	0.92	0.81	0.82	0.82	0.87					
Adjusted M	-	2.06	2.20	-	1.97	2.01					
Module 4											
M	1.62	1.74	1.90	1.63	1.64	1.70	144.336***	0.958	0.172	2.347	0.048
SD	0.84	0.76	0.74	0.84	0.72	0.80					
Adjusted M	-	1.74	1.91	-	1.64	1.70					
Module 5											
M	1.18	1.08	1.30	1.32	1.32	1.26	64.389***	3.796	0.405	0.089	0.002
SD	0.69	0.58	0.48	0.71	0.66	0.58					
Adjusted M	-	1.11	1.33	-	1.28	1.23					

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$

Effect of Intervention on Degree of Disturbance in relation to

Communication Difficulties

In Hypothesis III, it was postulated that individuals participating in the experimental group (psycho-educational program), would perceive a significantly lower *degree of disturbance* in relation to communication-related difficulties associated with their family member's cognitive limitations than individuals who participated in the comparison group.

With respect to the total score of the dependent variable *Degree of disturbance* related to communication difficulties, the covariate effect was statistically significant ($F(1,47) = 60.36, p < 0.001$). After controlling for the effect of pre-test scores, the total scores of the two groups were significantly different ($F(1,47) = 14.87, p < 0.001$). There was neither a significant Group X Time interaction nor Time effect. In regard to the total score, the group effect explained twenty-four percent (24%) of the total group variance. Results for the total scores and for the modules are presented in Table 7.

In conclusion, Hypothesis III was supported. Significant differences were found between the two groups in regard to the overall degree of disturbance at Post-test (Time 2) and at Follow-up (Time 3). Significant differences were also reported for certain modules.

Table 7

Results of ANCOVA: Degree of disturbance in regard to Communication difficulties (n = 50)

Variables	Experimental Group (n = 25)			Comparison Group (n = 25)			F				Partial eta squared (group)
	Pre-test	Post-test	Follow-up	Pre-test	Post-test	Follow-up	Covariate	Group X Time	Time	Group	
Total score											
M	1.04	0.60	0.51	1.10	0.97	1.05	60.360***	2.563	0.019	14.868***	0.244
SD	0.73	0.70	0.76	0.57	0.44	0.42					
Adjusted M	-	0.63	0.53	-	0.95	1.03					
Module 1											
M	0.95	0.59	0.44	0.97	0.81	0.92	23.029***	2.923	1.031	7.762**	0.147
SD	0.62	0.45	0.48	0.83	0.70	0.68					
Adjusted M	-	0.59	0.45	-	0.80	0.92					
Module 2											
M	1.31	0.71	0.72	1.13	1.08	1.27	43.848***	0.905	2.910	15.755***	0.255
SD	0.78	0.66	0.58	0.88	0.81	0.90					
Adjusted M	-	0.66	0.67	-	1.15	1.31					
Module 3											
M	0.81	0.42	0.35	0.96	0.88	0.94	35.973***	1.257	0.003	11.536**	0.204
SD	0.72	0.40	0.43	0.74	0.72	0.85					
Adjusted M	-	0.46	0.39	-	0.84	0.89					
Module 4											
M	0.90	0.59	0.52	1.19	0.97	1.03	39.74***	0.767	0.021	3.744	0.077
SD	0.60	0.47	0.50	0.86	0.84	0.87					
Adjusted M	-	0.67	0.61	-	0.88	0.94					
Module 5											
M	1.09	0.72	0.58	1.30	1.16	1.10	33.808***	0.090	2.113	7.321*	0.140
SD	0.66	0.61	0.48	0.84	0.77	0.81					
Adjusted M	-	0.77	0.64	-	1.11	1.04					

$*p < 0.05$, $**p < 0.01$, $***p < 0.001$

After Bonferroni correction, only results at $p < .01$ are considered significant for the tests on the modules.

Effect of Intervention on Self-efficacy related to Communication Skills

In Hypothesis IV, it was postulated that individuals participating in the experimental group (psycho-educational program), would perceive a significantly higher degree of *self-efficacy* in relation to communication skills associated with the family member's cognitive limitations, as compared to individuals who participated in a comparison group.

As mentioned earlier, the assumption of homogeneity of regression curve was not upheld for the Self-efficacy total score. Examination of outliers revealed aberrant values for one participant. A correction was made by removing this participant's scores. The assumption was then upheld for the majority of modules, albeit with slight deviations for Module 3 score ($p = 0.042$) and for the Total score ($p = 0.03$).

Therefore, a Group X Time analysis of variance (2 X 3 ANOVA) was carried out. A statistically significant Group X Time interaction was detected ($F(2,94) = 15.45$, $p < 0.001$) and the decomposition of this interaction showed that the total group mean scores were not significantly different at Pre-test, however significantly different at Post-test (Time 2) ($F(1,47) = 4.88$, $p < 0.05$), and at Follow-up (Time 3) ($F(1,47) = 12.71$, $p < 0.001$). Simple effects for time showed that this effect was present only for the experimental group $F(1,47) = 28.55$, $p < 0.001$. Tukey (a) post hoc comparisons showed significant differences at an alpha level of 0.01 between T1 and T2 and between T1 and T3 for this group. Moreover, twenty-two percent (22%) of the variance was explained by the time effect. Results for the total scores and for the modules are presented in Table 8.

In conclusion, Hypothesis IV was supported. The mean scores were significantly different between the experimental and comparison groups at Post-test and at Follow-up. Significant differences were also reported for certain modules.

Table 8

Results of ANOVA : Self-efficacy for Communication Skills

Variables	Experimental Group (n =25)			Comparison Group (n = 24)			F	GROUP simple effects			Partial eta squared (group)	TIME Simple effects	
	Pre-test	Post-test	Follow-up	Pre-test	Post-test	Follow-up	Group X Time	Pre-test	Post-test	Follow-up		Comparison Group	Experimental Group
Average score (50 items)													
M	87.79	93.48	94.44	89.68	90.33	88.93	15.454***	0.81	4.88*	12.71***	0.045	1.04	28.55*** [a]
SD	8.99	5.00	5.00	5.12	5.00	5.82							
Module 1													
M	88.01	93.34	94.63	87.92	89.73	88.94	5.311***	0.00	4.49*	12.30***	0.069	1.05	20.24*** [a]
SD	10.13	6.33	5.32	6.45	5.56	6.03							
Module 2													
M	88.19	94.11	94.62	90.80	90.53	89.24	13.621**	1.27	5.54*	10.45***	0.035	1.07	16.67 *** [a]
SD	9.91	5.21	5.21	5.61	5.44	6.42							
Module 3													
M	85.21	91.60	93.62	89.42	89.48	88.20	18.170***	2.81	1.4	10.43***	0.008	0.77	29.88 *** [a]
SD	11.07	6.80	5.62	5.49	5.65	6.11							
Module 4													
M	89.16	94.02	94.43	90.70	90.85	89.39	11.451***	0.61	4.37*	10.01***	0.045	1.26	17.49 *** [a]
SD	8.68	5.03	5.66	4.37	5.58	5.48							
Module 5													
M	88.36	94.34	94.92	89.54	91.05	88.86	7.655***	0.24	5.19*	13.79***	0.063	1.4	15.43 *** [a]
SD	9.70	4.97	5.09	6.88	5.14	6.30							

*$p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

[a] Tukey (a) post-hoc comparisons showed significant differences (alpha= 0.01) for T1 vs T2 and T1 vs T3 for each module and average score

After Bonferroni correction, only results at $p < .01$ are considered significant for the tests on the modules.

Effect of Intervention on Communication Skills

In Hypothesis IV, it was postulated that individuals participating in the experimental group (psycho-educational program), would report a significantly higher use of effective *communication skills* with their family member than individuals who participated in a comparison group.

An analysis of covariance conducted on the total score showed a statistically significant covariate effect $(F(1,47) = 18.13, p < .001)$. A significant Group X Time interaction was identified $(F(1,47) = 4.76, p < .05)$, revealing a significant group effect only at Follow-up (Time 3) $(F(1,47) = 10.94, p < .001)$. Significant differences were also reported for certain modules. Results are for the total scores and for the modules are reported in Table 9.

In conclusion, Hypothesis V was partly supported. The outcomes indicated that there were significant differences between the two groups in regard to communication skills, albeit only at Follow-up (Time 3). Significant differences were also reported for certain modules.

Table 9
Results of ANCOVA: Communication skills

Variables	Experimental Group (n = 25)			Comparison Group (n = 25)			F				Partial eta squared (group)	Simple effects of Group	
	Pre-test	Post-test	Follow-up	Pre-test	Post-test	Follow-up	Covariate	Group X Time	Time	Group		at T2	at T3
Total score													
M	3.05	3.43	3.70	2.97	3.25	3.02	18.135***	4.757*	3.374	5.453*	0.104	0.43	10.94**
SD	0.89	0.75	0.48	0.94	1.03	0.93							
Adjusted M	-	3.41	3.69	-	3.27	3.03							
Module 1													
M	2.85	3.54	3.84	2.85	3.28	3.00	19.245***	3.675	4.637*	6.418*	0.12		
SD	1.20	1.16	0.70	1.21	1.33	0.98							
Adjusted M	-	3.54	3.84	-	3.28	3.00							
Module 2													
M	3.13	3.42	3.49	3.20	3.29	2.93	15.824***	1.460	0.105	2.481	0.05		
SD	1.11	1.00	0.92	1.36	1.29	1.28							
Adjusted M	-	3.44	3.51	-	3.27	2.92							
Module 3													
M	3.09	3.70	3.79	3.09	3.61	3.28	13.844**	2.856	4.002	2.483	0.05		
SD	1.01	0.73	0.67	1.29	1.10	1.03							
Adjusted M	-	3.70	3.79	-	3.61	3.28							
Module 4													
M	3.25	3.32	3.71	2.77	2.84	2.72	0.082	3.782	3.029	7.317**	0.135		
SD	1.30	0.84	0.79	1.43	1.39	1.14							
Adjusted M	-	3.29	3.73	-	2.87	2.71							
Module 5													
M	2.85	3.11	3.52	2.72	3.02	2.98	1.116	1.203	0.879	1.020	0.021		
SD	1.27	1.29	0.87	1.30	1.37	1.49							
Adjusted M	-	3.10	3.51	-	3.04	2.98							

*p < 0.05, **p < 0.01, ***p < 0.001

After Bonferroni correction, only results at *p* < .01 are considered significant on the modules.

Reanalysis of Data with Education as a Control Variable

With respect to education, as reported earlier, no significant differences were identified between the experimental and comparison groups in the initial chi-square analyses using the following three categories: primary/secondary, collegial and university education. However, given that a larger number of university-educated individuals were identified in the experimental group than in the comparison group, it was decided to explore the variable of education in more depth. Chi-square analyses were performed using only two categories (university/non university education). As this analysis revealed significant differences between the groups (χ_1^2 = 4,023 p = 0.045), in order to control for the effects of education, a reanalysis of the data was performed on the total scores of all dependent variables (total scores). Results of ANCOVA for knowledge, communication difficulties, degree of disturbance and skills; and of ANOVA for self-efficacy, are presented in Table 10. The control variable 'education' was not significant for all variables. However, the reanalysis showed a change in the results for two variables, i.e., self-efficacy and communication skills. In regard to *self-efficacy*, significant results were identified only at Time 3, and for communication *skills*, the group effect at Time 3 became non significant (p = .07).

Table 10. Reanalysis Of Data (Total Scores) with Education as a Control Variable

ANCOVA	Experimental Group (n=25)			Comparison Group (n=25)			F					Partial eta squared (group)
Variables TOTAL SCORES	Pre-test	Post-test	Follow-up	Pre-test	Post-test	Follow-up	Covariate PRE TEST	Covariate UNIVERSITY	Group X Time	Time	Group	
Knowledge												
M	29.12	38.96	39.96	33.44	35.88	34.24	24.593 ***	2.619	0.597	6.118 *	8.576 ***	0.16
SD	9.42	7.65	7.48	9.95	9.86	10.17						
Adjusted M	-	39.81	40.32	-	35.03	33.84						
Communication difficulties												
M	1.65	1.74	1.86	1.65	1.70	1.68	68.729 ***	0.461	1.919	0.043	1.479	0.031
SD	0.57	0.55	0.54	0.61	0.59	0.57						
Adjusted M	-	1.75	1.86	-	1.69	1.67						
Degree of disturbance												
M	1.04	0.60	0.51	1.10	0.97	1.05	62.663 ***	1.715	2.228	0.019	10.644**	0.191
SD	0.73	0.70	0.76	0.57	0.44	0.42						
Adjusted M	-	0.65	0.56	-	0.93	1.01						
Communication skills												
M	3.05	3.43	3.70	2.97	3.25	3.02	14.423***	1.056	3.367	3.363	3.803	0.076
SD	0.89	0.75	0.48	0.94	1.03	0.93						
Adjusted M	-	3.40	3.65	-	3.29	3.07						

ANOVA	Experimental Group (n=25)						Comparison Group (n=24)						F	GROUP Simple effects			TIME Simple effects	
	UNIVERSITY yes (n=14)			UNIVERSITY no (n=11)			UNIVERSITY yes (n=7)			UNIVERSITY no (n=17)								
Variable	Pre-test	Post-test	Follow-up	Pre-test	Post-test	Follow-up	Pre-test	Post-test	Follow-up	Pre-test	Post-test	Follow-up	Group X Time	Pre-test	Post-test	Follow-up	Comp. Group	Experi-mental Group a
Self-efficacy (Average score: 50 items)																		
M	88.47	92.92	94.84	86.92	94.19	93.93	91.36	91.32	93.93	88.98	89.92	88.44	14.581 ***	0.48	3.870	9.13**	0.98	28.89***
SD	8.57	5.33	4.66	9.85	4.68	5.59	3.91	5.78	5.59	5.51	4.77	5.24						

*p < 0.05, **p < 0.01, ***p < 0.001
No significant effects of the variable University/Non University, no significant interaction for education.
a Tukey (a) post-hoc comparisons showed significant differences (p < 0.01,**) for T1 vs T2 and T1 vs T3

Results of Case Scenario Questions

A different case scenario – each focused on a particular cognitive difficulty – was presented at each measurement time to participants in both groups. The first case scenario (administered at Time 1) was concerned with short-term memory difficulties, the second one (at Time 2) addressed naming and word-finding difficulties, and the third one (at Time 3) was focused on problems primarily related to executive functions. Chi-Square analyses were conducted on the total number of appropriate responses reported by the two groups at each of the three measurement times. Significant differences between the two groups were identified at Post-test (Time 2) and at Follow-up (Time 3) $(\chi_2^2 = 6,098 = 0.047$ at $p < 0.05)$. See Table 11.

Table 11

Results of Case Scenarios

Category of Responses	Time 1 Frequency		Time 2 Frequency		Time 3 Frequency	
	EG	CG	EG	CG	EG	CG
Emotive	11	11	22	9	21	8
Behavioural	10	10	23	12	22	10
Others	6	5	16	5	14	8
Total	27	26	61*	26*	57*	26*

* p < 0.05 ;   EG: Experimental Group;   CG: Comparison Group

The 'appropriate' responses to the Case Scenario questions were further explicated in a number of additional communication strategies described by participants in the experimental group during the learning sessions. Several examples of such responses (strategies) are described and complement the case scenario responses. They serve to further illustrate the learning that took place by these participants in relation to the three areas of cognitive difficulties in the case scenarios.

Qualitative Data from Intervention Sessions related to Case Scenarios

Case Scenario Concerned with Short-term Memory Limitations

The first two examples deal with communication difficulties that arise around the subject of 'forgetting', typically related to short-term memory deficits. Strategies described as helpful by participants included the use of written notes and better structuring of the environment.

Strategy for Written Notes: A daughter had taken her mother's valuable jewelry to her own home for safekeeping, leaving a few sentimental, less valuable items in her mother's jewelry box. Her mother (diagnosed with AD), did not remember that her daughter had removed these items, and would call her daughter frequently, sometimes up to 10-15 times per day, stating that 'someone had taken her jewelry'.

The daughter became increasingly frustrated, and even angry, having to constantly repeat to her mother that she had taken these items to her home. It was suggested that the daughter place a brief note in her mother's jewelry box stating the following: 'Jane has my necklace and bracelets to keep them safe'. Shortly after the note had been placed in the jewelry box, Jane's mother stopped calling her daughter about the 'missing' jewelry, even though she would still call – albeit much less frequently – about other subjects. Jane stated that this particular intervention was especially helpful to her. She said:

> 'My mother drove me crazy with those calls. I felt so guilty telling
> her not to keep calling – before the note. But when she stopped
> calling, at first I thought that maybe something was wrong, and so I
> called her a couple of times to make certain that she was all right. I
> couldn't believe that a piece of paper could make such a difference.'

Strategy for Environment Changes: Mr. and Mrs. Black (*fictive name*) had moved to a new condominium shortly after Mrs. Black was diagnosed with probable early stage AD. Mrs. Black was having a difficult time locating things and finding her way around her new home. This was especially problematic in the kitchen where Mr. Black would help his wife to prepare meals. Mrs. Black was constantly asking her husband where things were located and he often became annoyed because he repeatedly had to tell his wife where to find utensils, food items, etc. In order to help Mrs. Black 'find' things, Mr. Black agreed to remove the doors from the kitchen cupboards.

As recommended, he also removed non-essential items from the cupboards, at the same time ensuring that 'old' dishes, pots and other items that his wife had used for many years were prominently displayed. In addition, as per recommendation, he organized the contents in the cupboards in the same manner as they had been placed in their previous home.

There was an immediate improvement in Mrs. Black's communications with her husband. Mr. Black reported that now his wife was able to locate things more easily and thus greatly decreased the repetitive questioning which had caused him so much grief. Meal preparation became a much more agreeable activity.

However, this environmental change also led Mrs. Black to express a particular concern. She would ask her husband from time to time as to why the cupboards had no doors. Given that Mr. Black had the financial resources, it was suggested that glass doors be constructed for the cupboards. This proved to be a helpful solution, and Mrs. Black no longer expressed concern about the lack of doors on the cupboards. He said:

> 'Having those glass doors helps a lot. My wife will sometimes just walk around looking into the cupboards and then she will start naming things that she can see inside. Everyone says that they look good too.'

Case Scenario Concerned with 'Word-finding' - 'Naming' difficulties

The next two examples are concerned with the communication difficulties that arise around the problems of 'word-finding' and 'naming'. Strategies described as helpful by participants included helping the person identify or 'find' the right word or saying the right word.

Strategy for 'Word-finding': Mr. White *(fictive name)* (who has AD) sometimes had difficulties 'finding' the right word(s). His daughter, Mary, believed that it was important for her father to keep trying to 'find' the word that he was unable to say or 'could not remember' as she believed that this 'trying' would help him to 'exercise' his brain. Although Mary was usually fairly certain that she knew the word that her father was trying to say, she nonetheless stayed silent and waited for her father to 'say the word'. Most of the time when Mr. White had this difficulty, he simply changed the topic of conversation, however sometimes he would get upset and even angry when he could not remember or find the right word. 'This would bother me a lot', said Mary; 'I didn't know what to do'.

When Mary learned that words were being 'lost' in her father's brain and that oftentimes it simply was not possible for him to remember a word because it had been 'removed' from his lexicon ('dictionary' in the brain), he agreed to help her father whenever he had this difficulty and to say the word he could not find (if she knew it) or to suggest alternative words. At the end of the program Mary said that she had been using this strategy 'a lot' to help her father.

> 'It really makes a difference', she said; 'Dad appreciates my help and doesn't get angry like before. I sure wish that someone had told me before about those disappearing words.'

Strategy for 'Naming': Among the communication difficulties that Mrs. Jones (fictive name) found disturbing with her husband was his habit of using 'wrong' words for certain things, or incorrect names for certain persons.

> 'It drives me crazy when he keeps calling our daughter by his sister's name. I keep telling him that 'Mary' (our daughter) is not 'Jean' (his sister), said his wife. 'It's just that it happens so often and my daughter's feelings are hurt. I make him repeat Mary's name, but it only helps sometimes.'

Mrs. Jones suspected that this problem was caused by his cognitive limitations, however she thought that if she kept correcting him he would eventually learn the right name. When she finally understood the reason for her husband's difficulty, she agreed to use a different approach. She would still 'correct' the word that her husband said, but she would not make a 'big deal' of his mistake. Her comments follow:

> 'He's not bad now, I guess. When I tell him the right word, he just says 'ok', and sometimes keeps on talking. I just keep telling myself that he can't help it, and that kind of helps me. Mary does the same thing and now she doesn't get so upset.'

Case Scenario Concerned with Problems related primarily to Executive Functions re: Activities of daily living – ADL's and Instrumental Activities of Daily Living – IADL's

The last two examples are concerned with communication problems that can occur when difficulties are encountered with activities of daily living and instrumental activities of daily living, these being linked, in part, to cognitive limitations related to executive functions. Strategies that were reported as particularly useful included the structuring of the environment and rendering better visibility of environmental components.

Strategy for 'IADL's – using new microwave': Louise had purchased a new microwave oven for her mother, one that could also be used as a 'regular' oven. Louise could not understand why her mother did not want to use it. Louise underlined;

> 'I thought she would love this new one with the convection features, but she won't even try. She keeps asking me to get her old one back. I keep telling her that once she gets used to this new one she'll be all right.'

Louise said that this subject comes up almost every time she visits, at which time she tries to teach her mother how to use it. Sometimes, she and her mother get into arguments about this. Once Louise learned about the difficulties that people with cognitive problems have in regard to 'problem solving' and especially how to 'operate' new technology devices, she was amenable to bringing back the old oven, (which had been given to a granddaughter, thus had been easy to retrieve).

> 'You know, I never would have believed it, once we brought back the old oven; Mother had no problem using it. She was so happy to have it back.'

Strategy for 'ADL's – Getting dressed': Mr. Malone's (*fictive name*) son, Bob, noticed that from time to time when he would visit his father (who lived alone) he didn't seem to always have his clothes on correctly. For example, he might be missing his socks or he would complain that he could not find his undershirt. Sometimes Bob would notice that clothes would be strewn all over the bedroom. Bob would often get frustrated with his father and say unkind things, which he later regretted. Several strategies were employed. First, clothes were sorted so that only the clothes that his father liked to wear were kept in the bedroom. Moreover, clothes that had difficult fasteners – i.e., zippers, tight buttonholes, etc., were also removed. Labels were then placed on the drawers of the dresser to indicate what was inside ('socks', 'undershirts', and so on). Bob reported that:

> 'I couldn't believe how well this worked. I still had to go in once in a while to make sure that things were in the right place, but it sure helped a lot to have those notes on the drawers.'

Summary of Results

In summary, five hypotheses were tested in this study. Three hypotheses were supported: Hypothesis I, which dealt with the acquisition of *Knowledge*, Hypothesis III, concerned with the *Degree of disturbance* in regard to communication difficulties and Hypothesis IV, which addressed *Self-efficacy* perceptions in relation to communication skills. In particular, significant differences were reported between the experimental and comparison groups both at Post-test (Time 2) and at Follow-up (Time 3) for *Knowledge* and *Degree of disturbance*. As well, a significant Time effect was identified between Post-test (Time 2) and Follow-up (Time 3) for *Knowledge*. However, in regard to *Self-efficacy*, when the reanalysis was conducted with the control variable 'education', significant results were only identified at Time 3. Significant Time effects were also reported for *Self-efficacy* between Time 1 and Time 2 and between Time 1 and Time 3.

Hypothesis II, concerned with the presence of communication *difficulties*, was rejected. Hypothesis V, which addressed the use of communication *skills* by caregivers, was partially supported, given that significant differences in total scores between the two groups were obtained only at Follow-up (Time 3). However, when the reanalysis was performed with education as a control variable, Hypothesis V was no longer supported, i.e., the effect on *skills* became non significant $(p = .07)$.

Selected modules of the program had significant effects for certain outcome measures at Time 2 and/or Time 3. More specifically, module 4 (in regard to communication difficulties related to ADL's and IADL's) showed significance effects for three variables (Knowledge, Self-efficay and Skills) at Time 3.

In regard to the Case scenario questions, significant differences were reported between the experimental and comparison groups at Post-test (Time 2) and at Follow-up (Time 3) in regard to the total number of 'appropriate' responses. Examples of effective communication strategies relevant to these Case scenarios were submitted by participants in the course of the learning sessions. This feedback provided supplementary information on the learning that had taken place.

CHAPTER V

DISCUSSION

This intervention study compared the effects of a communication-focused psycho-educational program with those of an information flier in two groups of family caregivers of persons diagnosed with cognitive problems associated with the early stage of Azheimer's disease. In this context, outcome variables were *caregiver* knowledge related to communication, perception of communication difficulties and degree of disturbance in regard to these communication difficulties, communication-related self-efficacy and communication skills. This final chapter is divided into five sections. In the first section, the principal attributes of the sample are discussed, along with certain details about the caregivers' family members (care receivers). Theoretical considerations are reviewed in the second section. The third part deals with the results in conjunction with the findings relevant to the hypotheses. The fourth section addresses the methodological aspects and includes the limitations of the study, and the last part examines the implications for nursing practice, education and research.

Principal Attributes of the Sample and Information about Care Receivers

The older-aged and largely female sample in this study was for the most part representative of the caregivers described in the literature (Canadian Study on Health and Aging Working Group, 1994). However, whereas the evidence indicates that spouses make up the larger portion of caregivers (Keating, Fast, Frederick, Cranswick et al., 1999; Schulz, 2000; Tarlow, Wisniewski, Belle, Rubert, et al., 2004), in the present study the majority of caregivers were children (54%), followed by spouses (36%). The remaining care providers (10%) were made up of other family relations and friends. Almost all of the caregivers (n = 48) provided some type of care and assistance to their family members-friends, this being comprised primarily of Activities of Daily Living and Instrumental Activities of Daily Living. Moreover, the nature and quantity of external services that were provided to each household were highly similar across the sample.

In regard to the care receivers, more than one-half lived in the community. This was slightly lower than the fifty percent figure reported in the literature, i.e., wherein one-half of care receivers are reported to be living in the home setting (McDowell et al., 2001). The most likely principal reason for this is that care needs of the family member with cognitive problems associated with Alzheimer's disease are less challenging for the caregiver in the early stage of this illness, thus accounting for the larger proportion of persons affected by this disorder that were still living at home in this study.

The random assignment of participants resulted in two generally comparable groups. The groups differed in regard to age, i.e., the experimental group was younger than the comparison group. However, given the evidence, this age difference was deemed not to be an important influencing variable. While differences in education were not identified in the first analyses, in the reanalysis (university/non university) significant differences were identified between the two groups.

As for care receivers, they were highly similar in terms of demographics (age, gender, ethnicity and language), as well as in regard to the external services that they were receiving and the care that their caregivers were providing. Moreover, care receivers were highly similar in terms of their cognitive status.

The relevance of this intervention study for these caregivers was reflected in the high acceptance rate, that is, out of the 57 potential participants who initially accepted to take part, 51 enrolled in the study. Moreover, there was a low attrition rate and only one participant (in the comparison group) left the study (after Time 1 measures) due to the illness of his spouse.

Theoretical Considerations

This experimental study was guided by the McGill model (Allen, 1977, 1982). Among the key variables of the model are included learning (Allen, 1986), and the development of the person's autonomy and self-efficacy (Gottlieb et al., 2006). Given that self-efficacy was an especially relevant concept in the present study, this conceptualization also provided important direction. More particularly, Self-efficacy theory guided the development of the particular teaching-learning strategies, and geragogy (within a constructivist orientation) provided the general pedagogical framework for the older learner. The following discussion will focus on how these conceptual orientations were used, and explicate their utility for this study, with a particular emphasis on the McGill model.

In the McGill Model, the client or 'person' is faced with a health-related 'life event' in the family context. This conception informed the present study, that is, the person was depicted as the caregiver in the context of the family member's recent diagnosis of Alzheimer's disease − 'a health-related life event'. Furthermore, the person in the model is considered to have the capacity to learn and to have particular knowledge about his/her context, both these postulates retained in this study. In regard to the prescription or nursing therapeutics, with respect to the McGill model, the prescription is portrayed in terms of a learning-focused 'situation-responsive' nursing therapeutic, i.e., the pyscho-educational program, actualized within a 'collaborative partnership' process − discussed henceforth.

In terms of processes of implementation, the McGill model served to explicate the nature of collaborative roles of the nurse and the person (i.e., caregiver), as partners (Gottlieb et el., 2006). Furthermore, the model was the inspiration for the role of the nurse who supports the caregiver as an active partner in the learning process and recognizes the caregiver as the principal source of information about his/her learning needs.

Within the general perspective of learning – the overriding concept in the McGill model, the nurse in this study fulfilled the role of the knowledgeable partner who structured learning opportunities, as articulated in the prescription or psycho-educational program, in response to the caregiver's particular communication-related needs relevant to the life event. The inputs from these two partners guided the evolution of the intervention, reflecting the collaborative nature of the partnership in the McGill Model. These collaborative interactions represented a dynamic process wherein the flow of new information from the caregiver and responses from the 'expert' nurse (in terms of adapted learning strategies), resulted in ongoing adjustments to learning priorities (i.e., learning goals) (Gottlieb et al., 2006).

As highlighted, the McGill model inspired the overall format of the psycho-educational program (i.e., therapeutic). More particularly, a key premise of the model, that persons learn to become situation-responsive to life events, guided the particular diverse learning situations. The ten topics in each module of the program reflected the life event 'situations' with which the caregiver was faced when looking after a family member in the context of early Alzheimer's disease.

Finally, the outcomes sought out in the present study were also informed by the McGill model. That is, given the focus of the model on learning, it was relevant to evaluate the effect of the intervention on learning, and retain *knowledge* as an outcome measure. Moreover, a key tenet of the Model; i.e., the role of the nurse being to facilitate the development of the person's autonomy and self-efficacy with the goal of augmenting the person's capabilities to manage problems (Gottlieb et al., 2006), informed – in part – the use of outcome measures relevant to *self-efficacy* and *skills* (the latter concerned with 'managing problems' in the McGill model).

In conjunction with the emphasis of the Model on learning, the modalities of learning retained in the program were informed by Self-efficacy theory. That is, the four evidence-based self-efficacy strengthening learning strategies with respect to augmenting self-efficacy perceptions and caregiver capabilities to actualize communication skills (i.e., mastery, persuasion, modelling and reduction of aversive thought) (Bandura, 1986, 1997), were retained for this investigation.

The overall pedagogical conception – geragogy (John, 1988; Lebel, 1978), addressed some of the important dimensions that need to be considered in the teaching-learning health-related context when elders are prone to frailty and a compromised health status, especially in relation to cognition and physical limitations (e.g., sensory limitations, muscle and bone loss, circulatory impairments, etc.) (Martha Tyler John, 1988). This geragogical perspective melded well with the theoretical orientation of this investigation, given that the majority of family caregivers of individuals with dementia-related problems are in the later phase of life development, thus are more likely to have health-related problems. This was confirmed by the participants in the present study, many of whom reported mobility related limitations, as well as auditory and vision related difficulties.

Therefore, in keeping with the gerogogical theoretical notions, particular attention was given to ensuring ease of access to, and comfort in the physical facilities where the learning sessions and measures were conducted, (e.g., proximal parking, access to wheelchairs and elevator, comfortable room temperature, ergonomically appropriate furnishings and ease of access to washrooms). In response to vision related limitations, strategies included no glare lighting and writing-display boards, thick nib markers for the writing board and the use of large sized letters (large print was also used for the documents – printed program and measures). The nurse addressed the auditory limitations of participants by sitting in proximity to them and providing a tranquil setting. In terms of cognition, the overall pace of the person was respected and additional time was provided – as needed, at the learning sessions and when completing questionnaires.

To summarize, given where elders are situated on the developmental continuum; that is, in the later phase of life, relevant factors need to be addressed in the learning context. In this regard, the pedagogical orientation of geragogy served as an appropriate adjunct to both the McGill Model and Self-efficacy theory.

In terms of the individualized delivery mode of the program, while the rationale for choosing this approach was underpinned by the scientific evidence, the particular notions related to a learner driven approach were informed by constructivist pedagogy. A central tenet of this philosophical orientation is that the pedagogue (the nurse in this study) must acquire indepth knowledge of the learner at both *individual* and *group* levels (Borg & Gall, 1989; Donald, 2000; Loewenberg Ball & Cohen, 1999). Both conceptions informed the actualization of the study. First, knowing the caregiver at the *individual* level was a key tenet that informed the specific communication related strategies. While the McGill Model accords importance to the person as a learner, the constructivist perspective provides more explicit direction to knowing the individual. The nature of knowledge about the person that was sought out by the nurse and then integrated into the particular learning modalities encompassed a wide range of perspectives relevant for individual learners. This information included (albeit not exclusively) language, life experiences, social history, employment background, socio-economic status, living context, hobbies, interests and education. This knowledge about each person was acquired, clarified and consolidated during the program, and on an ongoing basis was integrated into the specific learning situations that were actualized in conjunction with particular topics in each module.

The *group* perspective is reflected in the 'historical period' of the individual (Borg and Gall, 1989), and encompasses cohort differences from diverse worldviews and different learning approaches (Donald, 2000). Because most caregivers were older, particular attention was accorded to *cohort*-specific knowledge in regard to the learner's familiarity with instructional-learning styles (e.g., expository versus discovery learning), and knowledge about current-day technology (e.g., audio-video tools, informatics). An important element in the conception and actualization of this program revolved around the instructional-learning style of the overall cohort. Given that most participants had been educated in a 'pencil and paper' school era, a print format paper program was used. During learning sessions, the 'familiar' blackboard served as a teaching-learning medium. In considering the overall educational level of the cohort, the learning document was formulated at a comprehension level of grade five to six, respecting the 'lower denominator' of education of participants as a group.

An important contribution of this research is reflected in the theoretical perspective that oriented this nursing study, in conjunction with the communication focus of the intervention in *early* AD. More particularly, this study was guided principally by an integrated conception of the McGill nursing model, having it's origins – in large part – in Social Learning theory, and Self-efficacy theory – emanating from Social cognitive theory, the latter also underscored by Social Learning theory. To the best of the author's knowledge, the melding of these two theoretical perspectives, with their common roots, has not been retained for an experimental study such as the one conceived and conducted herein. Given that the McGill model accords importance to the development of the person's self-efficacy, with the goal of increasing his/her autonomy (thereby ameliorating health), this conceptualization is relevant for other nursing studies.

Moreover, further to a verification of the literature, the particular focus of the intervention on *communication* in *early* AD – a subject identified as a major problem for caregivers, in conjunction with the above theoretical perspective, also depicts an original focus, reflecting another key contribution of this research. As well, the complementary geragogy perspective represented an important innovation, as according to the literature, this conception has not been retained in nursing intervention studies with elders.

To summarize, these theoretical perspectives and the early AD communication focus, when combined, resulted in an innovative approach to the conception, development, actualization and evaluation of the effects of this bilingual (French and English) psycho-educational program for family caregivers.

Discussion of Principal Results

As reported in the preceding chapter, this nursing experimental study resulted in significant positive results on several variables. More specifically, this intervention had the greatest immediate impact on *caregiver* communication-related knowledge and degree of disturbance in regard to communication difficulties. As well, delayed results (i.e., at Time 3) on *self-efficacy* in relation to communication skills were identified.

In the following discussion, the principal findings will be addressed in relation to each hypothesis tested in this study. The outcomes concerned with the hypothesis in regard to caregiver knowledge will be discussed first, followed by results related to the other four hypotheses, that is, those which addressed the presence of communication difficulties, degree of caregiver disturbance in relation to these difficulties, self-efficacy in regard to caregiver skills and caregiver skills. The discussion will focus primarily on the overall findings for each of these outcome measures.

Effect of Intervention on Communication Knowledge

The first hypothesis, concerned with the effects of the psycho-educational intervention on the dependent variable of knowledge, was supported in this study. This intervention resulted in caregivers being significantly more knowledgeable about communication in the early AD context (as compared to the comparison group), one week after completing the program. Furthermore, these caregivers reported a further significant increase in overall knowledge between Time 2 (one week post intervention) and Time 3 (six weeks post intervention), indicating that they had continued to learn after completing the program.

This time-related amelioration between Time 2 and Time 3 was likely due – in part – to participants having been given provided with a personal copy of the complete program (about 500 pages - comprised of five modules). With this document in their possession after the end of the program, they had the opportunity to continue to review it at their convenience. Indeed, at Time 3 measures, a number of participants commented that they had referred to the program after completing the intervention, and shared their comments with the nurse in regard to this document at the meeting following Time 3 measures.

In conjunction with this time-related improvement in overall knowledge, one particular subject area was identified as seemingly especially important for these participants. Module 4, concerned with communication related to activities of daily living (ADL's) and instrumental activities of daily living (IADL's), played a key role in the overall significant improvement in knowledge between Time 2 and Time 3. This effect may have been due to the fact that these activities represent a large component of daily life 'events' for the care receiver, and so when this person encounters problems related to these activities, this gives rise to opportunities for communication difficulties with the caregiver. These two domains, i.e., ADL's and IADL's, around which many daily interactions between the caregiver and care receiver are likely to take place, are inextricably linked to the daily life of the caregiver. Given the propensity for the care receiver to experience difficulties in actualizing these tasks (even though many of these tend to occur only sporadically in the early AD context), the potential for miscommunication with the caregiver is augmented, thus underscoring this subject as a particularly important area of learning (i.e., knowledge) for the caregiver. It was likely for this reason that this module played a key influential role on knowledge acquisition by the caregiver.

The importance of these findings is reflected in the central role of knowledge and the modalities of knowledge transmission in the self-efficacy model (Bandura, 1986; 1997). While the literature clearly indicates that knowledge alone won't necessarily lead to behaviour change, acquisition of the requisite knowledge domain is a fundamental component of the self-efficacy model.

More particularly, knowledge is an antecedent to efficacy expectations. When knowledge is acquired through self-efficacy strengthening learning strategies, there is a much greater chance that it will lead to stronger perceptions in self-efficacy, which then are conducive to thought and behaviour change (Bandura, 1997). One example of such a strategy is the role of a competent model, i.e., the nurse in this study, who plays a key role in transmitting knowledge and facilitating the learning of effective skills and strategies (Bandura, 1986). The results of the intervention on knowledge and self-efficacy, demonstrated a number of links between these two variables. More particularly, six weeks after completing the program (at Time 3), caregivers reported overall higher significant levels for both knowledge and self-efficacy, as well as for modules 1, 2, 3 and 4 on these two variables. These findings clearly depict the parallels between increased knowledge and stronger self-efficacy perceptions.

Furthermore, the core tenet of self-efficacy is reflected in its relationship with a well-defined particular subject domain (Bandura, 1986; 1997); this tenet emphasizing the importance of a clear definition of the relevant specific knowledge or subject area. In this study, the knowledge domain relevant to early AD was clearly articulated to encompass communication in relation to preserved cognitive functions on the one side and, on the other side, difficulties related to memory, attention-concentration, perception, executive functions, judgement, reasoning and orientation; these subjects subsequently being integrated into the learning strategies.

In sum, the positive results in regard to the knowledge variable furnished confirmatory data that overall significant increases in knowledge (acquired through self-efficacy strengthening learning strategies), paralleled the significant augmentations in caregivers' self-efficacy perceptions (the latter will be discussed henceforth). Knowledge transmission is thus a key component of the self-efficacy model, and in this study it represented a central role.

Effect of Intervention on Perceived Communication Difficulties

The second hypothesis, which addressed the effects of the intervention on the presence of communication difficulties, was not supported in this study. No statistically significant differences were identified between the groups, neither for total scores nor module scores. Participants in both experimental and comparison groups perceived the presence of communication difficulties in a similar manner at all three measurement times.

The rationale for this hypothesis initially was that after the program, participants – who were expected to be more knowledgeable and more self-efficacious – would become less sensitive or more oblivious to the family member's communication difficulties, thus perceiving their presence (occurrence) to a lesser degree. This was not found to be the case. Several participants in both groups reported that after responding to this measure – even as early as at Time 1 – they became more sensitized to the existence of certain communication difficulties. That is, the questionnaire was a trigger that alerted them to problems that previously had gone unnoticed. These unexpected findings shed new light on this hypothesis, and so in retrospect, the results identified on this variable probably are not surprising.

Moreover, given that the time frame of the study for each participant was only about twelve weeks (i.e., from Time 1 to Time 3 measures), it would be expected that the overall cognitive status of the care recipient should remain fairly stable in such a short time period. Consequently, the communication difficulties that this person would experience within this time frame should also remain generally unchanged. Furthermore, by augmenting one's knowledge and/or increasing one's self-efficacy perceptions and/or communication skills, this should not be expected to have an effect on the actual presence of communication related difficulties. That is, these difficulties would still exist irrespective of one's knowledge about communication in the context of early AD. In sum, it is comprehensible that all participants in the sample perceived the overall presence of communication difficulties in a like manner.

Effect of Intervention on the Perceived Degree of Disturbance in Regard to
Communication Difficulties

The third hypothesis, which addressed the effects of the intervention on the degree to which participants were disturbed by the presenting communication difficulties, was supported in this study. Even though the nature and frequency of communication-related difficulties identified by the experimental and comparison groups remained constant throughout the three measurement times, perceptions in regard to the degree of disturbance related to these communication difficulties differed significantly between these two groups over time. More particularly, participants who had taken part in the program reported a significant overall lower degree of disturbance in regard to communication difficulties with their family member, one week after completing this program (as compared to the comparison group) and maintained these overall 'improved' perceptions six weeks after the program ended.

One likely reason for these favourable outcomes is a function of the increases in knowledge that were identified in these persons at Time 2 (with a further significant increase in knowledge at Time 3). That is, once these caregivers became more knowledgeable after completing the program, they had a better understanding of their family members' cognitive difficulties. Knowing that their family members – for the most part – could not control the behaviours which led to communication difficulties, it is highly plausible that caregivers were able to 'accept' these difficulties and so be less disturbed by them. In fact, comments such as, 'I know that he/she can't help it, so I don't make a big deal of the (communication) problem'; were received frequently from caregivers in the course of the program. It is also likely that these caregivers were now able to intervene in a more effective manner at an earlier moment, having learned certain skills (as will also be discussed in a subsequent section). That is, being equipped with these skills, caregiver interventions may have reduced the likelihood of certain communication difficulties from escalating into more disturbing situations.

Another reason for the significant decrease in perceived disturbance on the part of these participants may have been related to increases in their personal self-efficacy. Efficacy beliefs affect thought patterns (as well as behaviours), which in turn can enhance or undermine performance (Bandura, 1986; 1997). Having been exposed to a learning process wherein self-efficacy strengthening strategies had been used, and wherein self-efficacy levels had increased significantly at Time 3 (six weeks after the intervention), it is highly possible that these participants also had changed their 'thought patterns' or ways of thinking, and strengthened their self-efficacy beliefs in regard to their perceptions of the degree of disturbance. Even at one-week post intervention (Time 2), caregivers perceived these communication difficulties as less disturbing, possibly because their self-beliefs in regard to these difficulties were already stronger.

Two caregiving studies in the dementia context were identified which lend support to this proposition. In the first one, Gottlieb and Rooney (2003) found that the amount of upset that caregivers experienced in response to memory and behavioural problems (problem areas directly linked to potential communication difficulties in the present study) was highly and inversely associated with communication linked 'relational self-efficacy'. That is, the higher the level of caregiver communication-related relational self-efficacy, the lower was the degree of upset in regard to memory and behavioural problems of their care receivers. Similar findings were reported in another caregiving intervention study with caregivers of cognitively impaired older adults (Steffen et al., 2002). These caregivers reported increased levels of self-efficacy in relation to 'replying calmly' to interruptions of their family members, and simultaneously reported being less upset (i.e., less angry) in response to disruptive behaviours of their family members. In sum, in both these studies, at such time that caregivers expressed stronger efficacy perceptions; i.e., higher levels of relational self-efficacy in Gottlieb and Rooney's (2003) study, and stronger levels of self-efficacy perceptions in regard to communication-related disruptive situations in Steffen et al.'s (2002) investigation; they simultaneously reported being less upset with their family members' communication-related behaviours.

Both 'relational' self-efficacy (Gottlieb and Rooney, 2003) and self-efficacy for 'responding calmly' (Steffen et al., 2002) can be readily interpreted as self-efficacy concerned with communication-related modes of response (communication skills). Indeed, 'responding calmly' to diverse communication-related difficulties was one of the skills that caregivers learned in the present study. Thus, the outcomes of these two studies offer an interesting complementary and relevant perspective to the current study.

Effect of Intervention on Self-efficacy in regard to Communication Skills

The fourth hypothesis, which dealt with the effects of the intervention on the perceptions of *self-efficacy* as related to communication skills, was also supported in the study. Significant improvements were reported at both one-week (Time 2) and six weeks (Time 3) post intervention. However, after reanalysis with education (university/non university) as a control variable, a significant effect was present only at Time 3.

After Bonferroni correction, results for the modules indicated significant effects of all five modules at Time 3. Given the key role of self-efficacy as a precursor to thought and behaviour change, the above results were of importance in this study. With respect to the delay in the significant effects at Time 3 of both the overall scores and modules, the explanation for these findings may be related to the delayed effect of self-efficacy development when task demands greatly exceed those that are commonly experienced on a day-to-day basis (Bandura, 1997), as in the 'day-to-day' context of communication challenges related to early AD addressed in this study. In such a case, people tend to hold their beliefs in a 'provisional' state, while testing their newly acquired knowledge (and skills) and gradually raising their judgements (self-efficacy perceptions) about what they are able to do (Bandura, 1997).

These significant outcomes lend support to the key tenets of the self-efficacy model. In particular, the four evidence-based self-efficacy strengthening strategies (Bandura, 1986, 1997), that were actualized in this investigation, most likely contributed to the favourable results in regard to self-efficacy. Participants were given opportunities to practice communication skills (i.e., enactive *mastery* experiences), communication skills were *modelled* by the nurse and symbolic *models* were integrated into the 200 'stories' in the program, the nurse carried out *persuasory* feedback, and the nurse implemented strategies to *reduce aversive feelings* – putting the participant at ease throughout the intervention.

In the literature, support for the effectiveness of these four strategies on self-efficacy perceptions is depicted in the following longstanding noteworthy examples. Competent models have been shown to promote efficacy beliefs and skill development (Lirgg & Feltz, 1991, in Bandura, 1997). Mastery experiences were found to lead to high perceptions of self-efficacy and expectation of successful performance (Maibach & Murphy, 1995; O'Leary, 1985). Persuasory feedback highlighting personal capabilities of students was found to lead to increased self-efficacy (Schunck, 1982, 1987; Schunck & Cox, 1986), and framing of persuasory feedback in terms of avoiding potential losses in the present (rather than securing potential future gains), was successful in raising efficacy beliefs for adopting health promoting behaviours (Meyerowitz & Chaiken, 1987). With respect to the effects of aversive affective states on self-efficacy, induced positive mood enhanced perceived efficacy, whereas despondent mood diminished it (Forgas, Bower & Bower, 1990).

As mentioned in Chapter Two, intervention studies in the dementia caregiving context that include a skills training component related to communication, and that measure self-efficacy in relation to said skills, are not abundant in the scientific literature. Two intervention studies with skills components were identified in which communication dimensions were also present, and wherein self-efficacy measures were related to the particular skills (Gitlin et al., 2001; Huang, Shyu, Chen, Chen and Lin, 2003). More specifically, the self-efficacy measures in these studies were conceived in relation to 'managing' behaviours; the word 'manage', implying that skills of some type were used to respond to the particular behaviours.

In the study conducted by Huang and her colleagues (2003), the intervention group, in comparison to a control group, reported significant increases in self-efficacy related to managing agitation post intervention. In Gitlin et al.'s (2001) study, the intervention resulted in enhanced self-efficacy (albeit not statistically significant) for managing troublesome behaviours. Gitlin (2001) proposed that one likely reason for the lack of strength in the results was that caregivers might have needed more time to practice the use of the relevant strategies, this being a proposition in keeping with the postulates of self-efficacy theory.

While it was not clearly explicated, it is highly plausible that these two studies, in which self-efficacy was concerned with managing troublesome behaviours (Gitlin et al., 2001), and managing agitation (Huang et al., 2003), encompassed a communication perspective – given the nature of the variable 'manage'. Thus, the favourable self-efficacy outcomes related to managing behaviours in these studies with skill building components represent certain links to the positive outcomes in regard to self-efficacy related to skills in the present skills-building study.

A third study, conducted by Lovett and Gallagher (2003), also bears mention in this discussion, even though the parameters of their investigation are not as closely linked to the present study as those of Gitlin et al.'s (2001) and Huang et al.'s (2003) research. The outcomes of Lovett and Gallagher's (2003) intervention (albeit without an explicit skills building component), depicted higher levels of self-efficacy for maintaining pleasant events and solving caregiver problems in the intervention group. While the specific nature of the two self-efficacy related variables was not explicated, it would not be unreasonable to propose that they encompassed both communication and skills-related dimensions. In terms of the links between the present study and Lovett and Gallagher's (2003) investigation, it could be proposed that self-efficacy for 'maintaining pleasant events' and 'solving caregiver problems' (the latter variable depicting a more obvious skills related activity), bear a certain relationship to self-efficacy for communication skills in the present study.

Effect of Intervention on Communication Skills

The fifth hypothesis, which addressed the effects of the intervention on the actualization of communication *skills*, was partially supported in this study. It was only at Time 3 – six weeks after completing the intervention program, that caregivers reported a significant overall higher use of skills. However, when education (university/non-university) was added as a control variable, significant results were no longer present.

It is possible that these findings are related to the way in which self-efficacy influences thought and behaviour change, wherein a time lag can occur further to increased self-efficacy perceptions and prior to actual changes in behaviour or thought (Bandura, 1986). This can be further explicated in terms of how mastery experiences and modeling influence self-efficacy in relation to behaviour change (Bandura, 1994; 1997).

First, mastery experiences, the strongest source of self-efficacy, do not necessarily lead to immediate significant changes in behaviour. As the person practices a skill, his mastery of the skill increases. Each success in turn augments self-efficacy perceptions and these stronger beliefs in turn support the person's attempts to continue to try to master the skill. This process reflects reciprocally increasing mastery and self-efficacy perceptions (Ibid). In the course of the program, participants were encouraged to continue to use their skills. Indeed, six weeks post intervention, after completing Time 3 measures; several participants reported that in preceding weeks, they had been using the skills that they had learned on a regular basis with success, these performance successes being reflective of mastery experiences (Bandura, 1987, 1997).

Modeling, the second most important influence on self-efficacy, also does not necessarily lead to immediate changes in behaviour. At the six-week post-intervention meeting, participants also reported that they had consulted the program in preceding weeks, and a number of these individuals stated that they had found the 'stories' (i.e., models) especially helpful. As mentioned earlier, this document included 200 'symbolic models' (depicted by short stories-scenarios), one-half of which represented effective communication strategies, and the other half demonstrated less effective communication strategies. With respect to the influence of models, the evidence supports the postulate that when one is exposed to symbolic models that exhibit useful skills and strategies (such as the models in the printed program), this raises one's self-efficacy beliefs that one can actually carry out the related skills (Bandura, 1987, 1997; Schunk, 1987). It is possible that as participants continued to refer to the program document over time and became increasingly exposed to the program models or 'stories', their self-efficacy perceptions increased, and in turn they used their new skills with progressively greater effectiveness and with increasing frequency, albeit at a later moment in time.

In sum, it is possible that these two influences on self-efficacy, i.e., continued mastery experiences (i.e., practice of skills with successful results) by participants and access to symbolic models (i.e., in the printed program), were two key influencing factors that resulted in increased self-efficacy perceptions, which in turn led to the increases – albeit delayed – in skills. The same argument could be proposed for the results of the reanalyzed data wherein significant effects on self-efficacy were identified at a later time (Time 3) and wherein results were no longer significant for communication skills at Time 3. More specifically, it could be argued that even though self-efficacy reached significance at Time 3, not enough time had elapsed in order for the skills to be 'mastered', and in turn to demonstrate significant results at this moment (Time 3). The size of the sample (to be discussed later) may have also influenced the skills outcome.

Results of Case Scenario Questions

The answers to the second and third Case Scenario questions (conducted post intervention) complemented the results of the skills-related measure just discussed. In particular, the responses to these two case scenario questions upheld – in part – the learning that had taken place in regard to two communication topics in module 2, (i.e., 'naming' and 'word-finding'), and one topic in module 4 (i.e., activities of daily living – ADL's and instrumental activities of daily living – IADL's). Caregivers who had completed the program identified a significantly larger number of effective verbal-behavioural, emotive and other strategies – including environmentally oriented approaches in relation to these case scenario topics, in comparison with individuals who had been given the information flier.

In addition, six qualitative examples relevant to these case scenario topics (selected from the extensive feedback received from participants during the program sessions – and reported in Chapter 4), which depicted the effective use of communication strategies in relation to 'naming' and 'word-finding' problems, and difficulties related to ADL's and IADL's, provided further support to the positive outcomes of the intervention on communication skills. The importance of these findings is reflected in their alternate perspective, i.e., qualitative data that supported the favourable effects of the intervention in regard to communication skills, albeit in relation to only three specific topics in two modules (i.e., modules 2 and 4).

Methodological Considerations and Limits of the Study

Four principal methodological dimensions of this study will be addressed: first, the characteristics of the conception of the intervention; second, the measures used to evaluate the effects of the intervention and their limits; third, the size of the sample; and fourth, issues related to internal and external validity of the study.

The characteristics of the conceptualization of the program and their inherent strengths are depicted in the following four areas: its relevance for the population for which it was developed; its adherence to the requisite stages of development of an intervention; the integrity of actualizing the intervention; and the strong evidence base that underpinned the program (Burns & Grove, 2001).

First, the program was conceived in response to an important – if not the most important – problem identified by caregivers in the early context of Alzheimer's disease, i.e., depicted in the communication difficulties experienced by the caregiver with the family member/friend affected by this disorder. No such intervention program, guided by a theoretical framework as conceived in the present study, was located either prior to the conception of the study, nor in a more recent verification of the literature. Second, the requisite stages of development of an intervention program were followed, from conception of a prototype, to pilot testing and finally formal testing through an experimental design. Third, the integrity of the intervention was respected throughout the actualization phase, i.e., the intervention was implemented in the same way as it was designed, this being a critical aspect of a formal test of an intervention (Ibid). Fourth, the evidence base of the intervention program emanated from an exhaustive literature review (until saturation), which was confirmed as relevant and comprehensive by experts.

The second methodological dimension is related to the measures used in this study. Four quantitative measures were used in the investigation (one of which was made up of two parts). Two measures were developed by the researcher and two others were adapted to test the effects of the program. All were focused on communication in the early AD context. One could speculate that a potential limitation of the study is related to instrumentation, given that two of the measures were newly conceived (i.e., caregiver *knowledge* and *communication skills*) and the other two were adapted (i.e., *self-efficacy* and *communication difficulties* and *degree of disturbance* - a 2-part measure).

However, given that two of these measures did not exist prior to the inception of the study; first, in order to ensure their content validity, great care was taken to ascertain that they were underpinned by the scientific evidence (i.e., as already reported, through an exhaustive review of the literature until saturation and by a subsequent verification by experts who confirmed the measures as relevant and comprehensive, i.e., covered the subject domain fully). Second, the format of the instruments (e.g., length, response modalities, etc.) was informed by the methodology-psychometrics literature, and third, the reliability of these measures was tested and results showed a high internal consistency for all measures.

The newly conceived measures will be discussed first, i.e., *knowledge* and *communication skills*, followed by the adapted measures, i.e., *self-efficacy* and *communication related difficulties* and the *degree of disturbance*. The two new quantitative tools (*knowledge* and *communication skills*) were conceived in the absence of such measures in the literature. An important aspect of these measures is, as stated earlier, that they must be underpinned by a comprehensive content domain.

The *knowledge* questionnaire was the first measure conceived. This was a pivotal instrument since from a content perspective it informed the other measures. The conception of subject domains for the five modules was conducted with great care to ensure that they reflected the relevant cognition-related content areas and the topics (items) for the modules were selected to ensure that the full range of key communication-related situations were covered in each module. Great care was also taken in regard to their formulation (wording) and to ensure that they were easy to understand. The internal consistency coefficient for this measure was 0.91.

Another new instrument, concerned with communication related *skills*, is highlighted as a unique measure in terms of its utility as an evaluation tool in the caregiving domain. An exhaustive assessment of what a participant 'does' or carries out subsequent to an intervention is generally not incorporated into caregiving intervention studies, as confirmed by a review of the literature. Such a post intervention evaluation of caregiver actions can help to identify what 'worked' in the intervention, thus provide valuable data and inform further initiatives, e.g., inspire refinements to interventions. The skills evaluation model in this study offers a self-report prototype, with a high degree of specificity in regard to post intervention assessment modalities for participant actions-skills; which is adaptable to other outcome (subject) variables. A Cronbach's α of 0.94 was reported for this measure.

The *self-efficacy* measure related to communication skills was adapted from the self-efficacy scale format developed by Bandura (1986, 2001). As required, it was formulated in terms of self-efficacy being a 'state' rather than a 'trait' variable, thus the particular tasks-activities were conceived in relation to the subject matter drawn from empirical studies. The format of the measure also respected the requisite parameters (i.e, a '0' to '100' scale and appropriate wording of response) (Ibid), these elements supporting the strength of its format.

Furthermore, since "the construct of self-efficacy is imbedded in a theory that explains a network of relationships among various factors, *construct validation* is a process of hypothesis testing" (Bandura, 2001, p.7). Thus, people who score high on perceived self-efficacy should differ in distinct ways from individuals who score low in ways specified by the theory. Verifications of predicted effects thus increase the evidence for the validity of the construct (Bandura, 2001; Burns & Grove, 2001). Support for construct validity was evidenced in the outcomes of the present study wherein a significant increase in self-efficacy was accompanied by a significant reduction in perceived disturbance in regard to communication difficulties in the experimental group – as had been predicted in the relevant hypotheses. An internal consistency reliability coefficient of 0.96 was reported for this measure in the present study.

The last quantitative measure, comprised of two components (i.e., the presence of *communication related difficulties* and the *degree of disturbance* in relation to said difficulties), was an expanded version of a validated measure developed by Teri and her colleagues (1992). More specifically, the tool adapted for this study retained all seven subjects in Teri's questionnaire, and added (to it) the 'missing' topics that had been identified in the expansive literature review. Thus, an inherent strength of the tool adapted for the present study is that it is based upon a validated tool, the 'Revised Memory and Behaviour Problems Checklist' (RMBPC) (Teri et al., 1992). A further strength is that its content was 'completed' by the addition of relevant items drawn from the literature. A Cronbach's α of 0.92 was reported for the first component of this measure, i.e., the presence of *communication related difficulties*.

As already underlined, all measures had been reviewed by experts who judged the subject matter in these tools to be representative of the cognitive domain associated with early stage AD, comprehensive (i.e., covered the complete spectrum of the domain), easy to understand and appropriate for the potential users. Given that a highly important dimension of these measures relates to content - face validity, the endorsement by these experts accorded further strength to this aspect of validity.

However, even though a great deal of attention was given to the format and content validity of the measures, and while they were piloted prior to implementation in the study, a number of potential improvements were identified during the investigation. Among these were included the rewording of certain topics (items), substituting alternate subject matter in several topics, and possibly reducing and/or eliminating those items that overlapped between module five and the other modules (this 'overlap' approach having been a purposeful pedagogical strategy of the researcher). Last, while all participants were able to complete all measures at each of the measurement times, several individuals reported that the tools were lengthy. These recommendations, along with further testing of the measures, need to be taken into consideration in subsequent psychometric initiatives.

Finally, the three Case scenario questions (a qualitative approach) provided an alternate source to assess the effects of the intervention, albeit on a small number of topics. This triangulation strategy permitted an indepth examination of learning at the specific topic or item level and provided further supportive evidence in regard to the particular skills-related outcomes. That is, this strategy provided additional insight as to how caregivers were responding, or said they would respond, to communication difficulties.

Another methodological consideration is related to the sample size in the study. Variables that had a favourable influence on the effect size (ES) in this investigation included first, *equal numbers* of participants in the two groups; second, an *individualized* intervention – which rendered a high degree of intensity of the intervention and third, delivery of intervention by the *same person* – thus a greater propensity for participant retention given the increased opportunity to establish a participant-researcher relationship.

Fourth, given that the phenomenon of unidirectional 'large changes' in self-efficacy has been shown to exist in diverse domains (as stated in Chapter Two), this intervention was also expected to lead to a large change in self-efficacy, so by extrapolation, a larger ES. Last, given that caregiving interventions delivered via primarily a *group* mode and administered over 3 – 5 sessions are considered to have a 'moderate' impact (Brodaty et al., 2003), it was posited that the five-session *individualized*, thus more intense intervention, would have a stronger effect on the outcomes.

As articulated in chapter III, given the recruitment difficulties, and guided by Cohen (1988), the final sample size was established at 50 (25 per group) to be able to capture medium to large effects. We recognized that this sample size likely would not permit the detection of small effect sizes, and given that we did not have significant results for selected outcome variables, it is possible that a larger sample size may have resulted in different outcomes.

Finally, issues concerning internal and external validity are addressed. Having assessed the statistical conclusion, i.e., examined the significant differences between the groups (this being the first step in establishing validity) (Cook & Campbell, 1979; Shadish, Cook & Campbell, 2002), *internal validity* issues could then be addressed. More particularly, the modalities of *measurement* of the *dependent variable* need to be considered in that sometimes treatment results may only be evident with certain types of measurements. For example, a teaching strategy that is tested with a multiple-choice test may produce superior results, whereas show no differences when the effectiveness of the study is measured with an essay test, or vice versa. Thus, alternate measurement approaches of a content area may need to be examined in order to determine, for example, if knowledge is being evaluated in an optimal manner (e.g., true/false).

The *implementation of the intervention* was carried out by one person, and along with a highly structured, easy-to-follow program, ensured a consistent approach thus reducing the impact of this threat of internal validity.

Instrumentation was not viewed as an internal validity concern, as the measurement methods and their administration did not change and data collectors remained stable in the course of the study. Similarly, *testing* was not viewed as a problem because the presence of a control group rendered it possible to conduct repeated measurements (pre-tests and post-tests) on the same variables with both groups (in one-group studies, this can be a problem in that practice on a pre-test can influence subsequent results).

External validity, related to the generalizability or applicability of the results of a study to other – typically *real* – situations, settings or populations at another time, could be considered as limited in this study. In terms of *selection*-treatment interaction, as the sample in the present study was not randomly selected at the outset, this dimension has to be considered when addressing the generalizability of the results. However, given that the key parameters of the sample were clearly defined in terms of inclusion and exclusion criteria, along with randomization to groups, these features help to support a certain degree of external validity. Furthermore, the high response rate in this study greatly minimized the response rate error – a major threat to external validity (Lindger & Wingenbach, 2002). The low attrition rate gives further credence to the applicability of findings to other *similar* settings.

Social desirability response bias, wherein people respond in ways that they think are socially desirable, can be an influencing factor on construct validity. This type of bias tends to be most common in relation to threatening or sensitive questions (e.g., on drug use or sexual behaviour), or strong social norms (e.g., church attendance). While the possibility of social desirability response bias cannot be ruled out completely in this study, the possibility of this type of influence is probably lower, given that the nature of the inquiry did not encompass the types of 'threatening' or 'sensitive' questions typically recognized as problematic. It is possible however, that there may have existed a tendancy for participants to want to 'please' the researcher and to 'study' the program in depth between sessions so as to do better on the measures. However, having a control group that also completed the same measures in the same manner counterbalances this particular concern.

Implications for Practice

The number of individuals diagnosed with dementia disorders, such as Alzheimer's disease, is expected to grow for many years henceforth. Moreover, curative treatments for these disorders are not anticipated in the near future. Thus, nurses will continue to provide care both to those afflicted by these illnesses and their families. Given the positive outcomes of this program, it can serve as a resource document for these clinicians and can be adapted for different settings, i.e., Geriatric Assessment Units, Memory Clinics, Community based care services, etc.

The practical application of this program for the clinical domain is depicted in its ease of comprehension (grade five to six level) and the highly structured, 'easy to follow' format. Each of the fifty topics follows the same learning steps. The program can be conducted in small portions – by reviewing an individual topic (over 10–15 minutes), or a complete module (10 topics per module), at a time. Each of the five modules is conceived around one or two particular subject domains, relevant to specific learning area(s). By anchoring each module thematically, it is rendered more cohesive, thus easier to actualize. The program can also be adapted easily to each person. By reviewing the list of topics in the program with the client, learning needs can be identified rapidly, and learning activities can focus on topics useful for the learner.

The modalities of implementation of the program (underpinned by self-efficacy strengthening learning strategies) are also easy to carry out since they are generally well known to nurses. That is, nurses are already familiar with these strategies and use them regularly in their practice, even though they may not recognize them as such. To give a few examples, in their daily practice, nurses serve as *models* to their clients, whether to show these persons how to carry out a dressing or use a technological device.

Furthermore, when patients practice new skills – such as when testing their blood sugar levels, competent nurses *persuade* or encourage them to continue to practice until they have *mastered* the task-skill (or have carried it out effectively). Last, nurses favourably influence the *affective* and *physiological states* of their patients by carrying out interventions in a manner that augments their comfort levels and reduces their anxiety – be it with their choice of words, calming tone of voice, or any of the other numerous strategies used by nurses (also depicted in the program).

Implications for Education

The most important contribution of this investigation to education is concerned with the Communication-focused Program that was developed and validated for the context of early stage Alzheimer's disease. This evidence-based program provides a reference document for nurses (and for other professionals) for 'in-house' education of care providers in diverse health care settings wherein individuals with Alzheimer's disease are diagnosed and to whom care and services are provided. With minimal adaptation, this program can also serve as an education tool for care providers of persons diagnosed with other dementia-related disorders (e.g., vascular dementia and fronto-temporal type affectations).

The program can be used as a teaching aid for educators in formal education settings (e.g., high schools and colleges) for programs for health care providers (e.g., special care counsellors, nurses, nursing assistants, nursing aids...). Furthermore, this tool can also serve as a resource document for provincial and national/federal organizations such as the Alzheimer's Society and for local-regional groups such as 'Baluchon Alzheimer' (in Québec), when developing educational materials for families. Last, the conception of this program lends itself to self-learning, and with certain adaptations could be transformed into a computer assisted self-learning tool.

Implications for Research

This research project offers several applications for the research domain. The first one is concerned with the theoretical frameworks that were retained in this study, in particular the McGill model and Self-efficacy theory. Given that self-efficacy strengthening teaching-learning strategies are inherent to nursing practice, and that there is a growing utilization of the McGill model in the nursing profession, these combined theoretical orientations lend themselves to providing direction to a wide range of potential nursing research initiatives. More particularly, this conceptualization could be used to guide studies wherein teaching-learning interventions are tested with clients or health care providers in health care-services organizations. Examples include testing of educational interventions focused on continence care, pain management, oral-buccal care, and integument-related care (e.g., pressure ulcers), to give a few examples.

Another target group that could serve as a prospective population for research purposes for this program is the large (and growing) number of trained and untrained workers in long term care facilities, community care centres (CLSC's in Québec) and acute care facilities. Again, adaptation of the program for testing with these care provider groups would need to be taken into consideration

This evidence-based program represents a resource document that can be adapted (i.e., restructured or reformulated) for research initiatives with other similar or related populations. More specifically, these participants could include family caregivers of individuals in more advanced stages of Alzheimer's disease, or family caregivers in other dementia contexts or in other cultural contexts. Such research initiatives wherein the intervention is modified and the findings are replicated are important for strengthening an intervention (Burns & Grove, 2001).

According to Burns & Grove (2001), it is feasible to move to the advanced testing stage of an intervention once 'sufficient evidence is available that the intervention was effective in achieving desired outcomes'. Given that the results of this study lend support to this tenet, the present intervention can now proceed to the next stage (of testing). In particular, as recommended by Burns and Grove (2001), this advanced testing can focus on identifying variations in effectiveness based on first, participant characteristics (e.g., recruiting a sample from a more culturally diverse population); second, setting characteristics (e.g. conducting the study in an alternate setting, such as in a different metropolitan area); and third, the strength of the intervention (e.g., using a 'lower intensity' group mode with a larger sample size).

In regard to the intervention, the outcomes of this study (and other new empirical findings) could be retained its content would need to be updated in relation to new evidence, and adapted or restructured if considered for alternate delivery mode (e.g., for groups). In terms of the utility of the subject focus of this intervention, given the importance of communication for caregivers in dementia contexts, it is highly relevant that the subject of *communication* be included as a key component of multi-component or 'global' education related interventions for dementia caregivers.

Another area that offers possibilities for research is concerned with the four measures that were adapted-developed for our study. According to Burns and Grove (2001), after the initial development of an instrument, further testing in alternate studies adds to the validity information of the measure. Further research will be required to determine the independence of the five themes of the modules, i.e., the presence of independent factors. Exploratory factor analyses can be conducted to examine relationships among the items in these subject areas and help to determine how the final conception of these measures can be better articulated. Alternate formats could be considered (e.g., combining the measures into a more concise or 'synthesized' structure). Further to confirmation of their psychometric properties and translation, these bilingual tools (French and English) could serve as useful instruments for future research initiatives.

Conclusion

With the aging of populations in industrialized countries, the number of persons affected by Alzheimer's disease is expected to rise substantially; in Canada alone, the projected increase is expected to be around one-half million persons by 2030. In view of the fact that no treatment is forthcoming for this debilitating disorder in the near future, families and friends of persons affected by this illness of long duration will continue to play a major role in providing care to their loved ones. Moreover, given that the large majority of family caregivers of individuals with dementia related disorders are also older and themselves at higher risk of health related problems, they represent a target group for relevant interventions.

It is also generally accepted that people prefer to live in their home settings rather than resort to institutional care. This perspective is a primary consideration of the present-day orientation of health care services delivery toward the home-based care model. Since nurses are well placed in our health care system to provide care to families in the dementia context, this program serves as a useful resource to these health care professionals, both as a learning tool for themselves, and as an instrument that they can use with ease in their practice. Moreover, given that the communication focus of this program represents an area identified as extremely relevant for family members who are faced with the challenges of Alzheimer's disease, the applicability of this tool, either stand alone or as part of a more global program, renders it especially useful.

Research is conducted to generate essential knowledge to address practice concerns, with the ultimate goal of providing evidence- or research-based nursing care (Burns and Grove, 2001). In this research study, a major practice concern was addressed, and an intervention relevant to this need was conceived and tested with significant outcomes. Even at this early stage of development, this program already provides a reponse to a major concern of caregivers – the communication perspective in relation to difficulties with their family members and friends diagnosed with Alzheimer's disease.

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APPENDICES

APPENDIX A :

List of Recruitment Guidelines – Documents

1. Guidelines for Professional at Health Care Facility to Facilitate Contact with Family Caregiver or Patient

2. Information Flier for Family Member or Friend of Person with Cognitive Problems

3. Guidelines for Telephone Contact with Potential Participant (Caregiver)

1. GUIDELINES for the PROFESSIONAL at the Health Care Facility

to Facilitate Contact with Family Caregiver or Patient about the

COMMUNICATION RESEARCH PROJECT

In the absence of the researcher, your help is greatly appreciated to inform family members about the *Communication Research Project* for caregivers of individuals with cognitive difficulties associated with early stage Alzheimer's disease. The following instructions will help to guide you in making the initial contact with the caregiver. In the absence of the caregiver, the initial contact may take place with the patient (person with cognitive problems) in order to seek permission for the researcher to communicate with this person's *principal caregiver*.

The *principal caregiver* is the individual who, according to the person with cognitive problems, *plays the most important role in his or her life on a day-to-day basis*. In most cases this caregiver is the spouse; however this person could also be another member of the family, a friend or a neighbour.

<u>Procedure to follow</u>:

1. The *caregiver* who qualifies for the study is a) aged 55 or older, b) able to communicate in English or in French, and c) a family member or friend of the patient (person with cognitive problems) who has a score of 20 to 28 on the MMSE.

2. This *caregiver* is given the information flier. Contact information is obtained (i.e., telephone, email, address) to facilitate future communication with the caregiver.

3. If the *caregiver* is <u>not</u> available, the patient (or person with cognitive problems), who meets the above cognition criterion, is informed about the research study, and is asked if he/she would agree to having a researcher communicate with his/her *principal caregiver*. If the patient agrees, the Information flier describing the study is given to the person with cognitive problems to remit to the caregiver.

2. INFORMATION FLIER for the <u>FAMILY MEMBER or FRIEND</u>

of a person with cognitive or 'memory' problems:

'A RESEARCH PROJECT ON THE SUBJECT OF *COMMUNICATION*'

We are presently looking for family members (and friends) of persons who are having cognitive (or 'memory') problems, to participate in a research project at the Sherbrooke Geriatric University Institute. The main purpose of this project is to help family members (and friends) to become better informed about how to communicate with someone who has memory problems.

This project is for the person who is the main caregiver of the individual who is having cognitive ('memory') problems, that is, *the person who plays the most important or most significant role in the daily life of the person with cognitive (or 'memory') problems.*

Persons who wish to participate in this study must meet certain criteria or have certain characteristics. In particular, we are looking for family members or friends who are 55 years or older and who are able to communicate in English or French. If you are 55 years or older and you can communicate in English or French; and if you are interested in taking part in this study, we would like to give you more details about it.

You can communicate with the nurse researcher:

Name: **Krystyna Kouri**

Telephone: **(819) 821-1150 (Extension 2687)**

Email: ████████████████████

Address: **Sherbrooke Geriatric University Institute, 375 Argyll St., Sherbrooke, J1H 3H5**

N.B.: If your name has already been given to the nurse researcher, she will communicate with you in the near future to give you more information about the study, so you can decide whether it would be of interest to you.

3 a.) Guidelines for TELEPHONE CONTACT 'A':

CAREGIVER REFERRED BY PATIENT

HELLO Mrs., Mr., _____

My name is _____ and I am calling from the Sherbrooke Geriatric University Institute. How are you today?

Wait for the person to answer.

'I am calling you because a member of your family (or a friend) who [*recently received care*] or [*is scheduled to receive care*] at the Institute (Sherbrooke Geriatric University Institute) has provided us with your name in regard to a new research study that we have developed. This study is concerned with communicating with a family member or friend who has memory problems. Do you remember receiving an information sheet about this study from your family member (or friend)?'

Wait for the person to answer. If the caregiver did NOT receive the flier:

'So you don't remember receiving any information about the study? May I take a few minutes of your time now to tell you about this project?

If the caregiver does not wish to receive any more information about the study, then the researcher thanks him for his/her time and says good-bye. However, if the caregiver is favourable to receiving more information, the researcher continues:

'This study is concerned with the subject of communicating with someone who has memory problems. In the study there are two educational approaches that are provided to two groups of persons such as yourself, that is, the family member (or friend) of the person who has memory problems.

In the *first* approach, each person will receive <u>written</u> information on the subject of *memory problems.*'

In the *second* approach, each person will <u>meet</u> with a nurse on five occasions, and will *learn about how to communicate with someone who has memory problems.*

Individuals in both educational approaches will also complete several questionnaires. These will be completed at three meetings; at the *first* meeting with a research assistant, then seven weeks later at a *second* meeting, and *third*, five weeks after the second meeting.

'Because this is a research study, individuals will be placed in these two approaches (or 'groups') *by chance*, so I cannot tell you today to which group you could be assigned.'

'Do you have any questions up to now?'

The researcher waits for the caregiver's reply, and then responds to any questions. If there are no questions, the researcher carries on.

Since you do not have any questions, do you think that this study could be of help to you?

*If the caregiver is not interested, then the researcher thanks him for his/her time and says good-bye. However, if the caregiver is **interested** then the researcher carries on.*

I thank you for your interest. In the next few days I will send you a letter with the information that I shared with you today along with other information about the study. May I now verify (or obtain) your address and email (if available)?

Address and email are recorded.

Thank you for your time and interest Mr. _____, or Mrs. _____. Have a good day – (afternoon) – (week-end). Good-bye.

3 b.) Guidelines for TELEPHONE CONTACT <u>B</u>:

CAREGIVER IS <u>*SELF-REFERRED*</u>

HELLO Mrs., Mr., _____

My name is _____ **and I am calling from the Sherbrooke Geriatric University Institute. How are you today?**

Wait for the person to answer.

"I am calling you because you indicated that you were interested in participating in our research study on the subject of communicating with a family member or friend who has memory problems.'

Wait for the person to answer.

If the caregiver is no longer interested in the study, then the researcher thanks him for his/her time and says good-bye. However, if the caregiver is favourable to participating, the researcher continues:

(As you may recall), in this study there are two educational approaches that are provided to persons such as yourself, that is, the family member (or friend) of the person who has memory problems.

In the *first* approach, each person will receive <u>written</u> information on the subject of *memory problems.'*

'In the *second* approach, each person will <u>meet</u> with a nurse on five occasions, and will *learn about how to communicate with someone who has memory problems.*

Individuals in both educational approaches will also complete several questionnaires. These will be completed at three meetings; at the *first* meeting with a research assistant, then seven weeks later at a *second* meeting, and *third*, five weeks after the second meeting.

Because this is a research study, individuals will be placed in these two groups *by chance*, so I cannot tell you today to which group you could be assigned.

Do you have any questions up to now?

The researcher waits for the caregiver's reply, and then responds to any questions. If there are no questions, the researcher carries on.

Since you do not have any questions, do you think that this study would be of help to you?

If the caregiver is not interested, then the researcher thanks him for his/her time and says good-bye. However, if the caregiver is interested then the researcher carries on.

I thank you for your interest. In the next few days I will send you a letter with the information that I shared with you today along with other information about the study. May I now verify (or obtain) your address and email (if available)?

Address and email are recorded.

Thank you for your time and interest Mr. _____, or Mrs. _____. Have a good day – (afternoon) – (week-end). Good-bye.

APPENDIX B:

Letters to Participants to Confirm Participation and Group Assignment

LETTER to Participant to confirm participation in study

Sherbrooke, day, month, 200_

Dear Mr/Mrs …

Further to our recent conversation, I thank you for the interest that you showed in our research project on the subject of *'communicating with someone who has memory problems'*. As I had mentioned, our study includes two educational approaches, one of which will be offered to you. The selection of the educational approach for each person will be made on a random ('chance') basis. Each person will receive <u>either</u> written information on the subject of 'memory problems' <u>or</u> will meet with a nurse on five occasions and learn how to communicate with someone who has memory problems. Individuals in both approaches will also reply to a general question and complete four questionnaires with the help of a research assistant on the subject of communicating with a person who has memory difficulties. These questionnaires will be completed on three occasions as follows; at a first meeting, then at a second meeting – seven weeks later and last, at a third meeting – six weeks after the second meeting.

I have been given permission by the University Institute of Geriatrics of Sherbrooke to communicate with you about this study. In the next few weeks I will be in touch with you once again to provide you with more information about the specific approach that will be offered to you, and also to give you the date of the first meeting. As well, at this meeting you will be told about the consent procedure and you will be asked to sign a consent form. This is a usual procedure for research projects. Please be assured that the information that you share with us will be kept strictly confidential. I look forward to talking to you in the near future about this study.

Yours truly,
Krystyna Kouri,
Nurse Researcher

LETTER to Participant in regard to Group assignment

Sherbrooke, day, month, 200_

Dear Mr/Mrs ...

Thank you for agreeing to participate in our research project on the subject of 'communication with a family member or friend with memory problems'. I am pleased to inform you that you will be included in **(Educational activity 'A': Information Flier) or (Educational activity 'B': Program).**

The first meeting will be held on <u>DATE</u>, at <u>HOUR,</u> at <u>PLACE.</u> There is a $2.00 charge for parking, which will be reimboursed to you at each meeting.

If you have any questions, I can be reached at the Sherbrooke Geriatric University Institute, telephone: (819) 821-1150 (extension 2687). If I am not in my office, please leave me a message and I will return your call as soon as possible.

I look forward to meeting with you on <u>DATE,</u> at the <u>PLACE.</u>

Yours truly,

Krystyna Kouri
Nurse Researcher

APPENDIX C:

Summary of Psycho-educational Program (Intervention)

A Psycho-educational Intervention focused on Communicaiton for the Caregiver of a Family member with Cognitive Difficulties Associated with Early Stage Alzheimer's disease

PEDAGOGICAL ORIENTATION

The *psycho-educational* intervention in this study encompasses elements of an *educational* perspective, which is knowledge acquisition, and an explicit *cognitive* dimension, which is that of strengthening *self-efficacy* (Bandura, 1997). A central foundational variable is *learning*, which in terms of the nursing perspective, emanates from the McGill model. The particular learning context of the *older learner* is respected according to geragogy principles; that is, a physical environment conducive to learning (e.g., adequate lighting, comfortable room temperature, ergonomic seating arrangements, proximity to washroom, etc.), and appropriately conceived learning resources (e.g., larger print material, non-glare resources, etc).

The *individualized, learner-driven* orientation of *constructivist* pedagogy underscores that the learning opportunities in *each session* respond to the particular learning needs of the individual participant. Consideration is given to the participant's 'history', knowledge and literacy level, preferred learning style, language and cultural aspects, affinity for particular audio-visual media, among other aspects. The particular learning strategies are guided by four *self-efficacy* strengthening sources (*mastery, modeling, persuasion* and *normalization of negative physiological and affective states*) wherein the goal is to strengthen beliefs about the actualization of new knowledge in regard to communication skills relevant for the context of early stage Alzheimer's disease.

PRINCIPAL COMPONENTS OF PROGRAM

OVERVIEW OF THE PROGRAM

The overall orientation of the program is to help family caregivers of individuals with cognitive problems to *learn* skills about how to communicate more effectively. There are five modules included in the program, each one concerned with a particular theme or subject area. These are listed as follows:

Module 1: *'Memories are important: What do we do today?'*
> *Learning* about and strengthening *self-efficacy* for communication related areas that are preserved in the early stage of Alzheimer's disease.

Module 2: *'Remembering and forgetting: Where did I put the keys?'*
> *Learning* about and strengthening *self-efficacy* for communication strategies related to 'forgetting' and 'remembering'.

Module 3: *'Why doesn't he – she listen? How can I get his – her attention?'*
> *Learning* about and strengthening *self-efficacy* in regard to dealing with communication problems related to environment and attention variables.

Module 4: *'Caring for my family member'*
> *Learning* about and strengthening *self-efficacy* in regard to communication strategies related to 'everyday' care areas (ADLs & IADLs).

Module 5: *'Emotions and my family member: What can I do to help?'*
> *'Learning* about and strengthening *self-efficacy* for communication strategies relevant to the emotive/affective changes experienced by the family member.

These five modules are described in more detail in a subsequent section.

OVERVIEW OF *PEDAGOGICAL MODALITIES* OF MODULES

1. **SETTING THE TONE – ENSURING THAT THE CAREGIVER IS PUT AT EASE:** The nurse researcher, as the 'credible' and 'knowledgeable' model, welcomes the participant warmly at each session and ensures his/her comfort putting him/her at ease prior to beginning the learning activity. (Self-efficacy perceptions are favourably influenced when the individual's affective or physiological state is modulated, i.e., he/she feels relaxed).

2. **REVIEW OF OBJECTIVES OF THE MODULE:** Prior to each module/session the nurse prepares herself by reviewing the objectives that have been formulated for the module.

3. **IDENTIFICATION OF COMMUNICATION PROBLEMS (LEARNING NEEDS):** At the outset of each module the nurse helps the caregiver to identify his/her particular learning needs by exploring with him/her the nature of communication problems (*sic* needs) that he/she is currently experiencing with the family member/friend in relation to the *theme* of the module. This renders it possible to individualize the content of the module to the caregiver's particular situation by selecting relevant topics from the subject areas in the module. (The caregiver is invited to add other learning needs *at any time* during the session.)

4. **SELECTION OF TOPICS FOR DISCUSSION FROM THE SUBJECT AREAS LISTED IN THE MODULE:** In response to the *specific* communication difficulties that are identified by the caregiver in each module, *relevant* topics are selected from the ones available in the module as pertinent for the caregiver's needs.

N.B. It is underlined that the sequence of the above modalities is adapted to the needs of the caregiver.

5. **PEDAGOGICAL PROCESS IN REGARD TO** *EACH TOPIC or SUBJECT* **IN THE MODULE:** Each *topic* is conceived to follow a specific pedagogical process. Given that 'skills mastery' is the strongest source of self-efficacy, and that skills are best 'mastered' by moving from lower to higher levels of complexity, whenever possible the practice *exercises* in each subject also move from lesser to greater levels of difficulty. Thus, *at the outset* exercises are conducted in terms of more simple 'everyday' communication situations, and after mastering these, other exercises are conducted for more complex communication contexts as relevant to the caregiver's context.

<u>First</u>, the topic is placed into a context of 'everyday' communication exchanges. The credible and knowledgeable nurse facilitator provides examples of 'everyday' communication situations relevant to the topic (illustrated in the module), and invites the caregiver also to think of examples. Each time that the caregiver '*masters*' the exercise and/or provides relevant examples, the nurse recognizes this 'accomplishment' giving '*feedback*'. (This is especially important *early* in the session to consolidate learning and strengthen self-efficacy.)

<u>Second</u>, several examples of 'GOOD' and 'POOR' communication exchanges *relevant to the topic* (illustrated in each module) are reviewed. Using these examples as a point of reference, the caregiver is encouraged to think of examples or ways in which this communication subject area could be put into practice with the family member in the *caregiver's context*. The nurse acts as a credible 'model' (an important source of self-efficacy) and engages in practice exercises with the caregiver, ensuring that the exercises are *realistic* for the caregiver. The nurse continues to give persuasory feedback and encourages the caregiver on an ongoing basis – this strategy known to strengthen self-efficacy.

<u>Third,</u> the topic is articulated in terms of a 'TIP'. All the communication tips in each module are regrouped on several pages at the conclusion of each module to serve as a rapid 'cue' or reference list for the caregiver.

<u>Fourth,</u> the participant is left with this thought: 'Has this discussion helped you to feel more more confident in your ability to :.........(*whatever the particular topic may be*).

6. **COMPLETION OF ALL RELEVANT TOPICS OR SUBJECTS OF MODULE:** This process continues for each of the topics in the module that have been identified as relevant for the context of the caregiver. If there are too many topics for a particular module they are either moved forward to a subsequent module, or to the last module where additional time has been provided. If, however there are too many topics identified by the caregiver as being relevant, then it may be necessary to address the most important ones identified by the caregiver during the sessions, and leave the 'less important' ones for the caregiver to review at home. They are then addressed at the subsequent meeting.

SUMMARY OF PROGRAM MODULES

MODULE NO. 1: 'Memories are important: What do we do today?'

This module introduces the caregiver to the overall program. The particular focus of the module is on the communication dimensions that are preserved in the early stage of Alzheimer's disease. Its' focus is on maximizing the communication potential of the affected person, and addresses the ways in which these strengths can be exploited in regard to response time, contextual cues, succinct speech, verbal validation, and so forth.

OBJECTIVES

- To establish a relationship between the facilitator and participant-caregiver.

- To familiarize the caregiver with the objectives, contents and plan of the program.

- To help the caregiver to identify his/her principal needs and concerns in regard to communication with the family member.

- To help the caregiver to identify his/her principal needs and concerns in regard to the communication related areas that are preserved in early AD.

- To facilitate caregiver learning in regard to the caregiver's needs and concerns, especially about communication areas preserved in early AD.

- To augment self-efficacy in regard to communication strategies relevant for communication areas preserved in the early AD stage.

CONTENT AREAS

- Review of the program (objectives, content, plan of program)

- Identification of principal needs, concerns and learning expectations of caregiver concerning communication, focused on the areas that are preserved in early AD. Facilitate caregiver learning via self-efficacy strategies about communication; especially about areas preserved in early AD – *first*, in relation to caregiver's expressed needs, and *second*, in regard to the other components of the module.

MODULE NO. 2: 'Remembering and forgetting: Where did I put my keys?'

This module deals primarily with short term memory limitations that lead to communication difficulties related to forgetfulness and repetitive speech, which are experienced by all persons in this stage. It encompasses such topics as loosing things, forgetting to accomplish or complete tasks, not remembering what one had heard/read and orientation difficulties. The participant learns about the nature of this problem, and acquires strategies and skills on how to minimize this problem, and how to respond when difficulties occur (e.g., through contextual support; and using effective verbal communication strategies such as how to help *'find the word'*).

OBJECTIVES

- To help the caregiver to identify his/her principal needs and concerns in regard to the communication problem of 'forgetfulness'.

- To facilitate caregiver learning in regard to effective communication skills, with a focus on the subject of 'forgetfulness'.

- To augment/increase caregiver self-efficacy in regard to actualizing effective communication strategies concerning 'forgetfulness'.

CONTENT AREAS

- Review of subject matter covered in Module 1 in regard to the preserved communication areas in early AD.

- Identification of principal needs and concerns of caregiver in regard to the communication area of 'forgetfulness' and 'remembering' in Module 2.

- Facilitate caregiver learning via self-efficacy strengthening strategies in regard to effective (verbal and nonverbal) communication skills concerning the family member's 'forgetfulness'.

MODULE NO. 3:

'Why doesn't he – she listen? How can I get his – her attention?'

This module deals with physical environment aspects and the relationship to attention-concentration deficits that contribute to communication problems. It includes the role of such environmental influences or distracters as noise, social events, crowds, and similar contexts. The participant becomes knowledgeable about how external stimuli affect communication and learns strategies and skills to deal with these influences. This theme includes the problem of the individual who periodically 'gets lost' – even at home. Strategies include creating a home setting conducive to communication (uncluttered milieu, role of radio/television, etc.); how to deal with external influences (e.g., multi-person conversations, visitors, shopping centres, crowds, social activities, etc.), and how to gain and maintain the attention of the other person.

OBJECTIVES

- To help the caregiver to identify his/her principal needs and concerns in regard to the influence of the environment on communication.

- To facilitate caregiver learning in regard to effective communication skills, with a focus on managing the environment.

- To augment/increase caregiver self-efficacy in regard to actualizing effective communication strategies concerning managing the environment.

CONTENT AREAS

- Review of subject matter covered in Module 2 in regard to managing effective communication strategies concerning 'forgetfulness'.

- Identification of principal needs and concerns of caregiver in regard to communication strategies for managing the environment in Module 3.

- Facilitate caregiver learning via self-efficacy strengthening strategies in regard to managing the environment with the goal of ameliorating communication.

<u>MODULE. 4:</u> Caring for my Family Member.

This module deals with the 'everyday' care areas wherein communication difficulties are experienced, generally referred to as 'activities of daily living' (ADLs) and 'instrumental activities of daily living' (IADLs) and encompasses such areas as judgement, reasoning and visual-spatial and executive functions. The participant learns about the communication problems that can arise in carrying out ADLs and IADLs, and acquires strategies and skills concerned with alleviating communication related difficulties. Also included in this module are *motor skill* activities (playing instruments, knitting, gardening, bicycling, golf, etc.); to help the participant learn how to support the family member in activities that he/she enjoy or has enjoyed in the past.

OBJECTIVES

- To help the caregiver to identify his/her principal needs and concerns in regard to the communication difficulties experienced in 'everyday' care areas (ADLs & IADLs).
- To facilitate caregiver learning in regard to effective communication skills related to everyday care areas (ADLs & IADLs).
- To augment/increase caregiver self-efficacy in regard to actualizing effective communication strategies concerning 'everyday' care areas (ADLs & IADLs).

CONTENT AREAS

- Review of subject matter covered in Module 3 in regard to managing the communication environment.
- Identification of principal needs and concerns of caregiver in regard to communication strategies concerning 'everyday' care areas (ADLs & IADLs) in Module 4.
- Facilitate caregiver learning via self-efficacy strengthening strategies in regard to communication strategies concerning 'everyday' care areas (ADLs & IADLs).

MODULE NO. 5: 'Emotions and my family member: What can I do?'

This module deals with the communication difficulties related to the emotive – affective domain and addresses such problems as mood variability, unawareness, sadness and confusion, among other subjects. As well, it addresses other communication related subjects that are problematic for the participant and which have not yet been covered (e.g., repetitive speech, disturbing behaviours, etc.). This module serves as an overview for the first four modules albeit from an emotions perspective.

OBJECTIVES

- To help the caregiver to identify his/her principal needs and concerns in regard to the communication difficulties experienced in the emotive or affective changes experienced by the family member.

- To facilitate caregiver learning in regard to effective communication skills related to the emotive or affective changes experienced by the family member.

- To augment/increase caregiver self-efficacy in regard to actualizing effective communication strategies concerning the emotive or affective changes experienced by the caregiver.

CONTENT AREAS

- Review of subject matter covered in Module 4 in regard to communication strategies concerning 'everyday' care areas (ADLs & IADLs).

- Identification of principal needs and concerns of caregiver in regard to communication strategies concerning the emotive or affective changes experienced by the family member in Module 5.

- Facilitate caregiver learning via self-efficacy strengthening strategies in regard to communication strategies concerning the emotive or affective changes experienced by the family member.

SELF-EFFICACY STRATEGIES

The principal ways retained to strengthen self-efficacy in this program were:

1) Performance accomplishment or *Skills mastery* (or *Enactive mastery experience*):

As the *strongest source of self-efficacy*; *'skills mastery'* is a very important strategy in this program. Throughout the program, the caregiver was provided with numerous opportunities to *learn,* to *practice* and to *master* new skills or 'tasks', wherein practice exercises proceeded from lesser to greater levels of difficulty. The following key strategies were retained:

• *First,* to strengthen successful mastery of a task, the caregiver's *accomplishments* or *gains* were highlighted, (especially when 'success' was not recognized or was 'forgotten' by the caregiver). This is particularly *important* in the *early stages* of skill acquisition, where the caregiver may be inattentive to successful performances and focus instead on less successful attainments (leading to an underestimation of self-efficacy).

• *Second,* the researcher was vigilant to ensure that the *effort* being expended by the caregiver was *commensurate with* his/her *ability.* (Perceptions of self-efficacy can be lowered when favourable results are not achieved even though the individual *puts in extensive effort*; simply because he/she does *not have the ability.*)

• *Third,* practice exercises must commence from an easier level and move to a higher level of difficulty.

2) Modeling or Vicarious experience is a second source of self-efficacy.

• *First,* given that individuals are most influenced when a 'competent' model carries out a task or action, the *professional-facilitator* fulfills this role throughout the program.

• *Second,* the vicarious experience of being exposed to 'models' *similar to oneself* (in particular, in terms of age, gender, and facing similar challenges) is made available to the caregiver via video presentations (of peers), and through sharing of attainments of peers in regard to effective communication strategies.

3) Verbal persuasion is a third source of self-efficacy wherein continual _feedback_ in regard to performance successes and encouragement for continued progress is provided. The _knowledgeableness, expertness_ and _credibility_ of the facilitator, i.e., the _'persuader'_, are key elements in this efficacy source.

• _First_, the facilitator needs to ensure that persuasory _feedback_ is carried out _in concert_ with _'realistic' goals_ for the caregiver.

• _Second_, the _framing of feedback_ or 'encouragement' must be presented:

first, in terms of _avoiding potential losses in the present_ (e.g., "If you can do 'A', you can expect to have 'B'."); and
second, in terms of _achieved gains_ or _attained progress_ (e.g., "You have made 'X' amount of progress").

4) Normalizing negative physiologic and affective states is the fourth source of self-efficacy.

Along with the preceding three self-efficacy strengthening strategies, a number of other ones help to reduce the anxieties and 'fears' of people who are likely to perceive the learning context of the program as stressful include:

• _First_, ensuring a _relaxed atmosphere_ for the program from the _outset_ by making the person feel at ease (i.e., giving a warm welcome, seeing to the individual's comfort – offering refreshments, verifying bathroom needs, etc., engaging in small talk, etc.) Maintaining this 'informal' orientation throughout the program is likely to help reduce any anxieties that the individual may be experiencing.

• _Second_, reassuring the participant that this program is designed to meet his/her particular needs and that the _pace_ of the _individual_ will be respected.

• _Third_, providing an _empathetic_ approach by trying to put oneself into the individual's shoes to better understand what he/she is experiencing. For example, saying to the caregiver that "I am trying to put myself into your shoes to better understand what you must be experiencing" may help to allay the individual's fears.

• _Fourth_, other helpful strategies include having the person take a few deep breaths, or changing his/her state of mind/perspective by having him/her think about something else such as a favourable memory or positive event in his/her life.

APPENDIX D:

Intervention Monitoring Checklist

Intervention Monitoring Checklist

Identification Number of participant: _____

SUBJECTS COVERED

Check (✓) when module (session) completed:

MODULE NO. 1: Date _____

MODULE NO. 2: Date _____

MODULE NO. 3: Date _____

MODULE NO. 4: Date _____

MODULE NO. 5: Date _____

Intervention Monitoring Checklist

Example: MODULE NO. 1

MEMORIES ARE IMPORTANT: WHAT DO WE TALK ABOUT TODAY?

SUBJECTS

1. GIVE *EXTRA DETAILS* (OR *ADDITIONAL INFORMATION)* AND PROVIDE '*MEMORY AIDS'* FOR CONVERSATIONS |___|

2. DISCUSS *ONE* TOPIC (*ONE* QUESTION – *ONE* REQUEST) *AT A TIME*; *PREPARE* THE LISTENER *FOR A CHANGE IN TOPIC* |___|

3. HELP THE PERSON WITH *READING* AND *WRITING* |___|

4. HELP THE PERSON TO '*FIND'* THE RIGHT WORD, AND TO '*SAY'* THE RIGHT WORD |___|

5. USE *SHORT* AND *SIMPLE* SENTENCES |___|

6. SPEAK AT A *NORMAL* (OR '*MODERATE'*) RATE OF *SPEED* |___|

7. *USE NOUNS* (NAMES of PERSONS, PLACES...) and '*SPECIFIC' WORDS instead of* PRONOUNS (HE, SHE, THEY...) or *NON SPECIFIC WORDS* (IT, THAT...) |___|

8. USE *FAMILIAR* (OR 'COMMON') *WORDS* OR *EXPRESSIONS* |___|

9. PROVIDE HELP WITH ANSWERS: *YES-NO* AND

   TWO (2)-*CHOICE* REPLIES |___|

10. HELP THE PERSON TO *CARRY ON A CONVERSATION* |___|

SCHEDULE: MONITORING OF INTERVENTION

THEME NO. 1 *'Memories are important: What do we do today?'*

OTHER COMMENTS (Record of qualitative data):

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APPENDIX E:

Information Flier about Memory Problems

Communication, Memory and Aging

How does the brain store information?

The brain stores information in one's *memory*. The information that is held in one's memory includes things that have happened in the past, that is, what one has *seen, heard, smelled, tasted* and *felt.*

Things are stored in different parts of one's memory depending on when they happened to the person.

Information stored in the *short-term memory* may include the name of a person one met moments ago or a phone number that one just looked up.

Information stored in the *long-term memory* includes things that are stored in memory years ago, such as memories of childhood, what one wore on one's wedding day or the color of the first car you bought.

How does aging change the brain?

Beginning when one is very young, the brain starts to change and brain cells are lost – a few at a time. The body also starts to make fewer chemicals that are needed for brain cells to work. The older one is, the more these changes can affect one's memory.

Aging may affect memory by changing the way that information is stored. It may also affect memory by making it harder to remember information the brain has already stored.

Things to help one remember

- **Keep lists.**

- **Follow a routine.**

- **Make *associations* (connect things in your mind), such as using landmarks to help you get around.**

- **Keep a detailed calendar.**

- **Put important items, such as your keys, in the same place every time.**

- **Repeat names when you meet new people.**

- **Do things that keep your mind and body busy.**

- **Run through the ABCs in your head to help you think of words you're having trouble remembering. "Hearing" the first letter of a word may jog your memory.**

What about when one knows a word but can't recall (remember) it?

This is called a "tip-of the-tongue" experience. It is usually just a glitch in one's memory. One will almost always remember the word with time.

This can become more common as one gets older and can be very frustrating. But don't worry. This is not serious unless it interferes with your daily activities.

What are other causes of memory problems?

Many things other than aging can cause memory problems.

These include depression, side effects of drugs, strokes, head injury and alcoholism, and illnesses such as *dementia* (which causes severe problems with memory and thinking).

Hearing and vision (seeing) problems can add to memory problems by making it more difficult to communicate.

Memory problems that are NOT a part of normal aging

- Forgetting things much more often than you used to.
- Forgetting how to do things you've done many times before.
- Trouble learning new things.
- Repeating phrases or stories in the same conversation.
- Trouble making choices or handling money.
- Not being able to keep track of what happens each day.
- Changes in how you act.
- Loss of social graces.
- Losing interest in daily activities and how you look.
- Feeling more depressed, confused, restless and anxious.

Communication and Memory Problems

When communicating with someone who has cognitive ('memory') problems it is helpful to :

1. Talk to him or her in a quiet place.

2. Place yourself in front of him or her so that he/she can see you more easily.

3. Use simple words and short sentences.

4. Use a low tone of voice, especially if the person has hearing problems.

5. Talk about only one subject at a time.

6. Ask questions which permit a 'yes' or 'no' answer.

7. Repeat the 'message' using the same words when the the person does not understand the first time.

8. Show 'memory aids' (such as photos or meaningful things) to the person to help him/her to understand better.

9. Check off dates on the calendar to help the person to remember the date.

10. Place medications in 'pill' containers with reminders to indicate when to take them.

11. Write important telephone numbers in large print and place them next ot the telephone.

12. Place labels (words or pictures) on cupboards and drawers to indicate what is inside.

Source: College of Family Physicians of Canada (1996)

APPENDIX F:

Dependent Variables (Measures)

LIST OF MEASURES

QUANTITATIVE MEASURES

1. Questionnaire on Caregiver Knowledge about Communication

2. Questionnaire on Communication Difficulties Perceived by the Caregiver and the Degree of Perceived Disturbance in regard to these Problems

3. Caregiver Self-efficacy Questionnaire in regard to Communication Skills

4. Communication Skills Questionnaire

QUALITATIVE INSTRUMENT

1. Three Case Scenarios – Open Questions

Quantitative measures

GENERAL INSTRUCTIONS FOR ADMINISTRATION OF MEASURES

These measures are conceived for *caregivers* of individuals with cognitive problems, frequently associated with the early stage Alzheimer's disease. Instructions are provided for the overall administration of each of these measures.

To encourage frank answers, it is helpful to explain to the respondents the importance of their contribution to research. They need to be informed that the resulting knowledge will help professionals to better identify the areas in which programs need to be developed and improved in order to help people learn about better communication approaches with a family member or friend who has memory problems.

In each of these questionnaires or scales, practice items are provided to help familiarize respondents with the measure so they can be better prepared to reply to the questions. Once participants understand how to use the measure, they can proceed to respond to the questions.

Instructions are also provided in each measure as to the appropriate modalities for *responding* to the measure. In most instances, respondents either write or give their response(s) orally; however, in some cases where health problems interfere with these modes, participants may point to their response.

QUESTIONNAIRE ON CAREGIVER *KNOWLEDGE* ABOUT COMMUNICATION

IN REGARD TO COGNITIVE PROBLEMS

Instructions for INTERVIEWER

GENERAL INFORMATION

This 'Knowledge' Questionnaire is conceived for *caregivers* of individuals with cognitive problems, associated with early stage Alzheimer's disease.

In conducting this knowledge assessment, individuals are asked to respond to <u>ONE</u> of the following three options that are offered in the questionnaire: 'TRUE', 'FALSE' or 'DON'T KNOW'.

The following section provides information to the respondent and includes practice exercises to help familiarize respondents with the questionnaire so they can be better able to reply to the questions. Once respondents understand how to use this tool, they can proceed to answer the questions in the questionnaire.

This questionnaire can be self-administered or in collaboration with the interviewer. Individuals can *write* their responses privately, or if they prefer, *say* them *orally*.

QUESTIONNAIRE ON CAREGIVER *KNOWLEDGE* ABOUT COMMUNICATION

Theme No. 1:

'Memories are important: What do we talk about today?'

1. *Sometimes,* the person with cognitive ('memory') problems finds it EASIER to talk about something, *(for example,* a wedding, a book, or an activity), if he/she has a MEMORY AID (such as a picture or object), in front of him/her.

TRUE_____   FALSE_____   DON'T KNOW_____

2. The person with cognitive ('memory') problems *always* finds it EASIER to follow the conversation, when someone talks about MORE THAN ONE subject *at a time.*

3. *In general,* the person with cognitive ('memory') problems has MANY problems with *reading* and/or *writing.*

4. *Sometimes,* the person with cognitive ('memory') problems does NOT say a word CORRECTLY, *(for example,* he/she does not say the *right word* for something, or does not say the *right name* of someone or a place).

5. The person with cognitive ('memory') problems can *always* understand LONG *sentences.*

6. *In general,* it is important to speak VERY, VERY SLOWLY to someone who has cognitive ('memory') problems.

7. *In general,* it is helpful to use NAMES of *people and places,* instead of words like 'there', 'him' or 'her' when talking to someone with cognitive ('memory') problems.

8. <u>*Sometimes*</u>**, the person with cognitive ('memory') problems finds it *difficult* to understand NEW WORDS or EXPRESSIONS (that he/she has never heard before).**

9. <u>*Sometimes*</u>**, it is *easier* for the person with cognitive ('memory') problems to ANSWER QUESTIONS that have only TWO choices,**
(*for example*, with 'YES-NO' answers).

10. <u>*Sometimes*</u>**, the person with cognitive ('memory') problems has difficulties to CARRY ON a conversation (or to talk about something).**

<u>Theme No. 2</u> :

'Remembering and forgetting: Where are my keys?'

1. <u>*Sometimes*</u>**, the person with cognitive ('memory') problems will START to do something and FORGET to *finish* the task, (*for example*, the person starts to make a snack and forgets to finish it).**

2. The person with cognitive ('memory') problems <u>*always*</u> remembers where he/she has placed an IMPORTANT ITEM (*for example*, the house keys or glasses or wallet).

3. <u>*Sometimes*</u>**, the person with cognitive ('memory') problems goes on an ERRAND and *forgets* what he/she *was supposed to do*, (*for example*, the person goes to the store to buy something and forgets what he/she was supposed to buy).**

4. _Often,_ the person with cognitive ('memory') problems finds it helpful to have a WRITTEN _reminder_ (or note) to help him/her remember, _(for example,_ if he/she is to be left alone for a few minutes or hours).

5. _In general,_ it is helpful for the person with cognitive ('memory') problems to have one _convenient_ PLACE at home where helpful or important INFORMATION is placed (such as a calendar, clock, and/or information-bulletin board).

6. _Sometimes,_ the person with cognitive ('memory') problems has difficulties to PUT THINGS BACK where they belong or in the 'right place',

(for example, he/she might put the jam in the dishwasher).

7. The person with cognitive ('memory') problems _always_ remembers RECENT news that happened NOT long ago,

(for example, what he/she heard on the radio or television).

8. _Sometimes,_ the person with cognitive ('memory') problems _forgets_ TO TAKE his/her MEDICATION (or pills).

9. The person with cognitive ('memory') problems _always_ remembers to turn ON (or OFF) household items or appliances

(for example, the stove, television/radio, lights or tap (or faucet).

10. _Sometimes,_ the person with cognitive ('memory') problems asks the SAME _question_ or repeats the SAME '_story_' over and over.

Theme No. 3:

'Why doesn't he/she listen? How can I get his/her attention?'

1. **_Sometimes_,** the person with cognitive ('memory') problems does not understand what someone says the FIRST time; and sometimes does not understand even when it is repeated a SECOND time.

2. **_Sometimes_,** it is difficult to FOLLOW THE CONVERSATION of the person with cognitive ('memory') problems, *(for example*, he/she may change the subject *without warning* and talk about something completely *different*).

3. **_In general_,** it is MORE difficult for the person with cognitive ('memory') problems to understand, when someone talks to him/her FACE to FACE.

4. **_Sometimes_,** it is MORE difficult for the person with cognitive ('memory') problems to FOLLOW a conversation (or to talk), when SEVERAL persons TALK *at the same time*.

5. **_Sometimes_,** the person with cognitive ('memory') problems finds it difficult to FOLLOW a conversation, when someone is both TALKING **and** DOING SOMETHING ELSE *at the same time*.

6. It is **_always_** easy for the person with cognitive ('memory') problems to communicate in a CROWDED place (where there are *many people*), *(for example*, in a shopping centre, theatre...).

7. It is **_always_** easy for the person with cognitive ('memory') problems to follow a conversation (or to talk about something), when there is NOISE around him/her (even a small amount of noise).

8. _**In general,**_ the person with cognitive ('memory') problems can _hear_ MUCH better when one speaks in a very, very LOUD voice.

9. _**In general,**_ when someone wants to get the ATTENTION of the person with cognitive ('memory') problems, one should NOT say his/her name before talking to him/her.

10. _**Sometimes,**_ the person with cognitive ('memory') problems needs EXTRA time to think, BEFORE replying to a question or comment.

Theme No. 4:

'Caring for my family member'

1. The person with cognitive ('memory') problems,
never has problems to use the TELEPHONE (or computer).

2. _**Sometimes,**_ the person with cognitive ('memory') problems has problems getting DRESSED, *(for example,* puts clothes on backwards or shoes on the wrong feet, or cannot do up buttons or zippers).

3. The person with cognitive ('memory') problems, _never_ has problems to do something that has SEVERAL STEPS, *(for example,* to prepare a meal; to heat food in the microwave, or to find a program on TV).

4. The person with cognitive ('memory') problems, _never_ has difficulties with PERSONAL HYGIENE or GROOMING, *(for example,* washing, shaving or looking after his/her hair).

5.   _Sometimes_, the person with cognitive ('memory') problems seems to move about a lot or 'CAN'T SIT STILL' (_for example_, he/she walks constantly or keeps doing the same activity 'over and over').

6.   _Sometimes_, the person with cognitive ('memory') problems, moves more SLOWLY, or does things at a SLOWER pace than usual.

7.   _Sometimes_, the person with cognitive ('memory') problems, 'WANDERS', that is, he/she doesn't know where he/she is, (even in his/her own home).

8.   _In general_, the person with cognitive ('memory') problems, needs much less SLEEP (or rest) than in the past.

9.   _Sometimes_, the person with cognitive ('memory') problems, has problems SLEEPING at night.

10.   The person with cognitive ('memory') problems, can _always_ COUNT 'things' (for example, count money, write cheques, pay bills).

Theme No. 5:

'Emotions: How can I communicate better with my family member?'

1.   _Sometimes_, the person with cognitive ('memory') problems _gets upset_: when he/she doesn't seem to know what is happening around him/her, (that is, he/she appears 'mixed up' or 'confused').

2.   _Sometimes,_ the person with cognitive ('memory') problems _gets upset_: when he/she CANNOT remember (or 'find') a word.

3.   _Sometimes,_ the person with cognitive ('memory') problems sometimes acts as if he/she does NOT want to be around others, (that is, he/she seems to 'IGNORE' those around him/her).

4.   _Sometimes,_ the person with cognitive ('memory') problems _appears to be_ SAD _for no apparent reason._

5.   _Sometimes,_ the person with cognitive ('memory') problems _gets upset_ when he/she is in an UNFAMILIAR _place_ (or a place that he/she does not know).

6.   _Sometimes,_ the person with cognitive ('memory') problems _gets upset_ if he/she has difficulties with _leisure activities_ or _sports_ that he/she has done in the past, (for example, _knitting,_ playing _golf,_ riding a _bicycle_ or _gardening_).

7.   _Sometimes,_ the person with cognitive ('memory') problems _gets upset_ or _angry,_ with others, _for no apparent reason._

8.   _Sometimes,_ the person with cognitive ('memory') problems _gets upset_ or _angry,_ when he or she CANNOT FIND _something._

9.   _Sometimes,_ the person with cognitive ('memory') problems _gets upset,_ when he/she does NOT UNDERSTAND NEW _words_ or NEW _expressions._

10.   The person with cognitive ('memory') problems _is never bothered_ (or disturbed) if furniture or other household things are moved about the house.

QUESTIONNAIRE ON
COMMUNICATION DIFFICULTIES PERCEIVED BY THE CAREGIVER
and the
DEGREE OF PERCEIVED CAREGIVER DISTURBANCE
IN REGARD TO THESE DIFFICULTIES

IN THE PERSON WITH COGNITIVE PROBLEMS

<u>Instructions for INTERVIEWER</u>

General Information

Each question in this Questionnaire has two parts: <u>first</u>, the '*perceived communication difficulties*' in the person with cognitive problems as identified by the caregiver; and <u>second</u>, the '*degree of perceived caregiver disturbance*' in regard to these communication difficulties (in the person with cognitive problems).

In the <u>first</u> part of each question, (which deals with the perceived communication difficulties identified by the caregiver), the individual responds to *one* of the following five options: 'NEVER' (*never occurs*), 'NOT VERY OFTEN' (*occurs infrequently and not in the past week*), 'SOMETIMES' (*occurred 1 to 2 times in the past week*), 'QUITE OFTEN' (*occurred 3 to 5 times in the past week*), 'ALL THE TIME' (*occurs several times per day or more often*).

In the <u>second</u> part of the question, (which deals with the *degree* to which the caregiver is disturbed by the communication difficulty), the individual responds to *one* of the following five options: 'NOT AT ALL', 'A LITTLE', 'SOMEWHAT', 'VERY MUCH' OR 'EXTREMELY'.

QUESTIONNAIRE ON
COMMUNICATION DIFFICULTIES PERCEIVED BY THE CAREGIVER
and the
'DEGREE OF PERCEIVED CAREGIVER DISTURBANCE'
IN REGARD TO THESE DIFFICULTIES

<u>Theme No. 1</u>:

'Memories are important: What do we talk about today?'

1. a) **My family member/friend finds it difficult to talk about a subject (for example, a wedding, a book or an activity) <u>unless</u> he/she has a *reminder* or *memory aid* in front of him/her (such as a picture, object)**

Never	Not very often	Sometimes	Quite often	All the time
(Never occurs)	*(occurs infrequently and not in past week)*	*(1 to 2 times in past week)*	*(3 to 5 times in past week)*	*(Several times per day or more often)*
(0) _____	(1) _____	(2) _____	(3) _____	(4) _____

1. b) *<u>It disturbs me</u>*

when my family member/friend finds it difficult to talk about a subject (a wedding, book or activity), <u>unless</u> he/she has a *reminder* or *'memory aid'* in front of him/her (such as a picture, object, etc.).

Not at all	A little	Moderately	Very much	Extremely
(0) _____	(1) _____	(2) _____	(3) _____	(4) _____

2. a) My family member/friend finds it difficult to *follow a conversation* when someone talks about <u>more than one</u> subject (or 'thing') at a time.

2. b) *It disturbs me* when my family member/friend finds it difficult to *follow a conversation* when someone talks about <u>more than one</u> subject (or 'thing') at a time.

3. a) My family member/friend has difficulties with reading and/or writing.

3. b) *It disturbs me* when my family member/friend has difficulties with *reading* and *writing*.

4. a) My family member/friend does NOT say the correct word(s), (*for example*, he/she <u>says</u> the *wrong name* of someone or a place, or says the *wrong word* for something).

4. b) *It disturbs me* when my family member/friend does NOT say the correct word(s), (*for example*, he/she <u>says</u> the *wrong name* of someone or of a place, or says the *wrong word* for something).

5. a) My family member/friend finds it *difficult to follow* or to *understand* LONG sentences.

5. b) *It disturbs me* when my family member/friend finds it *difficult to follow*, or to *understand* LONG sentences.

6. a) My family member/friend finds it *difficult to understand* when someone speaks SLOWLY to him/her.

6. b) *It disturbs me* when my family member/friend finds it *difficult to understand* when someone speaks SLOWLY to him/her:

7. a) My family member/friend finds it *difficult to understand* when others use words like '<u>it</u>', '<u>they</u>', or '<u>that</u>' (*instead of* NAMES of people (Mary, John) or places (Québec, Magog).

7. b) <u>*It disturbs me*</u> when my family member/friend finds it *difficult to understand* words like '<u>it</u>', '<u>they</u>', or '<u>that</u>'.

8. a) My family member/friend has *problems to understand* NEW words or NEW expressions.

8. b) <u>*It disturbs me*</u> when my family member/friend has *problems to understand* NEW words or NEW expressions.

9. a) My family member/friend has *difficulties to answer* QUESTIONS.

9. b) <u>*It disturbs me*</u> when my family member/friend has *difficulties to answer* QUESTIONS.

10. a) My family member/friend finds it *difficult* to CARRY ON A CONVERSATION (or to talk about something).

10. b) <u>*It disturbs me*</u> when my family member/friend finds it *difficult* to CARRY ON A CONVERSATION (or to talk about something).

Theme No. 2: *'Remembering and forgetting: Where are my keys?'*

1 a) My family member (friend) *begins* to do something, then leaves what he/she is doing mid-way and *forgets* to go back *to finish* it (*for example*, starts to make a snack and does not return to finish making the snack).

1 b) *It disturbs me* when my family member/friend *begins* to do something, then leaves what he/she is doing mid-way and *forgets to go back to finish* it. (*for example*, starts to make a snack and does not return to finish it)

2. a) My family member/friend *does not remember where* he/she has *placed something important*, (for example, keys or glasses or wallet/purse).

2. b) *It disturbs me* when my family member/friend *does not remember where* he or she has placed something *important*, (*for example*, keys or glasses or wallet/purse):

3. a) My family member/friend goes on errands, (*for example*, goes to the store to buy something), and then *forgets* what he/she was supposed to do.

3. b) *It disturbs me* when my family member/friend goes on errands, (*for example*, goes to the store to buy something), and then *forgets* what he/she was supposed to do.

4. a) My family member/friend does NOT remember *when I tell him/her something*; (or give him/her a message).

4. b) *It disturbs me* when my family member/friend *does not remember when I tell him/her* something (or give him/her a message).

5. a) My family member/friend has *difficulties* to find *important information, (for example,* the clock, calendar or reminders on the refrigerator - bulletin board, etc.).

5. b) *It disturbs me* when my family member/friend has *difficulties* to find *important information (for example,* clock, calendar - reminders on the refrigerator - bulletin board, etc.):

6. a) My family member/friend has *problems* to put things back where they belong *(for example,* he/she puts the jam in the dishwasher, or the iron in the sink, etc.).

6. b) *It disturbs me* when my family member/friend has *problems* to put things back where they belong *(for example,* he/she puts the jam in the dishwasher, or the iron in the sink, etc.).

7. a) My family member/friend *cannot remember* things that happened recently (not long ago), *(for example,* news that he/she read or heard recently).

7. b) *It disturbs me* when my family member/friend *cannot remember* things that happened recently (not long ago), *(for example,* news that he/she heard or read recently).

8. a) My family member/friend does NOT remember to take his/her *medications.*

8. b) *It disturbs me* when my family member/friend does NOT remember to take his/her *medications*:

9. a) My family member/friend does NOT remember to turn on (or turn off) household items or appliances, (*for example*, the stove, television, lights, taps, etc.)

9. b) *It disturbs me* when my family member/friend does NOT remember to turn on (or turn off) household items or appliances (*for example*, the stove, television, lights, taps, etc.)

10. a) My family member/friend asks the SAME question or repeats the SAME 'story' over and over.

10. b) *It disturbs me* when my family member/friend asks the SAME question or repeats the SAME 'story' over and over.

Theme No. 3:

'Why doesn't he – she listen? How can I get his – her attention?'

1. a) My family member/friend *does not understand* what is said to him/her the FIRST time.

1. b) *It disturbs me* when my family member/friend *does not understand* what is said to him/her the FIRST time.

2. a) My family member/friend has *difficulties* to carry on a conversation, *(for example,* he/she changes the subject without warning and talks about something completely different, or makes comments that have nothing to do with the conversation).

2. b) *It disturbs me* when my family member/friend has *difficulties* to carry on a conversation *(for example,* he/she changes the subject *without warning* and talks about something completely different; OR makes comments that have nothing to do with the conversation).

3. a) My family member/friend finds it *difficult to communicate,* when someone does NOT look at him/her *face to face* when talking to him/her.

3. b) *It disturbs me* when my family member/friend finds it *difficult to communicate* when someone talks to him/her, and does NOT look at him/her *face to face*.

4. a) My family member/friend finds it *difficult* to follow the conversation when <u>several</u> persons talk *at the same time.*

4. b) *<u>It disturbs me</u>* when my family member/friend has *difficulties* to follow a conversation when several persons talk *at the same time.*

5. a) My family member/friend finds it *difficult,* to follow a conversation when someone *both* talks <u>and</u> does something else *at the same time.*

5. b) *<u>It disturbs me</u>* when my family member/friend finds it difficult, to follow a conversation when someone *both* talks <u>and</u> does something else *at the same time.*

6. a) My family member/friend finds it *difficult to communicate* when he/she is in a crowded place, (*for example*, in a shopping centre or movie theatre).

6. b) *<u>It disturbs me</u>* when my family member/friend finds it *difficult to communicate* in a <u>crowded</u> place, (for example, in a shopping centre or theatre).

7. a) My family member/friend finds it *difficult to communicate* when there is noise around him/her (even a *small amount* of noise).

7. b) *<u>It disturbs me</u>* when my family member/friend finds it *difficult* to communicate when there is noise (even a *small amount* of noise) around him/her.

8. a) My family member/friend does NOT understand as well when someone speaks in a very, very loud voice.

8. b) *<u>It disturbs me</u>* when my family member/friend does NOT understand as well when someone speaks in a very, very loud voice.

9. a) If I want to get the attention of my family member/friend, I have to first say his/her name.

9. b) *It disturbs me* when I have to say my family member's/friend's name if I want to *get his/her attention.*

10. a) My family member/friend needs extra time to think before he/she answers or replies to my questions or comments.

10. b) *It disturbs me* when my family member/friend needs extra time to think before he/she answers or replies to my questions or comments.

Theme No. 4: *'Caring for my family member'*

1. a) My family member/friend has difficulties to use the *telephone* or *computer*.

1. b) *It disturbs me* when my family member/friend has difficulties to use the *telephone* or *computer*.

2. a) My family member/friend has difficulties *to get dressed* (*for example*, cannot do up buttons/zippers, or puts his/her clothes on backwards, or puts shoes on the wrong feet, etc.).

2. b) *It disturbs me* when my family member/friend has difficulties to get dressed, (*for example*, is not able to do up buttons/zippers, or puts clothes on backwards, or puts shoes on the wrong feet, etc.)

3. a) My family member/friend finds it difficult to do things which require several steps (*for example*, making a meal, operating the microwave or the TV control).

3. b) *It disturbs me* when my family member/friend finds it difficult to do things which require several steps (*for example*, making a meal, operating the microwave or TV control).

4. a) My family member/friend has difficulties with personal hygiene orgrooming, (*for example*, washing, shaving, looking after his/her hair, etc.).

4. b) *It disturbs me* when my family member/friend has difficulties with personal hygiene and grooming (*for example*, washing, shaving, looking after his/her hair, etc.).

5. a) My family member finds it difficult to sit still, (*for example*, he/she and moves about constantly, or keeps going from one activity to another).

5. b) *It disturbs me* when my family member finds it difficult to sit still (*for example*, he/she moves about constantly, or keeps going from one activity to another).

6. a) My family member/friend moves more slowly than usual or does things at a slower pace than before.

6. b) *It disturbs me* when my family member/friend moves more slowly than usual and/or does things at a slower pace than before.

7. a) My family member/friend 'gets lost', that is, doesn't know where he/she is, (even in his/her own home).

7. b) *It disturbs me* when my family member/friend 'gets lost', that is, doesn't know where he/she is, (even when in his/her own home).

8. a) My family member/friend rests (or sleeps) more than usual.

8. b) *It disturbs me* when my family member/friend rests (or sleeps more) than usual.

9. a) My family member/friend has difficulty sleeping at night.

9. b) _It disturbs me_ when my family member/friend has difficulty sleeping at night.

10. a) My family member/friend finds it difficult to _count 'things'(for example_, count money, write cheques, pay bills, etc.).

10. b) _It disturbs me_ when my family member/friend finds it difficult to count 'things' (_for example_, count money, write cheques, pay bills, etc.).

Theme No. 5: *'Emotions and my family member:*

How can I communicate better with my family member?'

1. a) My family member/friend <u>*becomes upset*</u> when he/she doesn't understand what is happening around him, *that is*, he/she seems to be 'mixed up' or confused.

1. b) <u>*It disturbs me*</u> when my family member/friend *becomes upset* when he does not understand what is happening around him, *that is*, he/she appears to be 'mixed up' or 'confused'.

2. a) My family member/friend <u>*gets upset*</u> when he/she cannot remember - or 'find' a word.

2. b) <u>*It disturbs me*</u> when my family member/friend *gets upset* when he/she can't remember (or 'find') a word.

3. a) My family member/friend seems to <u>*ignore me*</u>, (that is, he/she acts as if he/she doesn't want others around him/her or *does NOT pay attention* to others – even family members and friends).

3. b) <u>*It disturbs me*</u> when my family member/friend seems to *ignore me*, (that is, he/she acts as if he/she doesn't want others around him/her or *does NOT pay attention* to others – even family members and friends).

4. a) My family member/friend appears to be <u>*sad,*</u> *for no apparent reason.*

4. b) <u>*It disturbs me*</u> when my family member/friend *appears to be sad for no apparent reason.*

5. a) My family member/friend _becomes upset_ when he/she is in a place that is _not familiar_ to him/her (or that he/she _does not know_).

5. b) _It disturbs me_ when my family member/friend becomes upset when he or she is in a place that is _not familiar_ to him/her (or that he/she _does not know_).

6. a) My family member/friend _gets upset_ when he/she has _difficulties_ doing leisure activities, hobbies or sports (for example, knitting, playing golf, gardening, bicycling, etc.), which he/she used to do without difficulty.

6. b) _It disturbs me_ when my family member/friend has difficulties doing leisure activities, hobbies or sports, _(for example_, knitting, playing golf, gardening, bicycling, etc.) that he/she used to do without difficulty.

7. a) My family member/friend _gets upset_ or _angry_ with others, _for no apparent reason._

7. b) _It disturbs me_ when my family member/friend gets upset or angry with others, _for no apparent reason._

8. a) My family member/friend _gets upset_ or _angry_ when he/she cannot find something.

8. b) _It disturbs me_ when my family member/friend gets upset or angry when he/she cannot find something.

9. a) My family member/friend *gets upset*, when he/she can't understand something, (*for example*, when someone uses words or expressions that he/she has never heard before).

9. b) *It disturbs me* when my family member/friend *gets upset* when he/she can't understand something, (*for example*, when someone uses words or expressions that he/she has never heard before).

10. a) My family member/friend *gets upset* when furniture or other things in the house are moved around.

10. b) *It disturbs me* when my family member/friend gets upset when furniture or other things in the house are moved around.

CAREGIVER SELF-EFFICACY SCALE

FOR COMMUNICATION SKILLS IN REGARD TO COGNITIVE PROBLEMS

Instructions for INTERVIEWER

General Information

This Self-efficacy Scale is conceived for *caregivers* of individuals with cognitive problems, associated with early stage Alzheimer's disease. In their evaluation of self-efficacy, people are asked to judge their current beliefs in their <u>capabilities</u>, *NOT potential* or *expected future* capabilities. Although it is recommended that individuals record or <u>write</u> their responses *privately*, it has been demonstrated that <u>verbal</u> responses that are given *privately* are equally effective.

When the scale is presented to the participant, it is recommended that the scale be labelled with a nondescript title that does <u>not</u> contain the words *'self-efficacy'*. Thus, for <u>participant</u> use, *'self-efficacy'* is replaced with the expression *'confidence scale'* in the title of this tool. Consequently, the measure herein is referred to as the *'Caregiver <u>Confidence</u> Scale for Communication Skills in regard to Memory Problems'*.

Measurement Information

A visual analogue scale (100 millimetres in length and subdivided into 100 gradations – each one millimetre in length) in which gradations are *<u>not visible</u>* to the respondent is retained to measure each self-efficacy item.

The participant is asked to mark a <u>vertical</u> mark on the line where he/she judges his/her *present 'confidence'* level (i.e., level of self-efficacy), for only those items that are *pertinent* to the caregiver's context.

Not at all   *Completely*

Confident   0 |_____|_____|100 *Confident*

in my abilities   *(vertical mark)*   *in my abilities*
(noted by participant)

Calculation of Score

For example, in a given questionnaire with a total of 10 items, the participant identifies four (4) items that are relevant for him/her. For each of these four items, the participant then identifies a point on the scale where he judges his level of 'confidence' (or beliefs in his/her capabilities) to be at this time. When measured (in this example), these four vertical marks (on the four scales) represent the values 40 mm, 62 mm, 80 mm and 55 mm.

The SCORE of each self-efficacy sub-scale is computed as follows:

1) The scores of those items to which the caregiver responded are _added_ (i.e., 40+62+80+55=<u>232</u>). (NB: _items that were not retained, i.e., not scored, are eliminated_).

2) The total score (232), is _divided_ by the number of items (4) identified by the caregiver as relevant for him-herself in the subscale (i.e., 232/4=<u>58</u>). The subscale score is <u>58</u>.

Self-efficacy Measures for EACH Communication Theme (sic subscale)

The above procedure is conducted for _each_ of the subscales, thus providing _measures of self-efficacy_ for _each_ of the _communication themes_ in this scale.

Self-efficacy Measure for the OVERALL Communication Domain

In order to compute an overall self-efficacy measure for the communication domain relevant to memory problems, first the _five mean scores_ of <u>each</u> of the 5 subscales are _added_. Then the total is _divided by 5_ in order to arrive at <u>one</u> self-efficacy measure.

CAREGIVER *'CONFIDENCE SCALE'*
FOR COMMUNICATING WITH SOMEONE WHO HAS
COGNITIVE ('MEMORY') PROBLEMS

Confidence Scale No. 1:

'Memories are important: What do we talk about today?'

How *confident* are you that that you can do the following task or activity NOW?

1. If my family member/friend has difficulties talking with me,

   I am confident:

   that I can show him/her a 'MEMORY AID' (such as a picture or object) to help him/her remember what we are talking about.

   Not at all
   Confident 0|_____|100 *Confident*
   in my abilities   *in my abilities*

2. If my family member/friend has difficulty following a conversation,
   I am confident
   that I can talk about only ONE subject/thing at a time.

3. If my family member/friend has difficulties in READING and WRITING,

   I am confident: that I can help him/her, *for example*, read to him/her out loud or write his/her 'message' for him/her.

4. If my family member/friend has difficulties to say the right word (for example, SAYS the <u>WRONG</u> WORD for something or SAYS the <u>WRONG</u> NAME for someone or a place), *I am confident:* that I can SUGGEST possible words or ask him to describe or tell me MORE about the name or word that he/she is trying to say.

5. If my family member/friend has difficulties to understand me, *I am confident:* that I can talk to him/her using SHORTER sentences.

6. When I talk to my family member/friend, *I am confident:* that I can talk in a NORMAL 'speed' of voice (NOT too fast and NOT too slow).

7. When I talk to my family member/friend, *I am confident:* that I can say (use) NAMES of people (Jane, Bob) or places (Magog, Montreal), INSTEAD OF words like <u>it</u>, <u>his</u>, <u>she</u> or <u>that</u>.

8. When I talk to my family member/friend, *I am confident:* that I can use words or expressions that he/she KNOWS, (or which he/she has HEARD BEFORE and so is familiar with them).

9. When I ask my family member/friend questions, *I am confident*: that I can ASK questions in such a way that my family member/friend can answer 'YES' or 'NO', OR that he/she can choose between (only) TWO things (two answers).

10. When my family member/friend has difficulties to have a conversation with me (or to talk about something), *I am confident*: that I can show him/her that I AM INTERESTED by talking about things that interest him/her (or by sharing things with him/her about the subject of the conversation).

Confidence Scale No. 2:

'Remembering and forgetting: Where did I put my keys?

How *confident* are you that that you can do the following task or activity NOW?

1. If my family member/friend FORGETS to FINISH something (*for example*, starts a telephone conversation, then goes to do something else and forgets to finish the conversation or leaves the telephone off the hook),

I am confident: that I can REMIND him/her to finish what he/she started (for example, finish the phone conversation).

2. If my family member/friend looses something important (such as keys or a wallet/purse),

I am confident: that I can TELL him/her that I will help him/her to try to find it.

3. If my family member/friend forgets what he/she has to do when he/she goes on an errand (for example, forgets what to buy at the store),

I am confident: that I can TELL him/her that the errand can be done later.

4. If my family member/friend has difficulties to remember something that I have told him/her,

I am confident: that I can help him/her to remember by WRITING a reminder or note (*for example*, a list of things to buy at the store).

5. To help my family member/friend find INFORMATION (in the house) that is important or helpful to him/her,

I am confident: that I can place (put) this INFORMATION (*for example*, a calendar, a clock, memos/reminders, etc.), in ONE convenient place where my family member/friend can see it easily.

6. When my family member/friend has problems to PUT THINGS BACK where they belong (*for example*, he/she puts the jam in the dishwasher, or the dirty dishes in the refrigerator);

I am confident: that I can put the item (myself) in the right place.

7. When my family member/friend wants to talk about things that happened LONG AGO, (or even <u>very</u> long ago),

I am confident: that I can LET him/her talk about OLDER 'things', (and NOT 'make' him/her try to remember things that happened LATELY or NOT long ago).

8. When my family member/friend cannot remember if he/she took his/her MEDICATIONS (or 'pills'),

I am confident: that I can prepare (and give) his/her pills each day.

9. If my family member/friend does not remember to TURN ON or OFF household items or appliances (*for example*, the stove, television, taps (faucets) or lights),

I am confident: that I can OPEN or CLOSE them myself (as needed).

10. When my family member/friend asks the SAME question or repeats the SAME 'story' over and over,

I am confident: that I can talk about something else to him/her (or do another activity with him/her).

Confidence Scale No. 3:

'Why doesn't he – she listen? How can I get his – her attention?'

How *confident* are you that that you can do the following task or activity NOW?

1. If my family member/friend does not understand when I say something,

I am confident: that I can repeat what I said by using the SAME WORDS,

2. When my family member/friend CHANGES the SUBJECT *without warning* and talks about something completely different,

I am confident: that I let my family member/friend talk about the NEW topic/subject that seems to interest him/her now.

3. To help my family member/friend to communicate,

I am confident: that when I can talk to him/her I can look at him/her directly (or 'FACE TO FACE').

4. When my family member/friend finds it difficult to follow a conversation or to talk, when SEVERAL persons are TALKING in the room *(at the same time)*,

I am confident: that I can ask (or encourage) that ONLY ONE person talk at a time.

5. When my family member/friend has problems to follow a conversation or to talk, when the other person is both TALKING and DOING something (*for example*, he/she talks while sweeping the floor) *at the same time,*

I am confident:

that I can ask the other person to STOP what he/she is doing

while he/she talks to my family member/friend.

6. If my family member/friend finds it difficult to communicate

in a crowded place (such as at a shopping centre, restaurant, theatre),

I am confident:

that I can bring him/her to a QUIETER place, or go back HOME.

7. If my family member/friend finds it difficult to talk or to follow

a conversation when there is a NOISE nearby (even a SMALL NOISE),

I am confident:

that I can take him/her to a QUIETER PLACE, or STOP (or LOWER) the noise (such as, stop the vacuum, turn off radio, etc.).

8. To help my family member/friend to communicate,

I am confident:

that I can speak to my family member/friend in a 'PLEASANT' tone of voice (NOT angry or upset).

9. To get the attention of my family member/friend,

I am confident:

that I can FIRST say his/her name, BEFORE talking to him/her.

10. If my family member/friend needs more time to think (than usual)

before replying to a question or comment,

I am confident:

that I can be patient and WAIT for a LONGER time for him/her

to answer.

<u>**Confidence Scale No. 4**</u>:

'Caring for my family member'

How *confident* are you that that you can do the following task or activity NOW?

1. If my family member/friend has difficulties using the TELEPHONE (or COMPUTER),

<u>*I am confident*</u>:

that I can TELL him/her that I will help him/her (or try to get help).

2. If my family member/friend has problems to get DRESSED

(*for example*, he/she puts clothes on backwards or puts shoes on the wrong feet or does not do up zippers or buttons),

<u>*I am confident*</u>:

that I can TELL him/her that I will.

3. If my family member/friend finds it difficult to do something that requires several steps, (*for example*, he/she finds it difficult to make a meal or operate the microwave oven or television),

<u>*I am confident*</u>:

that I can TELL him/her that I will help him.

4. If my family member/friend has difficulties with personal HYGIENE and GROOMING, (*for example*, problems with *washing*, *shaving* or looking after his/her *hair*),

<u>*I am confident*</u>:

that I can TELL him/her that I will help him/her.

5. **If my family member/friend finds it difficult to 'SIT STILL', (for example, he/she MOVES ABOUT 'a lot' from one place to another, or does the SAME thing OVER and OVER),**

I am confident:

that I can ENCOURAGE (or ASK) him/her to 'slow down' or relax, *(for example*, sit down with me).

6. If my family member/friend MOVES MORE SLOWLY (than usual) or does things at a SLOWER PACE (than before),

I am confident:

that I can LET him/her do things at a SLOWER SPEED.

7. If my family member/friend gets 'LOST' (*that is*, he/she doesn't know where he/she is, even in his/her own home,

I am confident:

that I can TELL him/her where he/she is and talk about familiar things.

8. When my family member/friend needs MORE SLEEP or REST,

I am confident:

that I can LET him/her sleep or rest more and NOT DISTURB him/her, *(for example*, NOT talk to him/her while he or she is sleeping or resting).

9. If my family member/friend has DIFFICULTIES SLEEPING at night,

I am confident:

that I can TELL him/her what he/she can do to *get back to sleep*, (for example, drink warm milk/herbal tea, listen to quiet music, etc.).

10. When my family member/friend has difficulties to COUNT things (*for example*, count money, pay bills, write cheques, etc.),

I am confident:

that I can COUNT things with him/her, *for example*, count money, write cheques, pay bills, etc.).

Confidence Scale No. 5:

Emotions:
How can I communicate better with my family member/friend?

How *confident* are you that that you can do the following task or activity NOW?

1. If my family member/friend <u>GETS UPSET</u> when he/she does not seem to know what is happening around him/her (or appears to be 'mixed up' or 'confused'),

I am confident:

that I can TELL him/her where he/she is and TALK to him/her about FAMILIAR things.

2. If my family member/friend <u>GETS UPSET</u> when he/she CANNOT remember or 'find' the word for something,

I am confident:

that I can ask him/her to DESCRIBE or 'TELL ME MORE' about the word that is giving him/her problems.

3. When my family member/friend <u>IGNORES</u> me (that is, he/she does not to pay attention to me or acts as if he/she does not want to be around anyone),

I am confident:

that I can TELL him/her that I am ready to listen and to talk to him/her.

4. When my family member/friend seems to be <u>SAD</u> or '<u>DOWN</u>',

I am confident:

that I can TELL him/her that I am there for him/her, (that is, I am available to TALK and/or to LISTEN to him/her).

5. If my family member/friend <u>GETS UPSET</u> when he/she is in a place he/she does NOT KNOW,

I am confident:

that I can TELL him/her where he is and TALK about familiar things.

6. If my family member/friend <u>GETS UPSET</u> when he/she has difficulties doing a LEISURE ACTIVITY or SPORT (*for example*, knitting, golfing, bicycling or gardening), that he/she liked to do in the past,

   I am confident:

   that I can TELL (or ENCOURAGE) him/her to do something else for now.

7. If my family member/friend <u>GETS UPSET</u> with others for no apparent (or obvious) reason,

   I am confident:

   that I can ASK him/her what I do to help him/her.

8. If my family member/friend GETS UPSET when he/she cannot find something,

I am confident:

that I can TELL him/her that I will do my best to help find it.

9. If my family member/friend <u>GETS UPSET</u> when he/she can't understand NEW words or expressions (that he/she has never heard before),

I am confident:

 that I can SAY (or use) words or expressions that he/she knows or understands, (or that are familiar to him/her).

10. If my family member/friend <u>GETS UPSET</u>, when furniture (chairs, television, etc.) or other articles (magazines/newspapers, clothes, etc.), are <u>moved about</u> in the house,

I am confident: that I can put them back in their <u>usual</u> place.

COMMUNICATION SKILLS QUESTIONNAIRE
FOR THE CAREGIVER OF A FAMILY MEMBER WITH COGNITIVE PROBLEMS

Instructions for INTERVIEWER

<u>General Information</u>

This caregiver *'communication skills'* questionnaire is concerned with the skills or strategies that the caregiver actually carries out in relation to the communication difficulties encountered or 'perceived' in regard to the person with cognitive problems associated with the *early* stage of Alzheimer's disease. These 'perceived' communication difficulties are first identified in the *Questionnaire on communication difficulties and the degree of caregiver disturbance* in Appendix G.

In this 'skills' questionnaire, the caregiver evaluates the *extent* to which he/she actually carries out appropriate skills by choosing one of the six alternatives in the 'skills questionnaire' as follows: *'All of the time'; 'Most of the time'; 'About one-half of the time'; 'Less than one-half of the time'; 'On occasion';* and *'Does not apply'.*

To illustrate, we will use 'Theme no. 3, Subject no. 10' wherein the caregiver may have identified a problem with the family member who 'takes a longer time than usual' to respond to the caregiver's questions or comments. The caregiver now evaluates the *extent* to which he/she has actually carried out the appropriate skill(s) in response to the family member's communication difficulties. For example, if the caregiver responded appropriately (to the family member's problem of 'slow response'), about one-half of the time, then the appropriate answer would be: *'About one-half of the time*

COMMUNICATION SKILLS QUESTIONNAIRE FOR THE CAREGIVER OF A PERSON WITH COGNITIVE ('MEMORY') PROBLEMS

Skills Area No. 1

'Memories are important: What do we talk about today?'

1. When my family member/friend has problems to follow a conversation (or to talk), I show him/her a 'MEMORY AID' (such as a picture, object or some other item) to help him/her remember what we are talking about.

Does not apply	*On occasion*	*Less than one-half of the time*	*About one-half of the time*	*Most of the time*	*All of the time*
(0) ____	(1) ____	(2) ____	(3) ____	(4) ____	(5) ____

2. When my family member/friend has problems to follow a conversation, I talk to him/her about only ONE subject (or thing) at a time.

3. When my family member/friend has difficulties in READING or WRITING, I read to him/her or write a message for him/her.

4. When my family member/friend does NOT say the CORRECT word for something, I say the right word (if I know it) or suggest a word that may be correct.

5. When my family member/friend has *difficulties* to follow a conversation (or to talk),

 I use SHORT sentences.

6. When my family member/friend finds it difficult to follow a conversation (or to talk), I speak in a voice with a NORMAL SPEED

 (NOT too fast and NOT too slow).

7. To help my family member/friend to understand, I use NAMES of people (Jane, Bob), or places (Montreal, Magog),

 INSTEAD OF words like: 'it', 'him', 'they' or 'she'.

8. To help my family member/friend to understand

 I use FAMILIAR words or expressions, (that he/she knows).

9. When my family member/friend *finds it difficult* to answer QUESTIONS,

 I ask questions so hat he/she can answer 'YES' or 'NO', or

 so he/she can choose between TWO ANSWERS (or 'things').

10. When my family member/friend finds it difficult to follow a conversation (or to talk), I show him/her that I AM INTERESTED,

 by telling him/her things about the topic of the conversation.

Skills Area No. 2

'Remembering and Forgetting: Where are my keys?'

1. When my family member/friend starts to do something,

(*for example*, begin a telephone conversation or start to make a snack),

then stops midway to do something else, and forgets to finish the snack or leaves the telephone off the hook), I REMIND him/her TO FINISH the activity.

2. When my family member/friend cannot remember <u>where</u> he/she has placed something *important*, (*for example*, keys, glasses or wallet/purse)

I TELL him/her that I will help him/her to try to find it.

3. When my family member/friend has gone for an errand (*for example*, went to the store to BUY something), I tell him/her that the errand can be done later (if possible).

4. When my family member/friend does NOT *remember* when I tell him/her something (or when I leave him/her message), I give him/her a <u>WRITTEN</u> reminder (*for example*, a shopping list if he/she is going to the store).

5. I put 'INFORMATION' that is HELPFUL for my family member/friend

(*for example*, a calendar, clock and memos/reminders),

in a place that is easy to find (by my family member/friend).

6. When my family member/friend finds it *difficult* to PUT THINGS BACK where they belong, *(for example,* he/she puts the jam in the sink, or dirty dishes in the refrigerator), I put the items (things) back in the right place myself.

7. When my family member/friend wants to talk about things or events that happened 'some time' ago (or long ago), I let him/her talk about his/her older memories or things that happened LONG AGO.

8. If my family member/friend does not remember to take his/her

   MEDICATIONS (or pills), I prepare his/her medications (pills) every day.

9. When my family member/friend does not remember to TURN ON or TURN

   OFF household items or appliances, *(for example,* the stove, television,

   lights, taps, etc.), I open or close these items/appliances myself.

10. When my family member/friend asks the SAME question or repeats

    the SAME 'story' over and over, I talk to him/her about something else.

Skills Area No. 3

'Why doesn't he – she listen? How can I get his – her attention?'

1. When my family member/friend does not understand me when I talk

   to him, I repeat what I said using the SAME WORDS.

2. When my family member/friend *changes the subject* of a conversation 'without warning' and talks about something completely different, I LET him/her talk about the 'NEW' topic that seems to be of interest.

3. When I talk to my family member/friend, I look at him/her 'FACE TO FACE', so he/she can see me easily.

4. When my family member/friend finds it difficult to follow a conversation (or talk) when SEVERAL PERSONS talk at the same time; I encourage ONLY ONE person to talk at a time.

5. When my family member/friend finds it difficult to follow a conversation (or to talk) when someone else is talking WHILE DOING SOMETHING ELSE, I ask the other person to STOP what he is doing (while he/she talks to my family member/friend).

6. When my family member/friend finds it difficult to communicate in a CROWDED place, (for example, in a shopping centre, restaurant or cinema), I bring him/her to a QUIETER place or go back home.

7. When my family member/friend finds it difficult to talk or to follow a conversation when there is a NOISE nearby, (even a *small amount* of NOISE), I take him/her to a QUIETER place or I STOP (or lower) the noise (for example, I turn off the vacuum cleaner or lower the radio).

8. When I speak to my family member/friend, I speak in a PLEASANT tone of voice (NOT angry or upset).

9. When I want to get my family member's/friend's ATTENTION, I *first* SAY his/her NAME before starting a conversation.

10. When my family member needs MORE TIME to think before he/she answers a question/comment, I WAIT for a LONGER TIME for him/her to answer.

Skills Area No. 4

'Caring for my Family Member.'

1. When my family member has difficulties with using the TELEPHONE (or computer), I TELL him/her that I will help (if I can) or that I will try to get help for him/her.

2. When my family member has problems to get DRESSED, (*for example*, cannot do up zippers or buttons, or puts shoes on the wrong foot, or doesn't put clothes on properly) I TELL him/her that I will help.

3. When my family member has problems doing something that has several steps, (*for example*, preparing a meal, operating the microwave, etc.) I TELL him/her that I will help.

4. When my family member has difficulties with personal HYGIENE or GROOMING, (for example, washing, shaving, looking after his/her hair, etc.),

I TELL him/her that I will help.

5. When my family member finds it difficult to 'sit still', (for example, he/she MOVES ABOUT 'a lot' from one place to another or does the SAME thing OVER and OVER, I ENCOURAGE (or ASK) him/her to 'slow down' or relax, (for example, sit down with me).

6. When my family member needs MORE TIME to *move* about or to *walk*, or to *do something*; I do NOT tell him/her to hurry up, (that is, I LET him/her move at his/her SLOWER speed).

7. When my family member/friend seems to be 'LOST', (that is, he/she does NOT know where he/she is, even in his/her own home), I TELL him/her where he/she is, and talk about familiar things.

8. When my family member appears to need MORE REST or SLEEP than before, I do NOT disturb him/her while he/she rests or sleeps.

9. When my family member/friend has *difficulty sleeping* at night, I TELL him/her what he/she can do to get back to sleep, (*for example*, drink warm milk or herbal tea, listen to quiet music).

10. When my family member has problems to COUNT things (*for example*, count money or write cheques or pay bills), I COUNT 'things' with him/her, (for example, money, bills, etc.).

Skills Area No. 5

Emotions:

How can I communicate better with my family member/friend?

1. When my family member/friend <u>GETS UPSET</u> when he/she does not seem to know what is happening around him/herb (that is, he/she seems confused),

I TELL him/her where he/she is and TALK about familiar things.

2. When my family member/friend <u>GETS UPSET</u> when he/she can't remember (or 'find') a word, I ASK him/her to describe (or TELL ME MORE) about the word   that he/she cannot remember.

3.   When my family member/friend <u>IGNORES</u> me, (*that is,* he/she seems indifferent toward me or acts as if he/she does not want to be around others), I TELL him/her that I am available to listen or to talk, (and I leave him/her alone if that is what he/she wants).

4. When my family member/friend appears to be <u>SAD</u> (or DOWN),
    I TELL him/her that I am available to talk or to listen if he/she needs me.

5.   When my family member/friend <u>GETS UPSET</u> when he/she is in a place he/she does NOT KNOW, I TELL him/her where he/she is and TALK to him/her about   familiar things (that he/she knows).

6. When my family member/friend <u>GETS UPSET</u> when he/she has difficulties doing leisure activities or sports that he/she used to do (such as gardening, knitting, bicycling or golfing), I ENCOURAGE or TELL him/her to do something else for now.

7. When my family member/friend <u>GETS ANGRY</u> or <u>UPSET</u> with others for no 'good' reason, I ASK him/her if there is something that I can do to help.

8. When my family member/friend <u>GETS ANGRY</u> or <u>UPSET</u> when he/she cannot find something, I TELL him/her that I will try to find it; and talk about something else for the moment.

9. When my family member/friend <u>GETS UPSET</u> because he/she can't understand something, (*for example*, words or expressions that are NEW to him/her or that he/she has never heard before), I USE words that he/she knows or understands.

10. When my family member/friend <u>GETS UPSET</u> when *furniture* (chairs, television, etc.) or other *articles* (newspapers, clothes, etc.) are moved about in the house, I tell him/her that I will move the furniture or household items in their usual ('SAME') place.

<u>QUALITATIVE INSTRUMENT</u>
CASE SCENARIOS AND OPEN QUESTIONS
Instructions for INTERVIEWER

<u>General Information</u>

The following questions concerning three case scenarios represent communication related problem situations that are frequently encountered in the caregiving context of the individual with cognitive problems associated with early stage Alzheimer's disease. The caregiver is asked about how he/she would deal with each of these hypothetical communication-related situations. These case scenarios are presented to the caregiver <u>before</u> the other measures, at each of the measurement times (T1, T2 and T3), as indicated.

A. CASE SCENARIO ABOUT *'FORGETTING'* (Time 1)

The first case scenario is concerned with the communication problem area concerned with <u>forgetting</u>. It is presented to the caregiver at Time 1.

B. CASE SCENARIO ABOUT *'WORD FINDING' – 'MISNAMING'* (Time 2)

The second case scenario deals with the communication problem area concerned with <u>misnaming</u> and <u>word finding</u> difficulties. It is presented to the caregiver at Time 2.

C. CASE SCENARIO ABOUT *'DAILY CARE PROBLEMS'* (Time 3)

The third case scenario deals with the communication area which can become problematic when the individual with cognitive problems experiences periodic difficulties with everyday activities (ADLs), (e.g., dressing, bathing, etc.), and instrumental activities of daily living (IADLs) (e.g., using the telephone, going shopping, preaparing meals). It is presented at Time 3.

A. THE PROBLEM OF '*FORGETTING*

Instructions for PARTICIPANT

The following situation can take place when communicating with someone who is having cognitive ('memory') problems. We will read it together and then talk about what one might do in such a situation.

CASE SCENARIO 1.

A person with memory problems (perhaps a member of your family or a friend), always seems to be forgetting where he or she placed something. It could be that he/she misplaced the car or house keys, or his/her wallet, or some other important item. He (or she) may become upset over this, and may even think that *someone else* has moved this item from the place where he/she *believes* that he/she placed it. When the person with cognitive ('memory') problems makes this 'mistake' over and over, it is easy for those around him/her to become upset and even angry.

What do you think that one could do to help a family member or friend in such a situation? In your own words, *tell me* <u>or</u> *describe in writing*, what you think one could do to be helpful.

B. TRYING TO *FIND* THE 'RIGHT' WORD – *SAYING A WORD INCORRECTLY*

Instructions for PARTICIPANT

The following situation can take place when communicating with someone who is having cognitive ('memory') problems. We will read it together and then talk about what one might do in such a situation.

CASE SCENARIO 2.

A person with cognitive ('memory') problems (perhaps a member of your family or a friend), has difficulties in *finding* the right word for what he/she wants to say; or refers to someone or something by the *wrong name* or by a *'made-up' word*, even though he/she has never had this problem before. For example, he/she might say *'boat'*, when he/she really wants to say 'coat', or says *'Susan'* when referring to 'Mary'. Sometimes he/she cannot come up with a 'real' word or 'name' and says something like *'whatchamacallit'* instead of 'Peter', or *'that thing on wheels'* or *'thingamajig'* instead of the car. When the person makes this 'mistake' over and over, it is easy for those around him/her to become upset and even angry.

What do you think that one could do to help a family member or friend in such a situation? In your own words, *tell me* or *describe in writing*, what you think one could do to be helpful.

C 'PROBLEMS IN GETTING DRESSED, GROOMING...'

Instructions for PARTICIPANT

The following situation can take place when communicating with someone who is having cognitive ('memory') problems. We will read it together and then talk about what one might do in such a situation.

CASE SCENARIO 3.

A person with cognitive ('memory') problems (perhaps a member of your family or a friend), seems to have problems from time to time to get dressed or look after his/her hair. For example, sometimes he or she does not do up his/her buttons or zippers, or perhaps puts clothes on backwards. Those around him/her may wonder why this person has such problems on certain occasions and yet at other times he/she does not have these difficulties.

Sometimes when this happens it is easy to become frustrated and upset with him/her. What do you think that one could do to help one's family member (or friend) in such a situation? In your own words, can you *tell me* <u>or</u> *describe in writing* what you think one could in such a case.

APPENDIX G:

Assessment Grid for Experts

Assessment Grid for Experts

I. QUANTITATIVE MEASURES (Questionaires)

The following measures evaluate five perspectives relevant to the caregiver of the family member/friend who has cognitive problems associated with early stage Alzheimer's disease. These measures are conceived in an inter-related manner in that they are founded upon the *same* communication-related domain as depicted in the scientific evidence concerned with cognitive problems associated with the early stage of Alzheimer's disease.

The first measure, the caregiver *'Knowledge Questionnaire'* evaluates the knowledge of a caregiver of the family member or friend relevant to communication in this phase. The second measure has two components and is concerned with the identification of the *communication difficulties* actually experienced by the caregiver and the *degree of perceived caregiver disturbance* in regard to said difficulties. The third measure, the *Self-efficacy* scale is concerned with the caregiver's *beliefs* about being able to carry out relevant communication-related skills. The fourth measure is concerned with the actual use of communication *skills* by the caregiver in this context. Each measure is organized around five subject areas. Each subject area (in each measure) is comprised of ten items; therefore each measure is made up of fifty items.

Given your expertise in this field, your assistance is sought to judge the attributes of these tools on several dimensions. In order to assure the face validity of these measures, as well as ease of comprehension and appropriateness for the older population, it is important that your assessment of this questionnaire be forthright.

FIVE THEMES THAT UNDERPIN EACH MEASURE

1. 'Memories are Important – What do we do Today?': In this theme there is a focus on the communication related areas that are preserved (in the early stage of Alzheimer's disease).

2. 'Remembering and forgetting: Where did I put my keys?' addresses the communication problem of 'forgetfulness' in persons with early stage Alzheimer's disease.

3. 'Why doesn't he – she listen? How can I get his – her attention?' deals with physical environment and attention-related issues that lead to communication difficulties.

4. 'Caring for my family member' is concerned with the everyday care areas (ADL's and IADL's) wherein communication difficulties are routinely reported.

5. 'Emotions and my Family Member; what else can I do?' deals with communication problems related to the emotive – affective dimension.

Before proceeding to answer the following questions, please <u>first</u> review each of these measures to gain an overall appreciation of the *content* of the *communication domain* that underpins these instruments. This will also help you to better understand how these measures are *inter-related.* It will then be easier for you to conduct an evaluation of each measure. Evaluative questions address: 1.) each *item* in relation to the particular subject area (total - 50 items), 2.) each *subject area* (total - 5 subject areas) and 3.) the overall content domain of the *questionnaires* (total - 4 questionnaires).

EXAMPLE: Questionnaire on Caregiver *Knowledge* about cognitive problems

In the 'Knowledge' questionnaire the participant answers *true, false* or *don't know* to each of the questions.

1. Assessment of ITEMS

Experts responded to three questions when assessing each item in the four questionnaires. An example of an item extracted from Module 1 with the three 'item' assessment questions follows (50 items per questionnaire):

<u>Module 1</u>:*'Memories are Important – What do we do Today?'*:

<u>Item 1</u>. The person with cognitive problems sometimes finds it easier to talk about a subject (for example, a wedding, a book or an activity), if he/she has a 'memory aid' in front of him/her (such as a picture, object, etc.).

(*Correct answer*: TRUE)

Is this ITEM:

1. *Pertinent* to the subject area? YES |___| NO |___| If NO, explain why :

_____

2. *Easy to understand?*   YES |___| NO |___| (at a grade 6 comprehension level?)

If NO, explain why: (e.g., complex language, unclear phrasing, too long sentences, etc.)

_____

3. Other comments – recommendations: _____

(N.B.: This question in the Assessment Grid was used for all 50 items in the five Modules of the each questionnaire)

2. Assessment of MODULES

Experts responded to three questions when assessing each Module subject area (five Modules in each questionnaire). An example of a Module subject area (Module no. 1) with the two module assessment questions is presented as follows:

Subject Area 1: *'Memories are Important – What do we do Today?'*

1. Are there any relevant subject areas missing from this module? YES__ NO__
If YES, please list missing SUBJECT AREA(S)_____

2. If you have any recommendations or suggestions for improving this subject area, please add them here:_____

(N.B.: These two questions in Assessment Grid were used for all five Subject areas (Modules) in each questionnaire.)

3. Assessment of OVERALL QUESTIONNAIRE

Experts responded to one question when assessing the overall questionnaire (four questionnaires). An example of the 'questionnaire' question is presented as follows (5 Modules per questionnaire):

1. Does this questionnaire cover the full domain of communication-related difficulties that can arise in the caregiving context of the individual who has cognitive problems associated with the early stage of Alzheimer's disease?

YES ____ NO ____

If NO, please list the subject areas that are missing from the domain:_____

(N.B.: This question in Assessment Grid was used for all 4 questionnaires.)

II. CASE SCENARIOS – OPEN QUESTIONS

TO THE EXPERT: The following case scenario represents a frequently encountered communication-related problem in the caregiving context of the person with cognitive problems associated with *early* stage Alzheimer's disease. The caregiver is asked about how he/she would deal with such a communication-related situation. Please review this case scenario and answer the subsequent questions.

A. First CASE SCENARIO – subject area: *FORGETTING*

A person with cognitive problems always seems to be forgetting where he/she placed something. It could be that he/she misplaced the car or house keys, or wallet, or some other important item. He/she becomes upset, and may even think that *someone else* has moved this item from the place where he/she *believes* that he/she placed it. When the person with cognitive problems makes this 'mistake' over and over, those around him/her may become upset and even angry.

Question to participant: In your own words, *tell me* or *describe in writing*, what do you think one could do to help the person in this situation?

Evaluative Questions (for EXPERT):

1. Does this case scenario represent a problem that is typically encountered in the person with cognitive problems associated with early Alzheimer's disease?

YES _____ NO _____ If NO, explain WHY_____

_____

2. Is this case scenario <u>easy to understand</u> (at a grade 6 comprehension level?)

YES_____ NO_____ If NO, explain WHY (e.g., complex language, unclear phrasing, too long sentences, etc.) _____

3. Other comments or recommendations _____

(N.B.: These questions in Assessment Grid were used for all three case scenarios.)

APPENDIX H :

Socio-demographic Questionnaire

CODE : _____

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

1.   AGE: _____

2.   GENDER: Female   _____ (1)

                  Male   _____ (2)

3.   EDUCATION:

                  Elementary school (partial or completed)   _____ (1)

                  Secondary school (partial or completed)   _____ (2)

                  College (partial or completed)   _____ (3)

                  University (partial or completed)   _____ (4)

4.   PRESENT EMPLOYMENT STATUS:

                  Working (full-time)   _____ (1)

                  Working (part-time)   _____ (2)

                  Homemaker   _____ (3)

                  Retired   _____ (4)

5.   COMPARED WITH OTHER PERSONS YOUR AGE, WOULD YOU SAY THAT IN GENERAL YOUR HEALTH IS?

Excellent ( )   Very Good ( )   Good ( )   Average ( )   Poor ( )

6.   HOW WOULD YOU DESCRIBE THE QUANTITY OF SUPPORT THAT YOU RECEIVE FROM THOSE AROUND YOU (FAMILY MEMBERS, FRIENDS, ETC.)?

Great deal of support   _____ (1)

Average amount of support_____ (2)

Small amount of support   _____ (3)

No support   _____ (4)

7.   DO YOU RECEIVE HELP OR SERVICES?   YES: ____ NO: ____

IF YES, WHAT TYPE OF HELP OR SERVICES? (how often):

Several times per:	Day	Week	Month	Year
Transport:	____	____	____	____
Home Help:	____	____	____	____
'Meals on Wheels':	____	____	____	____
Nursing services:	____	____	____	____

Other Services:

(e.g., psychology, foot care, etc.)

* _____	____	____	____	____
* _____	____	____	____	____
* _____	____	____	____	____

8.   RELATIONSHIP TO PERSON WITH MEMORY PROBLEMS:

Married/civil union   _____ (1)

Child – son/daughter   _____ (2)

Other relative   _____ (3)

       *Specify*_____

Friend   _____ (4)

9.   LIVING ARRANGEMENTS:

Lives with person with memory problems   _____
(1)

Lives apart from person with memory problems _____
(2)

10.   HOW LONG HAS YOUR FAMILY MEMBER HAD MEMORY PROBLEMS?

Less than one year   _____ (1)

1 to 2 years   _____ (2)

More than 2 years   _____ (3)

11.   HAS YOUR FAMILY MEMBER OR FRIEND RECEIVED A DIAGNOSIS FROM A DOCTOR ABOUT HIS/HER MEMORY PROBLEMS?

Yes   _____ (1)

No   _____ (2)

12.   IF YES, SINCE WHAT DATE HAS HE/SHE HAD A DIAGNOSIS?

PROVIDE DATE (if you know): _____

WHAT IS DIAGNOSIS (if you know): _____

13.   SINCE   RECEIVING   DIAGNOSIS   HAS   YOUR   FAMILY MEMBER/FRIEND CONSULTED OTHER PROFESSIONALS?

PSYCHOLOGIST   _____ (1)

NURSE   _____ (2)

SOCIAL WORKER   _____ (3)

OTHER (specify)   _____ (4)

* _____

* _____

* _____

14.   AGE OF YOUR FAMILY MEMBER/FRIEND: _____

15.   GENDER OF YOUR FAMILY MEMBER/FRIEND:

Female _____ (1)

Male _____ (2)

16.   DOES YOUR FAMILY MEMBER NEED HELP OR SUPERVISION FROM YOU?

YES: _____   NO: _____

17.   IF YES, WHAT TYPE OF HELP OR SUPERVISION? (how often):

Several times per:	Day	Week	Month	Year
Dressing, eating, washing, grooming:	____	____	____	____
Going to the washroom:	____	____	____	____
Going for walks:	____	____	____	____
Going shopping:	____	____	____	____
Using the telephone or computer:	____	____	____	____
Preparing meals:	____	____	____	____
Doing errands:	____	____	____	____
Driving the car:	____	____	____	____
Doing the washing:	____	____	____	____
Taking his/her medications:	____	____	____	____
Paying bills:	____	____	____	____
Managing the budget:	____	____	____	____
Keeping the house clean:	____	____	____	____
Other: _____ :	____	____	____	____
Other: _____ :	____	____	____	____
Other: _____ :	____	____	____	____
Other: _____ :	____	____	____	____

APPENDIX I:

Consent Forms

PARTICIPANT CONSENT FORM

GROUP A: *'INFORMATION FLIER ON THE SUBJECT OF MEMORY'*

INFORMATION ABOUT THE STUDY

TITLE OF PROJECT:
Evaluation of a program focused on communication for the family caregiver or friend of a person with cognitive ('memory') problems.

PERSONS IN CHARGE OF THE PROJECT:
Krystyna Kouri, Nurse, Doctoral candidate in nursing sciences, Faculté des sciences infirmières (Faculty of Nursing) at the Université de Montréal and Nurse Clinician – Manager at the CSSS-l'Institut universitaire de gériatrie de Sherbrooke (Health and Social Services Centre – University Institute of Geriatrics of Sherbrooke).

Dr Francine Ducharme, *Desjardins* Research Chair in *Nursing Care for Seniors and their Families,* and Professor and researcher at the Faculté des sciences infirmières (Faculty of Nursing), Université de Montréal.

DECLARATION OF RESPONSIBILITY

The above named researchers are in charge of this research project and undertake to respect the obligations that are outlined herein.

Signature of the principal researcher of the project: _____

OBJECTIVE OF THE PROJECT

This study was developed for persons such as yourself (the family member or friend), to help you to communicate better with the person who has cognitive (or 'memory') problems.

NATURE OF PARTICIPATION

By accepting to take part in this study, you will take part in **Program 'A'**, in which you will participate in three meetings as described on the next page. These meetings will take place at the University Institute of Geriatrics of Sherbrooke.

I. THE FIRST MEETING:

At the first meeting, each person will receive written information (a flier) in regard to *communication* and memory. During this meeting, the researcher will help you in the following tasks:

1. **Reply to a question** about a communication problem. You can either write your answer or say it verbally (tell your answer to the researcher). **The verbal reply will be recorded (audio taped).**

2. **Reply to four questionnaires** in regard to the following subjects:

* the ways in which caregivers can communicate better with a family member or friend who has cognitive (or 'memory') problems,
* the perceptions of caregivers in regard to (or how caregivers view) their communication skills with their family member or friend with cognitive (or 'memory') problems,
* what caregivers know (or knowledge) about how to communicate with a family member or friend with cognitive (or 'memory') problems,
* identification (by caregivers) of communication problems with a family member or friend with cognitive (or 'memory') problems.

3. **Complete the consent form.**

Time for this meeting : about 2 to 2 ½ hours.

II. THE SECOND MEETING:

The second meeting is held seven (7) weeks after the first meeting. During this meeting, the researcher helps you in the following tasks for a second time:

1. **Reply to a question** about a communication problem. You can either write your answer or say it verbally (tell your answer to the researcher. **The verbal reply will be recorded (audio taped).**

2. **Reply to the same questionnaires** to which you answered in the first meeting.

Time for the second meeting: about 2 hours.

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III. THE THIRD MEETING:

The third meeting is held five (5) weeks after the second meeting. During this meeting, the researcher will help you in the following tasks for the third time:

1. **Reply to a question** about a communication problem. You can either write your answer or say it verbally (tell your answer to the researcher. **The verbal reply will be recorded (audio taped).**

2. **Reply to the same questionnaires** to which you answered in the second meeting.

Time for this meeting : about 2 hours.

BENEFITS THAT CAN RESULT FROM YOUR PARTICIPATION

By receiving written information (a flier) about *communication* and *memory,* you will become better informed about this subject. In additions, the information from the four questionnaires that you will have completed during the three meetings will help you to understand this subject better.

The meetings, even if they are of short duration, will provide you with the opportunity to meet and to talk with other persons who are experiencing similar situations to what you are having.

If you should need help from another professional, we will help you to find the necessary help.

POSSIBLE INCONVENIANCES CONCERNING YOUR PARTICIPATION IN THIS STUDY

You may experience certain inconveniences while participating in this study, for example, when you have to travel from your home to the hospital, and when you spend time at these meetings.

RISKS

There are no risks associated with your participation in this project.

LEAVING ('QUITTING') THE STUDY

While your collaboration in this study is important for the development of knowledge in nursing in regard to 'aging and memory problems', it is understood that your participation is entirely voluntary. You must feel completely free not to participate in this study.

If you accept to participate, you should feel free to leave the study at any time without having to give a reason, and without prejudice. Your decision will not influence in any way the care that you or your family member will receive at the University Institute of Geriatrics of Sherbrooke.

Your support of this study is very much appreciated. It is anticipated that the results will help us to develop learning strategies related to communication that will help family members or friends of individuals with memory problems.

ENDING (STOPPING) THE PROJECT BY THE RESEARCHER

The principal researcher reserves the right to end the projet at any moment without advance notice. She also reserves the right to exclude any participants from the project when it would be in their best interest to do so; for example, in the case of illness.
Given the possibility of the above situation, do you wish that the information that has been obtained be destroyed?

Yes → [   ]   No → [   ]

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FUTURE STUDIES

It is possible that the results obtained from this study will lead to another research project. In such a case, do you authorize the principal researcher of this project to communicate with you and ask if you would be interested in participating in a new research project?

Yes → [   ]   No → [   ]

MONETARY COMPENSATION

It is understood that you will not receive monetary compensation in regard to your participation in this research project. However, your parking costs will be reimbursed when you come to the hospital.

INFORMATION AND CONFIDENTIALITY

The information that you provide during this study, including the answers to questionnaires and tape recordings, will be kept in a confidential research file.

- In order to ensure confidentiality, your name will be replaced by a confidential code to which only the researchers have access.

- These anonymous files and the participant codes for the study will be kept locked in the office of the Nursing Department of the University Institute of Geriatrics of Sherbrooke.

- Access to these anonymous files of the study will be restricted to the members of the research team involved in this research project and only for the purposes of this study.

- Access to the codes of the subjects for this study will be strictly limited to the person responsible for the key..

- The audio tape recordings of the three questions on communication problems to which participants reply will be destroyed five years after the analyses have been completed.

- When the results are made public there will be no mention of your name, nor will the information be linked to your name. The information that is obtained will only be used for professional and scientific communications.

  Having been informed of the above modalities of the study, do you accept that the 'anonymous' information (not identified by your name) obtained from you during this study be used in professional and scientific communications?

- Yes → [   ]   No → [   ]

PERSONS TO CONTACT

Throughout this study, you can reach Krystyna Kouri, research nurse, at the telephone number : 819-821-1150 (extension 2687), or Dr Francine Ducharme, at the telephone number 514-340-3540 (poste 4772), for all supplementary information or for any problems concerning the research project.

For any ethical problems concerning the conditions of your participation in this project; after having discussed these with the person responsable for the project, you can explain your preoccupations to the president of the Ethics and Research Committee of the University Institute of Geriatrics. This person can be reached through the secretary at the following telephone number: 819-829-7131.

DECLARATION OF PARTICIPANT

I declare that I have been adequately informed about the nature and the reason for my participation in this research project. I have read and understood the terms of this consent frpm and I have been given a copy. I have had the occasion to ask quesitons and they have been answered to my satisfaction. I accept to participate in this study.

Signature of subject : _____

Signature of witness : _____

DECLARATION OF THE PERSON RESPONSABLE FOR OBTAINING THE CONSENT

I, the undersigned _____ certify that I have explained to the person who has signed up to take part in this study, the terms of this form, that I have answered questions that he/she presented to me, that I have explained to him/her that he/she is free at any time to terminate his/her participation in this study as decribed above.

Signature of person responsable for obtaining consent :

_____

Signature of witness : _____

Signed at Sherbrooke, the _____ 200_

Do you accept to receive the journal Encrâge, of the Research Centre on Aging?

Yes |___| No |___|

PARTICIPANT CONSENT FORM

GROUP B: THE PROGRAM

INFORMATION ABOUT THE STUDY

TITLE OF PROJECT:
Evaluation of a program focused on communication for the family caregiver or friend of a person with cognitive ('memory') problems.

PERSONS IN CHARGE OF THE PROJECT:
Krystyna Kouri, Nurse, Doctoral candidate in nursing sciences, Faculté des sciences infirmières (Faculty of Nursing) at the Université de Montréal and Nurse Clinician (Conseillère cadre à la direction des soins infirmiers) at the CSSS-l'Institut universitaire de gériatrie de Sherbrooke (Health and Social Services Centre – University Institute of Geriatrics of Sherbrooke).

Dre Francine Ducharme, Desjardins Research Chair in Nursing Care for Seniors and their Families, and Professor and researcher at the Faculté des sciences infirmières (Faculty of Nursing), Université de Montréal.

DECLARATION OF RESPONSIBILITY
The above named researchers are in charge of this research project and undertake to respect the obligations that are outlined herein.

Signature of the principal researcher of the project:_____

OBJECTIVE OF THE PROJECT
This study was developed for persons such as yourself (the family member or friend), to help you to communicate better with the person who has cognitive (or 'memory') problems.

NATURE OF PARTICIPATION
By accepting to take part in this study, you will take part in **Program 'B'**, in which you will participate in a learning program (comprised of 5 sessions), and three meetings as described on the next page. These meetings will take place at the University Institute of Geriatrics of Sherbrooke.

I. THE FIRST MEETING:

At the first meeting, the researcher will help you in the following tasks:

1. **Reply to a <u>question</u>** about a communication problem. You can either write your answer or say it verbally (**tell** your answer to the researcher). **The verbal reply will be recorded (audio taped).**

2. **Reply to <u>four questionnaires</u>** in regard to the following subjects:

* the ways in which caregivers can communicate better with a family member or friend who has cognitive (or 'memory') problems,

* the perceptions of confidence of caregivers in regard to their communication skills with their family member or friend with cognitive ('memory') problems,

* what caregivers know (or knowledge) about how to communicate with a family member or friend with cognitive (or 'memory') problems,
* identification (by caregivers) of communication problems with a family member or friend with cognitive (or 'memory') problems.

3. **Complete the <u>consent form.</u>**

<u>Time for this meeting</u> : about <u>2 to 2 ½ hours.</u>

II. PROGRAM :

The program starts one week after the first meeting. Each participant (caregiver) then meets individually with a nurse once per week over five weeks (for a total of five meetings).

Each meeting takes place over 1 hour and 30 minutes (90 minutes in total). During these meetings the nurse helps the participant to learn how to communicate better with the family member or friend with cognitive ('memory') problems..

II.   THE SECOND MEETING:

The second meeting is held seven (7) weeks after the first meeting. During this

meeting, the researcher helps you in the following tasks for a second time:

1. Reply to a <u>question</u> about a communication problem. You can either write your answer or say it verbally (tell your answer to the researcher. **The verbal reply will be recorded (audio taped).**

2. Reply to the same <u>4 questionnaires</u> to which you answered in the first meeting.

<u>**Time for the second meeting**</u>: about <u>2 hours.</u>

III.   THE THIRD MEETING:

The third meeting is held five (5) weeks after the second meeting. During this meeting, the researcher will help you in the following tasks for the third time:

1. **Reply to a <u>question</u>** about a communication problem. You can either write your answer or say it verbally (tell your answer to the researcher). **The verbal reply will be recorded (audio taped).**

2. **Reply to the same <u>4 questionnaires</u>** to which you answered in the second meeting.

<u>**Time for this meeting**</u> : about <u>2 hours.</u>

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BENEFITS THAT CAN RESULT FROM YOUR PARTICIPAITON

By participating in this five week program focused on *communication with the person with memory problems,* you will be better informed on this subject.

Furthermore, the information from the four questionnaires that you will have completed during the three meetings will help you to understand this subject better.

If you should need help from another professional, we will help you to find the necessary help.

INCONVENIANCES THAT MAY RESULT FROM YOUR PARTICIPATION IN THIS STUDY

You may experience certain inconveniences while participating in this study, such as having to travel from your home to the hospital, and to spend time at the meetings.

RISKS

There are no risks related to your participation in this project.

LEAVING THE STUDY

While your collaboration in this study is important for the development of knowledge in nursing in regard to 'aging and memory problems', your participation is entirely voluntary. If you do not wish to participate, you should feel completely free not to take part in it.

If you accept to participate, you should feel free to leave the study at any time without having to give a reason, and without prejudice. Your decision will not influence in any way the care that you or your family member will receive at the University Institute of Geriatrics of Sherbrooke.

Your support of this study is very much appreciated. It is anticipated that the results will help us to develop learning strategies related to communication that will help family members or friends of individuals with memory problems.

ENDING (STOPPING) THE PROJECT BY THE RESEARCHER

The principal researcher reserves the right to end the projet at any moment without advance notice. She also reserves the right to exclude any participants from the project when it would be in their best interest to do so; for example, in the case of illness.

Given the possibility of the above situation, do you wish that the information that has been gathered be destroyed?
Yes → [   ]   No → [   ]

FUTURE STUDIES

It is possible that the results obtained from this study will lead to another research project. In such a case, do you authorize the principal researcher of this project to communicate with you and ask if you would be interested in participating in a new research project?

Yes → [   ]   No → [   ]

MONETARY COMPENSATION

It is understood that you will not receive monetary compensation in regard to your participation in this research project. However, your parking costs will be reimboursed when you come to the hospital.

INFORMATION AND CONFIDENTIALITY

The information that you provide during this study, including the answers to questionnaires and tape recordings, will be kept in a confidential research file.

- In order to ensure confidentiality, your name will be replaced by a confidential code to which only the researchers have access.

- These anonymous files and the participant codes for the study will be kept locked in the office of the Nursing Department of the University Institute of Geriatrics of Sherbrooke.

- Access to these anonymous files of the study will be restricted to the members of the research team involved in this research project and only for the purposes of this study.

- Access to the codes of the subjects for this study will be strictly limited to the person responsible for the key..

- The audio tape recordings of the three questions on communication problems to which participants reply will be destroyed five years after the analyses have been completed.

- When the results are made public there will be no mention of your name, nor will the information be linked to your name. The information that is obtained will only be used for professional and scientific communications.

Having been informed of the above modalities of the study, do you accept that the 'anonymous' information (not identified by your name) obtained from you during this study be used in professional and scientific communicaitons?

Yes → [   ]   No → [   ]

PERSONS TO CONTACT

Throughout this study, you can reach Krystyna Kouri, research nurse, at the telephone number : 819-821-1150 (extension 2687), or Dr Francine Ducharme, at the telephone number 514-340-3540 (poste 4772), for all supplementary information or for any problems concerning the research project.

For any ethical problems concerning the conditions of your participation in this project; after having discussed these with the person responsable for the project, you can explain your preoccupations to the president of the Ethics and Research Committee of the University Institute of Geriatrics. This person can be reached through the secretary at the following telephone number: 819-829-7131.

DECLARATION OF PARTICIPANT

I declare that I have been adequately informed about the nature and the reason for my participation in this research project. I have read and understood the terms of this consent form and I have been given a copy. I have had the occasion to ask questions and they have been answered to my satisfaction. I accept to participate in this study.

Signature of subject : _____

Signature of witness : _____

DECLARATION OF THE PERSON RESPONSABLE FOR OBTAINING THE CONSENT

I, the undersigned _____ certify that I have explained to the person who has signed up to take part in this study, the terms of this form, that I have answered questions that he/she presented to me, that I have explained to him/her that he/she is free at any time to terminate his/her participation in this study as decribed above.

Signature of person responsable for obtaining consent : _____

Signature of witness : _____

Signed at Sherbrooke, the _____ 200_

Do you accept to receive the journal Encrâge, of the Research Centre on Aging?

Yes |___| No |___|

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APPENDIX J:

Approval from Research and Ethics Committee