

IMPLEMENTATION AND EVALUATION OF A SOCIAL SUPPORT PROGRAM  
FOR ALS CAREGIVERS USING PEER MENTORS

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The Faculty of Graduate Studies

Of

The University of Guelph

by

ISHTAR GABRIEL

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## ABSTRACT

### IMPLEMENTATION AND EVALUATION OF A SOCIAL SUPPORT PROGRAM FOR ALS CAREGIVERS USING PEER MENTORS

Ishtar Gabriel  
University of Guelph, 2007

Advisors:  
Dr. Scott Maitland  
Dr. Joan Norris  
Dr. John Turnbull

Twelve former ALS caregivers (known as mentors) were recruited and trained to provide informational and emotional support to twelve current ALS caregivers. The caregivers were assessed at onset, and prospectively every two months throughout a 12 month period, using several scales, which assessed the amount of social support, self-efficacy, satisfaction with program and disease progression. Mentors completed a tracking sheet after each visit outlining the topics discussed. Exit interviews were conducted to give both the mentors and caregivers an opportunity to share their observations about the program. In general, caregiver satisfaction with the program was high. Results indicated those caregivers caring for patients with limb onset reported higher levels of social support, self-efficacy and satisfaction with the program than those caring for patients with bulbar onset.

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## Introduction

It is well documented that those exposed to trauma or intense emotion (e.g., death of a loved one, terminal illness or divorce) tend to be more vulnerable to mental and physical illness (Greenberg, Wortman & Stone, 1996; Pennebaker, Hughes & O'Heeron 1987; Waid & Orne, 1982). Although several theories have been proposed, including the inhibition of emotion (Pennebaker et al., 1986, 1987, 1988) and faulty coping strategies (Herbert, Lacomis, Easter, Frick & Shear 2004; Stroebe, Schut & Stroebe, 2005; Thoits, 1995); the reason for this increased risk is still relatively uncertain. Many ALS caregivers are exposed to trauma or intense emotions when their loved one is diagnosed with ALS, including defenselessness, negative affect, hopelessness, sadness, depression, isolation and loneliness (Gauthier et al., 2007). Many of these caregivers also experience the physical stress associated with caregiving as they perform the obvious tasks required to care for someone who is disabled, in addition to working outside the home, managing household chores and even caring for young children. In fact, in a longitudinal study assessing quality of life and depression in ALS patients and caregivers, it was found that patients with ALS tend to be stoic despite their physical disability and experience depression less often than might be expected (i.e., between 11% and 48%). One would expect almost all ALS patients to experience, at least at some point during the course of the disease, episodes of depression and negative affect. Furthermore, quality of life for patients remained relatively stable throughout the course of the disease whereas ALS caregiver's quality of life and reports of burden worsened over time (Gauthier et al., 2007). More specifically, it was the amount of physical care required to care for an ALS patient and the lack of self-time that contributed to caregiver's low reports on quality of

life and high levels of burden. Fortunately, the adverse effects of stress associated with trauma and intense emotions can be buffered by social support networks (Greenberg et al., 1996; Heller & Thompson, 1991; Niederhoffer & Pennebaker, 2002; Sarson, Sarson & Gurung, 1997; Thoits, 1995). However, little is available in the way of social support for ALS caregivers and many simply do not have the time or physical means to attend support groups. The purpose of this study was to implement and evaluate a social support program using peer mentors designed by the ALS Clinic at McMaster University Medical Centre and The ALS Society of Ontario to meet some of the caregiver's needs by providing informational and emotional support, which was hoped to demonstrate a change in self-efficacy over the course of the program.

## Literature Review

### *What is ALS?*

Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disorder characterized by progressive loss of cortical and spinal motor neurons causing bulbar and spinal palsy which eventually involves the loss of speech, swallowing, mobility and breathing (Gauthier et al., 2007; Young & McNicoll, 1997). Most people who develop ALS are between the ages of 40 and 70 with an average age of 55 (Herbert et al., 2004). People diagnosed with ALS live between 2 to 4 years from first symptom and usually die from respiratory failure (Herbert et al., 2004). ALS is a relatively rare disorder with an incidence rate of 2 to 3 people in 100,000 and prevalence of 5 to 10 people per 100,000 with an equal distribution in major countries worldwide (Gauthier et al., 2007). Little is known about its etiology (Gauthier et al., 2007). Patients with ALS generally present

with symptoms referable either to the limb or bulbar muscles (Young et al., 1997). Bulbar complaints will consist of speech problems including slurred and nasal speech, difficulty chewing and swallowing, or a combination of both. Muscles of the throat, tongue, jaw, and face are known as bulbar because the area of the brain that controls these muscles – the lower brainstem – was once known as the bulb. In limb cases, symptoms initially affect one of the legs, and patients experience awkwardness when walking or running or they notice that they are tripping or stumbling; or a hand or arm and they experience difficulty with tasks requiring manual dexterity such as buttoning a shirt, writing, or turning a key in a lock. About 25% of ALS patients begin their disease with so-called “bulbar onset” and most patients who begin with purely bulbar difficulties will eventually develop symptoms in their limbs (Gauthier et al., 2007). The other 75% to 85% of patients with ALS whose first symptom occurs in a limb will usually develop bulbar symptoms and signs over time (Gauthier et al., 2007). Given the physical deterioration and quick progression ALS is one of the most demanding disorders, placing enormous physical, emotional, social and financial stress on the entire family, especially the primary caregiver.

### *Caregiver Burden*

According to Rabkin, Wagner, and Del Bene (2000) and Hecht et al. (2003) the burden of care among caregivers of ALS patients is high compared to those caring for patients with other diseases. Not only does ALS severely affect caregivers, the impact may continue long after the death of the patient (Martin & Turnbull, 2001). The majority of literature exploring the physical and psychological impact of caregiving

focuses on caregivers of patients with dementia (Goldstein, Atkins, Landau, Brown & Leigh, 2006; Hecht et al., 2003; Rabkins et al., 2000). The few studies exploring the impact of ALS on caregivers indicate primary caregivers spend 11 hours per day caring for the patient, experience financial distress, decreased quality of life, considerable sleep disturbances, depression, anxiety and limited social contact (Goldstein et al., 2006; Hecht et al., 2003; Rabkins et al., 2000). According to the health care professionals at the ALS Clinic at McMaster University Medical Centre (where this study was conducted), most caregivers struggle emotionally, mentally and physically as they transition into the caregiver role and attempt to negotiate their time between family, young children, work and household responsibilities. As the patient becomes more functionally impaired, caregiving becomes more physically and psychologically distressing. Furthermore, caregivers need to be made aware of enormous amounts of information and access multiple sources of support including financial support, community services, professional healthcare, home care and equipment support, immediately following diagnosis and throughout the course of the disease. These resources are available through family and friends, government, private and non-profit agencies at the community, provincial and federal level. Navigating through this maze of government departments, providers and agencies can be extremely difficult for caregivers already struggling with the disease on a daily basis. Moreover, key decisions the caregiver and patient need to make around their health care options are dependent upon access to adequate information and education. This may include deciding between home or institutional care, life support (e.g., permanent ventilation) and nutritional support (e.g., whether or not to get a feeding tube). Consequently, caring for an ALS patient places many demands on the caregiver and

successful caregiving requires caregivers to understand vast amounts of information quickly, master specific skills and organize the patient's care while coping with their own personal feelings about the diagnosis and prognosis.

### *Lack of Support for Caregivers*

Given the paucity of investigation into the psychological and physical effects of caregiving for ALS patients, it is not surprising that social support programs available to caregivers either do not exist or are not adequate (Gauthier et al., 2007; Goldstein & Leigh, 1999; Hecht et al., 2003; Rabkin et al., 2000). In a survey of doctors, nurses, and social workers working with ALS patients and caregivers, nearly all said that grief and bereavement support are important for caregivers (Herbert et al., 2004). However, less than half said that their centre provided adequate grief and bereavement support for caregivers. Although all respondents reported that caring for an ALS patient was stressful, less than half of the centres routinely screened caregivers for depression, anxiety, or complicated grief. The most common barriers cited to providing enhanced mental health support for caregivers included constraints on doctors', nurses', and social workers' time, constraints on caregiver's time, lack of administrative support, lack of qualified personnel, and expense. Further, the authors proposed that taking into account the well-being of ALS caregivers is important not only because of its potential benefits to caregivers but also because of its potential benefits to patients who rely extensively on their caregivers (Goldstein et al., 2006; Hecht et al., 2003; Rabkins et al., 2000).

### *Social Support Defined*

Social support is considered a coping resource and usually refers to the help provided by significant others to the individual (Thoits, 1995) and has been linked to both

physical and psychological positive health outcomes (Nijboer, Tempelaar, Triemstra, Van Den Bos & Sanderman, 2001; Pennebaker et al., 1986; Pot, Deeg & Van Dyck, 2000; Sarason et al., 1997). Although the social support literature provides several theories as to the exact underlying mechanisms producing these positive physical and psychological health benefits, there is little consensus. According to one school of thought (Badoux, 2000, Sarson et al, 1997; & Thoits, 1995), social support impacts mental and emotional health at a primary (direct) and secondary (indirect) level. Social support has a direct effect on physical and emotional health by meeting needs that require fulfillment on a day-to-day basis by facilitating access to information as well as influencing one's appraisal of stressful or threatening external stimuli. At a secondary level social support moderates response to external stimuli appraised as stressful or threatening by inhibiting faulty responses and encouraging adaptive behaviour. Another approach proposes social support in and of itself does not promote positive physical and emotional health but rather, the process of emotional disclosure (Greenberg et al., 1996; Pennebaker 1986, 1987; Stroebe et al., 2005). Trauma is seen as eliciting intense emotions and results in the need to talk to others in an effort to assimilate the "new" information and create a sense of normalcy and accuracy. This process is most successful achieved when the person providing support is most similar to the person disclosing and has shared a similar trauma.

A distinction between structural and functional support is also made, where structural support answers the question "what does it look like" and functional support answers the question "how does it work" (Badoux, 2000). The structural attempts to describe the quantitative aspects of the support, taking into account mainly the social network (marital

status, friends, community, coworkers, children and grandchildren). The functional approach attempts to describe the quality or type of social support and is usually divided into four distinct categories: emotional support, informational support, instrumental support (or tangible support) and appraisal support (or affirmational support). Emotional support includes things that others do to make the person feel loved, cared for, understood and encourage a sense of self-worth. Information support includes help offered in the form of suggestions or advice and instrumental support includes help or assistance with tangible needs. Finally, appraisal support includes validation and confirmation when others are making decisions and are facing challenges. Both structural and functional aspects of social support will be considered for this project including an assessment of information and emotional support (appraisal/affirmational are categorized together as they are closely linked).

### *Self-Efficacy Defined*

Perceived self-efficacy is an individual's belief in his/her ability to organize and execute a specific course of action to manage a situation (Bandura, 1977; Maddux, 2002). Moreover, the perception of self-efficacy can actually modify the outcome in a given circumstance (Bandura, 1977; Maddux, 2002). The key components of self-efficacy include mastery and personal control. Self-efficacy is not a fixed trait but rather an ability that develops over time and through experience (Maddux, 2002). According to Maddux (2002), self-efficacy begins to develop at birth and continues through life and is not static but open to factors, which can help as well as hinder its development. Self-efficacy has been widely used in research to explain the differences among those who experience chronic stress and coping, however, not until recently has the construct been

used to explain differences among caregivers' experiences (Maddux, 2002; Steffen, McKibbin, Zeiss, Gallagher-Thompson & Bandura, 2002; Zeiss, Gallagher-Thompson, Lovett & McKibbin, 1999). Self-efficacy has been used to account for the variability among caregivers, specifically those caring for patients with dementia, to explain the differences in how caregivers cope and overcome challenge (Fortinsky, Kercher & Burant, 2002; Steffen et al., 2002; Zeiss et al., 1999). Research findings indicate caregivers high on self-efficacy handle the caregiving role more successfully as the patient's condition worsens and tasks become more difficult than those caregivers low on self-efficacy (Steffen et al., 2002).

#### *Why Measure Self-Efficacy?*

Self-efficacy plays a crucial role in promoting psychological as well as physical health. Psychological well-being is directly linked to the perception that one has control over behaviour, environment and thoughts (Maddux, 2002). According to Maddux (2002), those high on self efficacy approach new situations and challenges more calmly and confidently, whereas those low on self efficacy doubt their skills and question their capabilities and tend to adopt a learned helpless mind set making them more susceptible to depression and anxiety. Self-efficacy is also directly linked to physical health in that there is a well documented physiological response to stress, which is caused by an actual or perceived loss of control (Amir, Roziner, Knoll & Neufeld, 1999; Weber et al., 2004). This response to stress, which is linked to activation of catecholamines, endorphins and the immune system, can increase risk of infections and illness (Greenberg et al., 1996). Most importantly, since the concept of self-efficacy stems from the social learning literature, it is viewed as a behaviour that can be learned and enhanced (Fortinsky et al.,



2002) and as such is something that can be taught to others. Furthermore, self-efficacy theorists indicate several tools that can be taught to develop and enhance self-efficacy in others which include, psychoeducational strategies, personal mastery of relevant skills and positive feedback (Weber et al., 2004; Zeiss et al., 1999), which could be delivered through social support programs, specifically a supportive dyad.

### *Social Support Programs*

Numerous studies suggest the beneficial health effects of social support groups for patients including increased health benefits in arthritis, cancer, heart disease and epilepsy (Greenberg et al., 1996; Lorig, Mazonson & Holman, 1993; Spiegel, Bloom, Kraemer & Gottheil, 1989). However, the literature is less clear on whether these benefits transfer to supportive dyads designed for caregivers. In fact, very little research exploring the benefits of peer dyads is available with the majority of the work focusing on supportive dyads between patients (Parent & Fortin, 2000). Moreover, there is very little investigation into the mediating factors between social support and beneficial health outcomes outside of the established social support theories describing its buffering and main effect benefits. Since the majority of research investigating the benefits of support programs has focused on social support dyads for patients a brief review of some of these results is provided here, before turning to peer support dyads for caregivers. Furthermore, it is important to note, although few studies on dyadic interventions exist, the majority of them have been designed to improve self-efficacy. In a study by Weber et al. (2003), long-term survivors of prostate cancer provided support to males undergoing prostatectomy surgery and found those men in the treatment group reported lower levels of depression and higher levels of self-efficacy than those patients in the control group.

Parent and Fortin (2000) investigated the benefits of a supportive dyad between former male patients who had successfully recovered from cardiac surgery and first time patients and found males with peer support were less anxious prior to the surgery and throughout their recovery period compared to controls. Those in the treatment group also reported significantly higher levels of self-efficacy expectations and reported higher levels of activity than those men in the control group. Finally, Riegel and Carlson (2004), who assessed dyadic interventions between former and current patients with heart failure, found higher levels of self-care for those patients in the experimental group.

Only two studies examining the benefits of supportive dyads between caregivers were found, including one looking at caregivers of Alzheimer's patients (Pillemer et al., 2002) and the other a descriptive study on caregivers of stroke patients (Stewart et al., 1998) and very little has been done to explore the underlying mechanisms of such programs. The research that does exist suggests peer support programs are beneficial because individuals are more likely to develop and maintain supportive relationships with others who are similar to them and who have experienced the same stressful transitions (Pillemer et al., 2002). Thoits (1995) believes this shared experience is crucial to the support process and increases empathetic understanding by normalizing caregiving experiences, creating acceptance and encouraging caregivers to receive help more positively. Furthermore, for some individuals dyadic relationships can be more comfortable and convenient than group support, especially for caregivers who are shy or who are unable to leave the patient home alone (Stewart et al., 1998). Peer programs also assist health care workers by addressing the daily needs of caregivers, which allows health care professionals to assist caregivers and patients who are in crisis. More

importantly, peer support programs provide social support, namely emotional and informational support, and it is our hope that this support will promote self-efficacy (specifically mastery and personal control) believed to enhance a caregiver's ability to cope.

The purpose of this pilot study was to design, implement and assess the effects of a peer support program between current ALS caregivers (diagnosis given to patient within last 12 months) and former ALS caregivers (more than 12 months since death of the patient). The intervention expected to increase self-efficacy was developed based on the self-efficacy theory proposed by Bandura (1977).

*Hypotheses:*

1. Caregivers will be satisfied with the mentor program. Caregiver satisfaction will increase over the course of the mentor program as the person with ALS becomes more disabled and will differ depending on disease onset.
2. Caregiver's perceived social support will increase over the course of the mentor program as the person with ALS becomes more disabled and will differ depending on disease onset.
3. Caregiver self-efficacy and general self-efficacy will increase over the course of the mentor program as the person with ALS becomes more disabled and will differ depending on disease onset.

## Methods

### *Participants*

The staff at the ALS Clinic at McMaster University Medical Centre contacted all former caregivers of ALS patients who had received care through the clinic (within the past 36 months) where contact information was still available and who met the following criteria:

- They were at least 18 years of age or older.
- They had been primary caregiver(s) living at home, caring for someone living with ALS.
- At least 12 months had passed since the death of the client.

Seventeen former ALS caregivers were eligible for the study but five declined the request to become a mentor stating they were not emotionally ready. The final sample included 12 mentors, six of whom were males and six females, ranging in age from 18 to 79 years. All of the mentors were Caucasian and had completed high school or post-secondary education. The majority of the mentors were Christian (75%) and were the spouse of the person who had died of ALS (83%). In most cases, the former patient with ALS had first experienced symptoms in a limb (67%) as opposed to the bulbar area and had died within the past 24 months (67%). Unsuitable mentors were screened using the following process:

- The prospective mentors were asked to share their own past experience as a caregiver for someone with ALS. During the conversation, the team (representative from the ALS Society, the ALS Clinic and the mentor group) assessed the ability and readiness of the candidate to become a mentor.

- The prospective mentors were briefed on formal volunteer registration requirements and were given the necessary volunteer registration and police check forms to complete and return (See Appendix A). They were also informed they would be contacted by telephone if they had been short listed for the next available training date.
- After the meeting, the screening team completed the screening form (See Appendix B) and evaluated whether the candidate would be entered into the Mentor program. Successful candidates were comfortable discussing their own experience and end of life issues, tolerant and accepting of a wide range of coping strategies and end of life decisions, had adequate support systems in place for themselves, expressed a willingness to ask for help and support and be coping well with their own bereavement.

All of the caregivers successfully passed the screening phase and were then required to attend a full day of training before officially becoming a mentor. Once these caregivers were trained the clinic began recruiting current caregivers interested in being matched with a mentor. Given the limited number of newly diagnosed patients within any one ALS clinic it made sense to simply approach all caregivers (where diagnosis of patient had been received within the past 12 months) to offer them the opportunity to participate in the mentor program. Recruitment of caregivers ceased once 12 caregivers had been recruited who met the following criteria:

- Referred to the program by ALS Society, ALS clinic or self.
- Ready and willing to participate in the program.
- Primary caregiver for someone newly diagnosed with ALS (not

more than 12 months since diagnosis)

### *Procedure*

The Research Ethics Boards at both the University of Guelph and McMaster University approved the study protocol and all the participants consented to participate after being informed of the risk and benefits of study involvement (See Appendix C).

The former caregivers were expected to attend a one-day training session before officially becoming mentors. The training session was conducted by professional counselors from Wellspring (a cancer support center which conducts their own peer support program for cancer patients). The training informed mentors about the details of the program outlined expectations and educated them about boundary setting, coping strategies and self-care techniques. It also included role-playing and outlined challenging potential scenarios. Once the training of mentors and recruitment of caregivers was completed mentors and caregivers were matched. The matching process was the joint responsibility of the ALS Society and the ALS clinic. Each mentor was assigned to one caregiver and was based on the following criteria:

- Similarity on the basis of gender, geographical area, family dynamics (single or married, with or without children) and onset (bulbar or limb onset).
- Age group: within 10-year difference on either side. For instance, if the age of the caregiver is 45 years, the mentor should be ideally between 35 and 55.

After the matches were completed the initial face-to-face contacts between the mentor, supervisor and caregiver were made. During the initial face-to-face meeting mentors and caregivers were given an opportunity to get to know one another and determine if they were comfortable with the match (all 12 mentors and caregivers approved match). The

expectations of the program were reviewed, the first phone contacts were scheduled and confidentiality agreements were signed. The mentors were expected to provide support to the caregiver for 1 year. The main form of contact (except for initial face-to-face contact) was by telephone. Telephone contacts were pre-scheduled and initiated by the mentor according to their convenience and to accommodate the time constraints of the caregiver. The plan for the 1-year mentorship was as follows:

- Months 1 to 3: included 1 call per week with each call lasting a maximum of 1 hour. The expectation was that a strong connection would be established between the mentor and caregiver during this period allowing for less phone contacts throughout the rest of the mentorship.
- Months 4 to 9: included up to 4 phone contacts per month each lasting a maximum of 1 hour. During this period it is expected a support network (including family, friends, community resources) would be established with the goal of transitioning the mentor out during the last few months of the program.
- Months 10 to 12: these months were spent transitioning the mentor out of the caregiver and family's support network. These discussions were made on an individual basis and the caregiver, mentor and supervisor were involved in this decision.

There were 2 supervisors each of whom monitored 6 mentors and their caregivers.

Supervision allowed clinic staff to monitor the program and address any issues or concerns and provided mentors with an opportunity to debrief. Once a month for the first three months and the last three months (in order to develop transition plan) supervision

was conducted on a one-to-one basis between the supervisor and mentor. Once a month from month 4 to 9 group supervision was provided and mentors were expected to attend. Supervisors were also available during office hours for consultation if the need arose for the mentors or the caregivers.

Initial face-to-face contacts were staggered to allow researchers enough time for monthly data collection and post-intervention interviews. Data were collected from the caregivers at baseline (during the initial face-to-face) and at months 2, 4, 6, 8, 10, 12. Mentors completed a tracking sheet after each visit outlining the issues/topics discussed, length of the conversation, and amount of time spent providing emotional/information support (See Appendix D). The mentors met as a group once a month to debrief. Upon completing the program, interviews were conducted and open-ended questions were included to give both the mentors and caregivers the opportunity to share their observations about the program (See Appendices E and F).

### *Measures*

*Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised* (See Appendix G). The ALSFRS-R (Cedarbaum et al., 1999) assesses disease severity (disability) in patients with ALS and includes 12 items that are rated on a scale from 4 (no impairment) to 0 (unable to perform task). The scale includes four domains: gross motor tasks, fine motor tasks, bulbar function and respiratory function. The ALSFRS-R demonstrates close agreement with objective measures of muscle strength and pulmonary function (ACTS, 1996). Internal consistency and test retest reliability have shown to be high (ACTS, 1999; Cedarbaum et al., 1999).



*Inventory of Social Supportive Behaviours* (See Appendix H). The ISSB (Barrera, Sandler & Ramsay, 1981) is a 40-item questionnaire designed to assess the frequency and type of support individuals have received during the preceding month (for the purposes of this study the duration of time was 2 months and caregivers were also asked to indicate from whom they received the assistance). The types of support include guidance, information, emotional support, tangible assistance and social interaction. Subjects were asked to rate the frequency of each item on a 5-point Likert Scale (1= not at all, 2 = once or twice, 3 = about once a week, 4 = several times a week and 5 = about every day). Internal consistency and test retest reliability are high (Barrera et al., 1981).

*The Caregiver Self-Efficacy Scale* (See Appendix I). The CGSES (Zeiss et al., 1999) is a 14-item measure of caregiver's self-efficacy (i.e., judgments regarding one's ability to perform effectively in specific situations). The measure is comprised of two subscales: caregiver self-care self-efficacy, which includes 10 questions, and caregiver problem-solving self-efficacy, which includes 4 questions. Respondents were asked to indicate whether or not the question relates to them by indicating "yes" or "no". If they responded "yes" they were then asked to rate their level of confidence for that item on a scale from 0% to 100%. Items they responded "no" to were given a score of 0%. The scale was assessed using 217 caregivers of frail and/or cognitively impaired elders and demonstrated strong reliability (Zeiss et al., 1999). Test-retest reliability for the self-care self-efficacy domain and the problem-solving self-efficacy domain are high (Zeiss et al., 1999). The self-care self-efficacy subscale correlates highly with the Arizona Social Support Interview Scale, intended to measure network size, specifically number of people one confides in and number of people providing support, indicating good construct

validity for this portion of the scale (Zeiss et al., 1999). The problem solving self-efficacy subscale correlates highly with the Daily Living Questionnaire, a portion of which is intended to measure logical analysis, demonstrating good construct validity of this portion of the scale this subscale of the measure (Zeiss et al., 1999).

*Generalized Self Efficacy* (See Appendix J). The GSE (Schwarzer, 1994) is designed to assess optimistic self beliefs used to cope with a variety of demands in life. The 10-item scale has been used to assess perceptions of GSE in a wide range of empirical studies, including research on stress, psychosocial adaptation, and health beliefs (Schwarzer, 1994). Respondents are asked to rate each statement from not at all true = 1, barely true = 2, moderately true = 3 and exactly true = 4. Results support the validity of the scale, revealing that GSE correlates positively with optimism, self-esteem, internal control and achievement motivation and negatively with anxiety, depression, and neuroticism (Schwarzer, 1994). The internal consistency is high and has been used in numerous studies usually demonstrating coefficient alpha values between 0.75 to 0.90 (Schwarzer, 1994).

*Satisfaction Rating* (See Appendix K). Caregiver satisfaction of the mentor program was rated using a single question asking respondents to rate, on a scale from 0 (being the lowest score) to 10 (being the highest score) their satisfaction with the mentor program over the past 2 months.

## Analysis

### *Sample Description*

Twelve former ALS caregivers were recruited and trained as mentors and matched with twelve current ALS caregivers based on demographic information (including gender, age, ethnicity, disease specifics, geographic area and occupation). Seven caregivers completed the twelve-month program and several of these dyads continued to contact each other well after the program was completed. One caregiver (age 14) dropped out at month 4, which his mentor (age 18) believed was related, in part, to his age and the mode of contact. Both the mentor and caregiver indicated alternative modes of contact (such as email and text messaging), would have been more appropriate and useful for participants in their age category. Four patients died (one at month 2, 8, 10 and 12), which meant four caregivers did not complete the program but whose mentors continued to provide support through bereavement. During exit interviews, these caregivers indicated this support was just as important, if not more important, than the support provided during active caregiving. There were no adverse effects related to participation in the peer support program and anecdotal information suggests all the caregivers (former and current) appreciated the program.

### *PROC MIXED Procedure*

Analyses were performed using SAS PROC MIXED, (SAS Institute Inc., Version 9.1, 2002-2003). The SAS procedure PROC MIXED is specifically designed to fit a variety of mixed linear models to make statistical inferences about the data using both fixed effects and covariance parameters. Mixed models calculate both fixed effects parameters (means) and covariance parameters and as such the data are permitted to

exhibit both correlation and heteroscasticity of variance (Littell, Henry & Ammerman, 1998). Unlike repeated measures ANOVA, which uses models based on means and probabilities, PROC MIXED uses models based on observed data and estimation methods (method used in this study is Maximum Likelihood Estimation). Furthermore, for any given dependent variable in this study (social support, caregiver self-efficacy, general self-efficacy or satisfaction) repeated measures ANOVA would have determined the probability of whether the within subjects difference were significant based on fixed parameters, whereas the PROC MIXED procedure determines the likelihood of the parameters based on fixed data (Littel at al., 1998). The aim of Maximum Likelihood Estimation is to find the parameter values that make the observed data more likely (Singer, 1998). Moreover, certain statistical assumptions including independence of independent variables and homogeneity of variance do not need to be met in order to determine likelihoods in PROC MIXED. Most importantly, PROC MIXED, unlike SPSS ANOVA, does not discard missing data and instead uses Maximum Likelihood Estimation, to run simulations to allow for the missing data points (Singer, 1998). PROC MIXED was selected to analyze the data in this study because of its ability to perform multiple comparisons, simulate missing data and accommodate heteroscasticity of variance, all of which make this procedure appropriate and powerful for a small data set with missing values and complex hypothesis.

### *Regression Models*

A series of multiple regression analyses were conducted to examine the hypotheses. Models were constructed to examine the relationship between each of the dependent or response variables (Social Support, General Self-Efficacy, Caregiver Self-

Efficacy and Satisfaction) and the three independent or explanatory variables (onset, progression and time). ALS onset included bulbar (where the patient's first symptom started in relation to the bulbar area) and limb (where the patient's first symptom started in an arm or leg). Disease severity (based on the ALSFRS) was divided into 3 arbitrary categories to facilitate the regression analysis, where 20 ("severely disabled") indicated person with ALS was disabled and all areas of functioning were effected, 30 ("moderately disabled") indicated person with ALS was showing signs and symptoms of disease in more than 2 areas of functioning and 40 ("mildly disabled") indicated person with ALS was showing signs and symptoms in less than 2 areas of functioning. Time was based on time points when data were collected (baseline, month 2, 4, 6, 8, 10 and 12) and indicated whether change in the dependent variable occurred over the course of the program.

### *Assumptions*

When using PROC MIXED the assumptions of normality and homogeneity of variance do not have to be met. PROC MIXED is designed to accommodate data with heteroscasticity of variance. In addition, PROC MIXED does not work on the assumption of independence and as such correlation analysis of the independent variables was not required.

### *Assessing Fit of Models*

Parameters for fixed effects (means) were estimated using maximum likelihood. The SAS program selects parameters for the model at random and then computes the likelihood of the data given these parameters. The parameters that are finally chosen are those with the greatest likelihood computed. These estimates are called Maximum

Likelihood Estimates because the parameters are chosen to maximize the likelihood of the observed data. The technique actually used to find Maximum Likelihood Estimations is known as numerical analysis, which works according to a series of automatic steps. First, the computer picks some initial parameter, then computes the likelihood of the data given these parameter estimates. Secondly, it will improve the parameter estimates and recalculate the likelihood of the data based on these improvements. It will continue to perform these recalculations until it is commanded to stop---which is usually done when there is little change in the parameter estimates (Little et al., 1998)

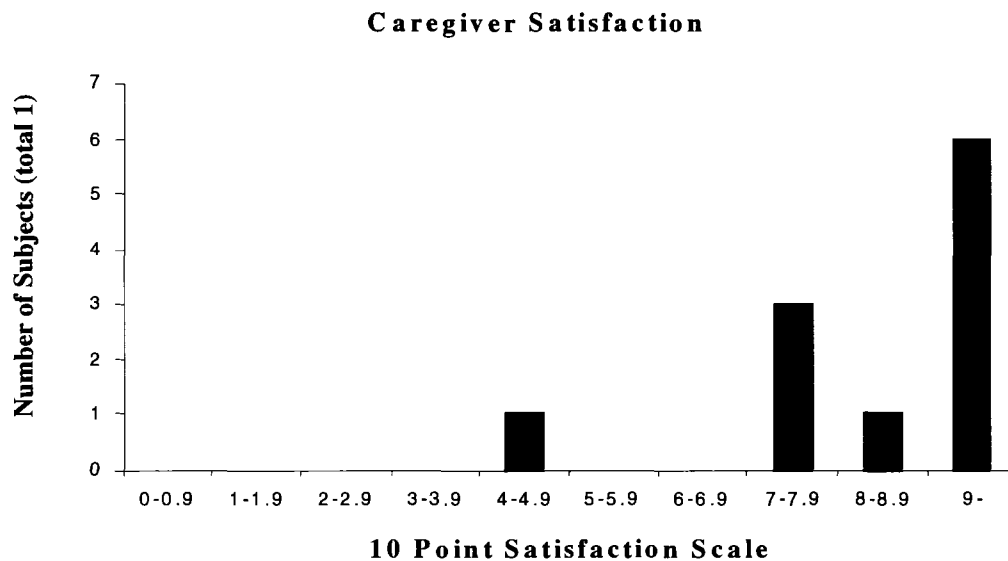
Parameters for covariance were estimated using variance component structures. PROC MIXED provides a variety of covariance structures to select from including, compound symmetry, unstructured, autoregression, factor analytic, spatial, general linear and variance components (Little et al., 1998). The variance component structure was chosen because it provided the minimum value for the mean squared error in each model (tightest fit). This structure is the default position in SAS. However, it is often used in repeated measures analysis with heteroscasticity of variance. The Fit Statistics,  $-2 \text{ Log Likelihood}$  ( $-2LL$ ) and AIC are references of how well the above models fit the observed data. The models with the “best fit” are selected from all other models computed by PROC MIXED. The models selected are those with the smallest  $-2LL$  and AIC values (Little et al., 1998).

## Results

### *Hypothesis One: Satisfaction*

The first hypothesis stated, “Caregivers will be satisfied with the mentor program. Caregiver satisfaction will increase over the course of the mentor program as the person with ALS becomes more disabled and will differ depending on disease onset.” Based on average scores over the course of the mentor program we can conclude that the majority of caregivers rated the program highly (See Figure 1), indicating that overall caregivers were satisfied with the mentor program.

Figure 1



A multiple regression model was constructed based on the second part of the hypothesis, where satisfaction was entered as the dependent variable and onset, disease severity and time were entered as the independent variables. Caregiver satisfaction for the caregivers caring for patients with bulbar onset was estimated to be 2 points lower on

this scale than for those caring for patients with limb onset,  $F(1, 9) = 10.74$ ,  $PR > F = 0.010$  (See Tables 1 and 2). Caregiver satisfaction did not increase over the course of the mentor program or as the disease progressed. Covariance Structure with Variance Components revealed best model (Fit Statistics:  $-2LL = 173$  and  $AIC = 183$ ) and used 43 time points (each subjects score at each time point) for the 12 caregivers during the study period (starting at month 2) with 41 missing information points.

Table 1

*Type 3 Tests of Fixed Effects for Satisfaction*

Effect	Num DF	Den DF	F Value	Pr > F
Onset	1	9	10.74	0.0096
Disease Severity	1	30	0.33	0.5697
Time	1	30	0.04	0.8396

Table 2

*Solution for Fixed Effects for Satisfaction*

Effect	Onset	Estimate	Standard Error	DF	t Value	Pr >  t
Intercept		10.6196	1.6403	9	6.47	0.0001
Onset (bulbar)	1	-1.9081	0.5823	9	-3.28	0.0096
Onset (limb)	2	0	.	.	.	.
Disease Severity		-0.02237	0.03891	30	-0.57	0.5697
Time		-0.02055	0.1007	30	-0.20	0.8396

Figures 2, 3 and 4 plot satisfaction over time at each level of disease severity (including severely disabled, moderately disabled and mildly disabled) for caregivers caring for patients with bulbar onset and limb onset.



Figure 2

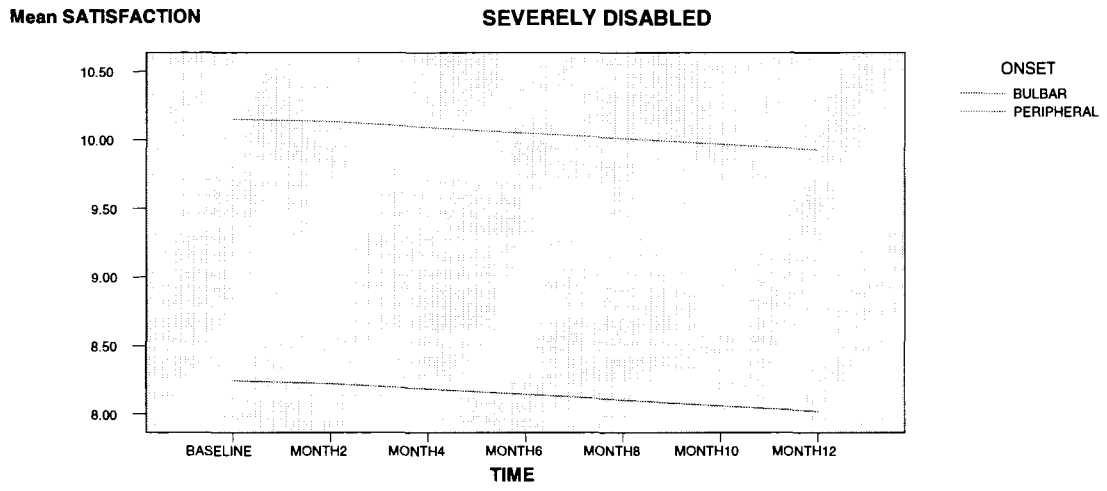


Figure 3

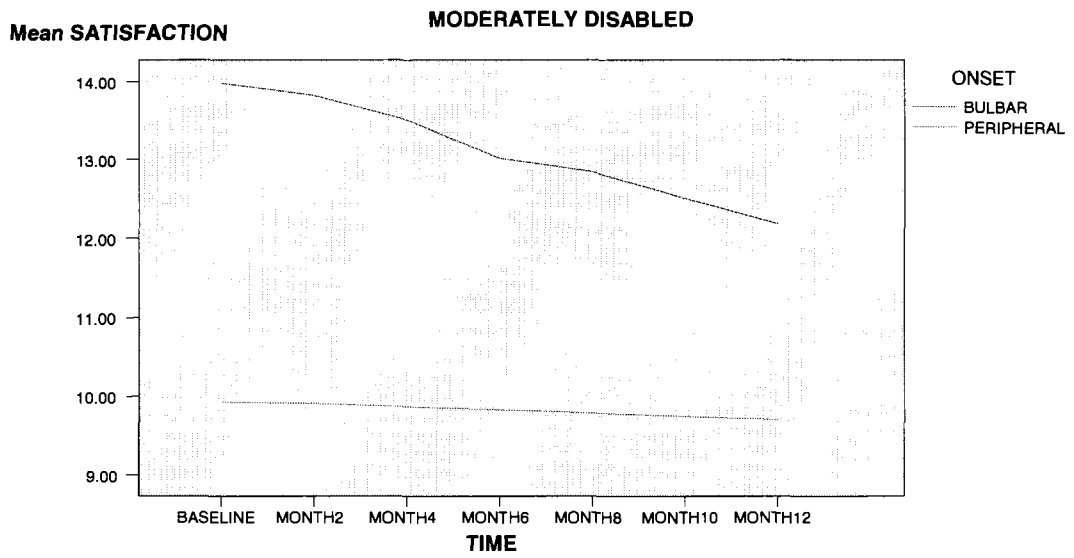
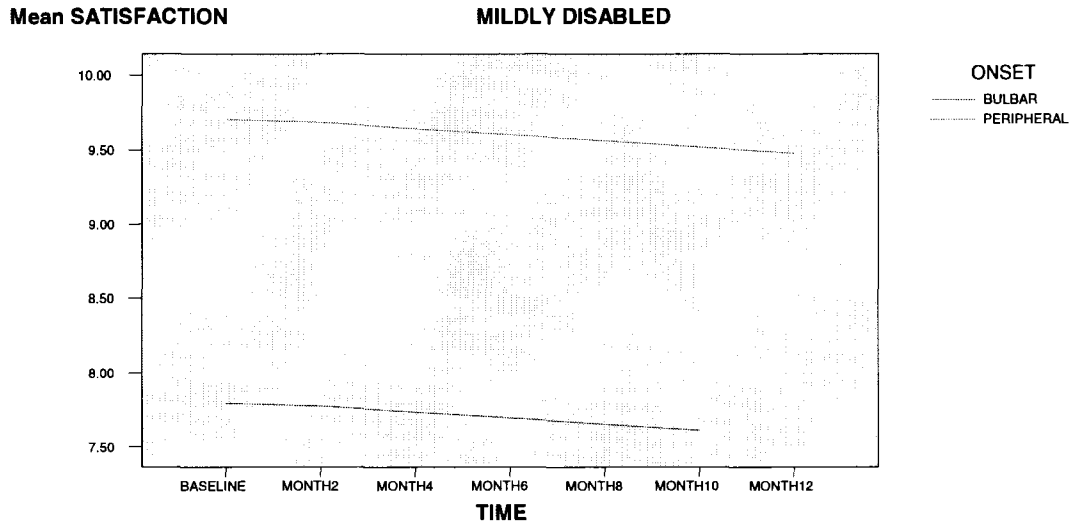


Figure 4



*Hypothesis Two: Social Support*

A multiple regression model was conducted based on the second hypothesis which stated, “Caregiver’s perceived social support will increase over the course of the mentor program as the person with ALS becomes more disabled and will differ depending on disease onset.” Caregiver perceived social support was entered as the dependent variable and onset, disease severity and time were entered as the independent variables. Caregiver perceived social support for those caregivers caring for patients with bulbar onset was estimated to be 19 points lower on this scale than for those caregivers caring for patients with limb onset,  $F(1, 10) = 6.77$ ,  $PR > F = 0.026$  (See Tables 3 and 4). Indicating caregivers caring for patients with bulbar onset reported less perceived social support than did caregivers caring for patients with limb onset. Caregiver perceived social support did not increase significantly over the course of the mentor program or as the disease progressed. Covariance Structure with Variance Components revealed best model (Fit Statistics:  $-2LL = 581.7$  and  $AIC = 591.7$ ), and used 61 time points (each

subjects score at each time point) for the 12 caregivers during the study period with 23 missing information points.

Table 3

*Type 3 Tests of Fixed Effects for Social Support*

Effect	Num DF	Den DF	F Value	Pr > F
Onset	1	10	6.77	0.0264
Disease Severity	1	47	0.64	0.4261
Time	1	47	0.18	0.6734

Table 4

*Solution for Fixed Effects for Social Support*

Effect	Onset	Estimate	Standard Error	DF	t Value	Pr >  t
Intercept		88.8082	22.9074	10	3.88	0.0031
Onset (bulbar)	1	-19.7648	7.5958	10	-2.60	0.0264
Onset (limb)	2	0	.	.	.	.
Disease Severity		-0.4334	0.5399	47	-0.80	0.4261
Time		0.5288	1.2467	47	0.42	0.6734

Figures 5, 6 and 7 plot social support over time at each level of disease severity (including severely disabled, moderately disabled and mildly disabled) for caregivers caring for patients with bulbar onset and limb onset.

Figure 5

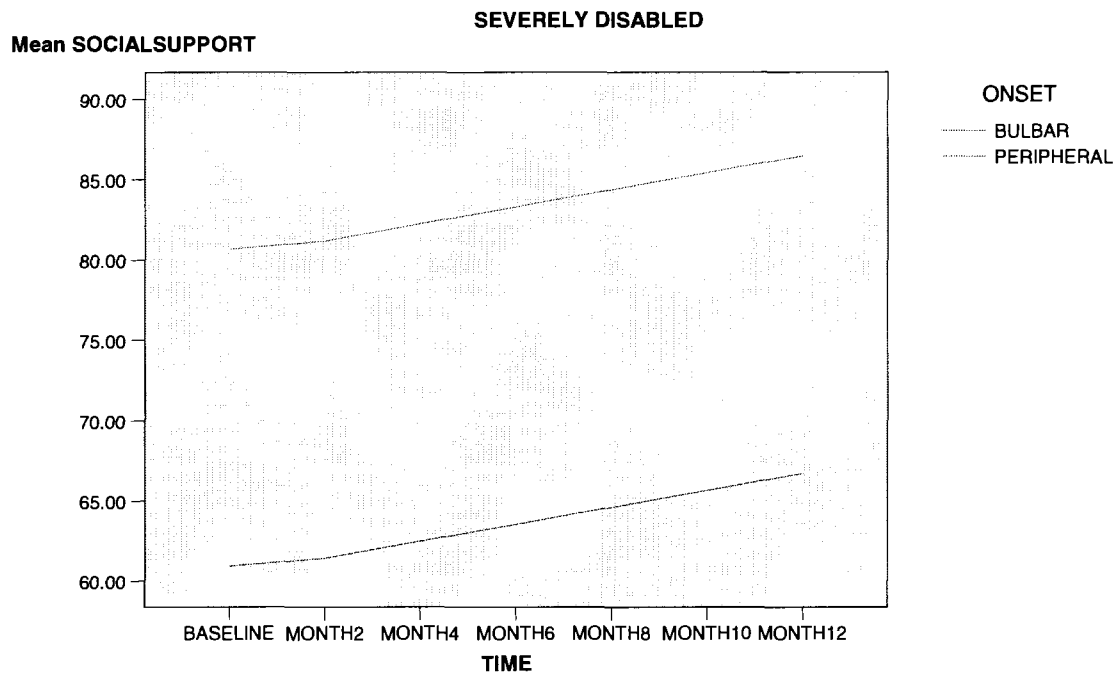


Figure 6

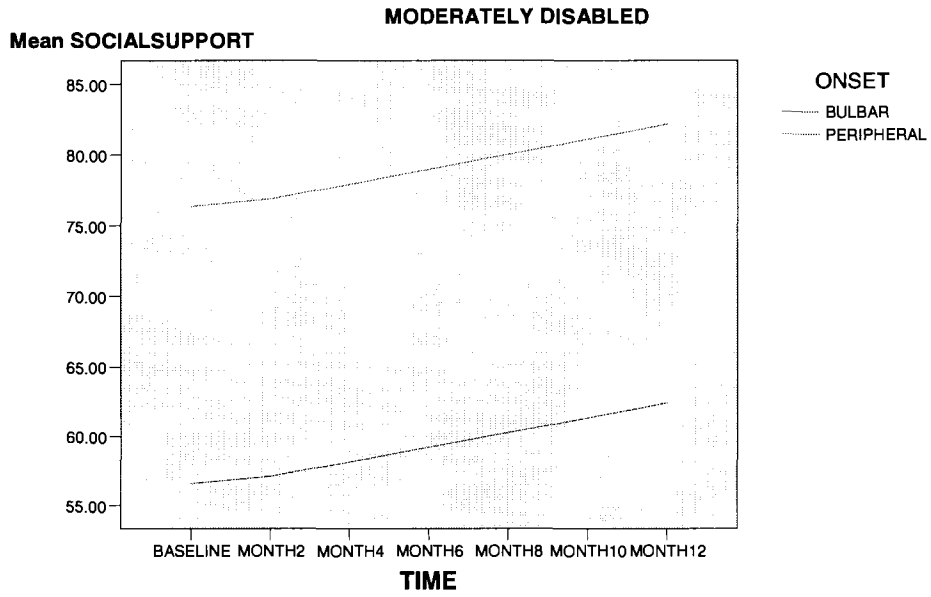
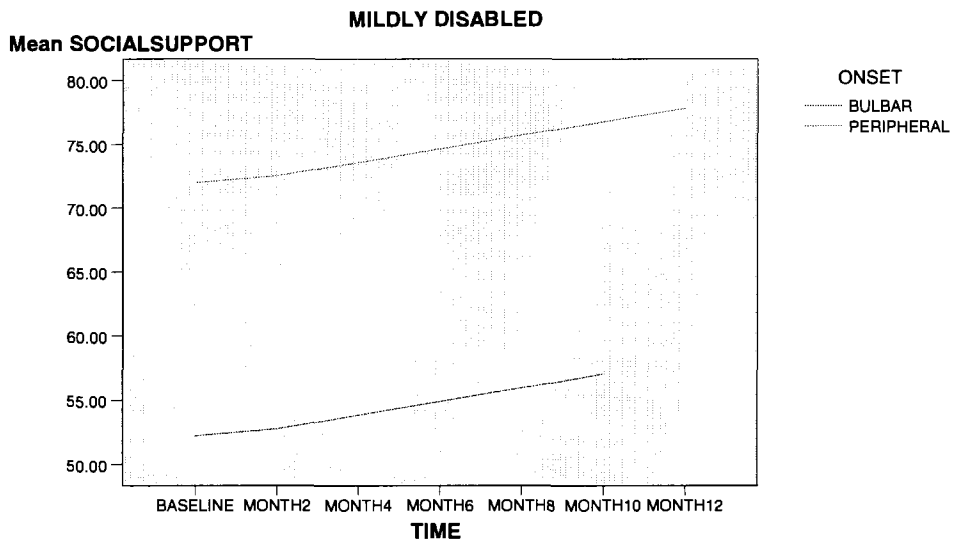


Figure 7



The subscale of emotional support for those caring for patients with bulbar onset was estimated to be 10 points lower on the social support scale than for those caregivers caring for patients with limb onset,  $F(1, 10) = 10.17$ ,  $PR > F = 0.010$  (See Tables 5 and 6). Indicating those caregivers caring for patients with bulbar onset reported less perceived emotional support than did those caring for patients with limb onset. Emotional support was approaching significance on time,  $F(1, 47) = 3.32$ ,  $PR > 0.075$  but was not significant on disease severity . Covariance Structure with Variance Components revealed best model (Fit Statistics:  $-2LL = 479.7$  and  $AIC = 489.7$ ), and used 61 (each subjects score at each time point) time points for the 12 caregivers during the study period with 23 missing information points.

Table 5

*Type 3 Tests of Fixed Effects for Emotional Support (subscale)*

Effect	Num DF	Den DF	F Value	Pr > F
Onset	1	10	10.17	0.0097
Disease Severity	1	47	1.85	0.1805
Time	1	47	3.32	0.0748

Table 6

*Solution for Fixed Effects for Emotional Support (subscale)*

Effect	Onset	Estimate	Standard Error	DF	t Value	Pr >  t
Intercept		24.5597	9.9303	10	2.47	0.0329
Onset (bulbar)	1	-10.5019	3.2928	10	-3.19	0.0097
Onset (limb)	2	0	.	.	.	.
Disease Severity		0.3182	0.2340	47	1.36	0.1805
Time		0.9846	0.5404	47	1.82	0.0748

The subscale of informational support was not significant for onset, disease severity or time (see Tables 7 and 8).

Table 7

*Type 3 Tests of Fixed Effects for Informational Support (subscale)*

Effect	Num DF	Den DF	F Value	Pr > F
Onset	1	10	3.29	0.0999
Disease Severity	1	46	2.35	0.1318
Time	1	46	0.14	0.7061

Table 8

*Solution for Fixed Effects for Informational Support (subscale)*

Effect	Onset	Estimate	Standard Error	DF	T Value	Pr >  t
Intercept		33.4103	9.2497	10	3.61	0.0048
Onset (bulbar)	1	-5.6666	3.1254	10	-1.81	0.0999
Onset (limb)	2	0	.	.	.	.
Disease Severity		-0.3344	0.2180	46	-1.53	0.1318
Time		-0.1952	0.5144	46	-0.38	0.7061

*Hypothesis Three: Self-Efficacy*

A multiple regression model for each of the different types of self-efficacy were constructed based on the second hypothesis which stated, “Caregiver Self-Efficacy and General Self-Efficacy will increase over the course of the mentor program as the person with ALS becomes more disabled and will differ depending on disease onset.” For the first regression model General Self-Efficacy was entered as the dependent variable and onset, disease severity and time were entered as the independent variables. For the

second regression model Caregiver Self-Efficacy was entered as the dependent variable and onset, disease severity and time were entered as the independent variables.

General Self-Efficacy for the caregivers caring for patients with bulbar onset was estimated to be significantly lower on this scale than for those caring for patients with limb onset,  $F(1, 10) = 14.66$ ,  $PR > F = 0.003$  (See Tables 9 and 10). Indicating caregivers caring for patients with bulbar onset reported a lower level of General Self-Efficacy than did those caring for patients with limb onset. General Self-Efficacy was estimated to increase by 0.3 points on this scale for disease severity at levels of 20, 30 and 40,  $F(1, 47) = 28.17$ ,  $PR > F < 0.001$  (See Tables 9 and 10). Indicating levels of General Self-Efficacy were highest when patients were the least disabled. General Self-Efficacy increased by 0.4 points on this scale at each time point including baseline, month 2, 4, 6, 8, 10 and 12,  $F(1, 47) = 5.64$ ,  $PR > F = 0.022$  (see Tables 9 and 10). Indicating General Self-Efficacy levels increased over the course of the program. Covariance Structure with Variance Components revealed best model (Fit Statistics: -2LL = 322.1 and AIC = 333.1) and used 61 time points (each subjects score at each time point) for the 12 caregivers during the study period with 23 missing information points.

Table 9

*Type 3 Tests of Fixed Effects for General Self-Efficacy*

Effect	Num DF	Den DF	F Value	PR > F
Onset	1	10	14.66	0.0033
Disease Severity	1	47	28.17	<.0001
Time	1	47	5.64	0.0216



Table 10

*Solutions for Fixed Effects for General Self-Efficacy*

Effect	Onset	Estimate	Standard error	DF	t Value	PR >  T
Intercept		23.7270	2.7282	10	8.70	<.0001
Onset (bulbar)	1	-3.4643	0.9046	10	-3.83	0.0033
Onset (limb)	2	0	.	.	.	.
Disease Severity		0.3413	0.06430	47	5.31	<.0001
Time		0.3528	0.1485	47	2.38	0.0216

Figures 8, 9 and 10 plot General Self-Efficacy over time at each level of disease severity (including severely disabled, moderately disabled and mildly disabled) for caregivers caring for patients with bulbar onset and limb onset.

Figure 8

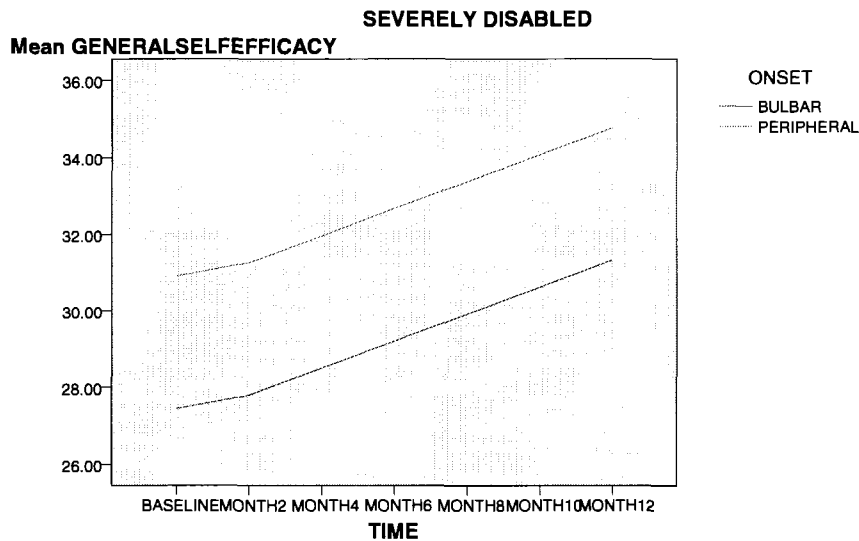


Figure 9

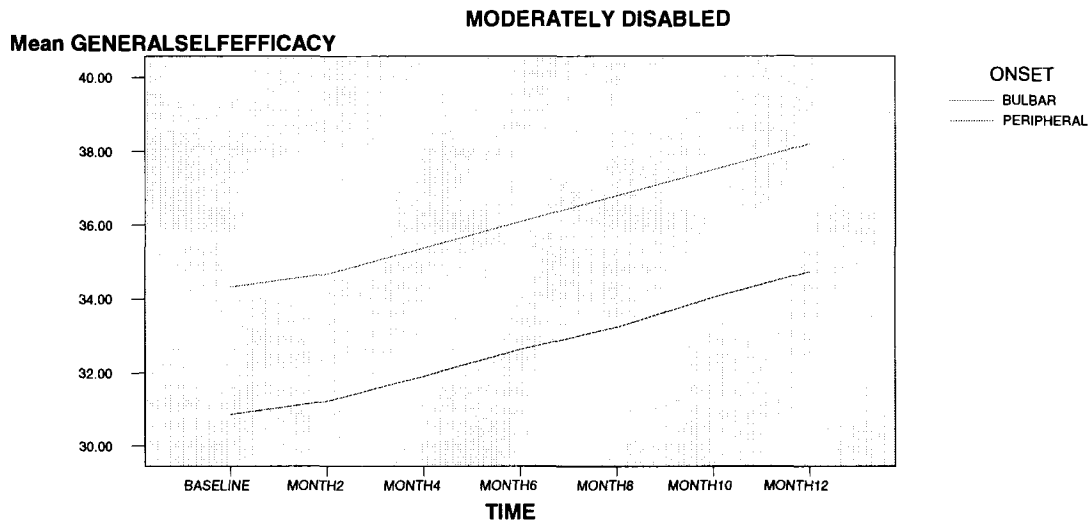
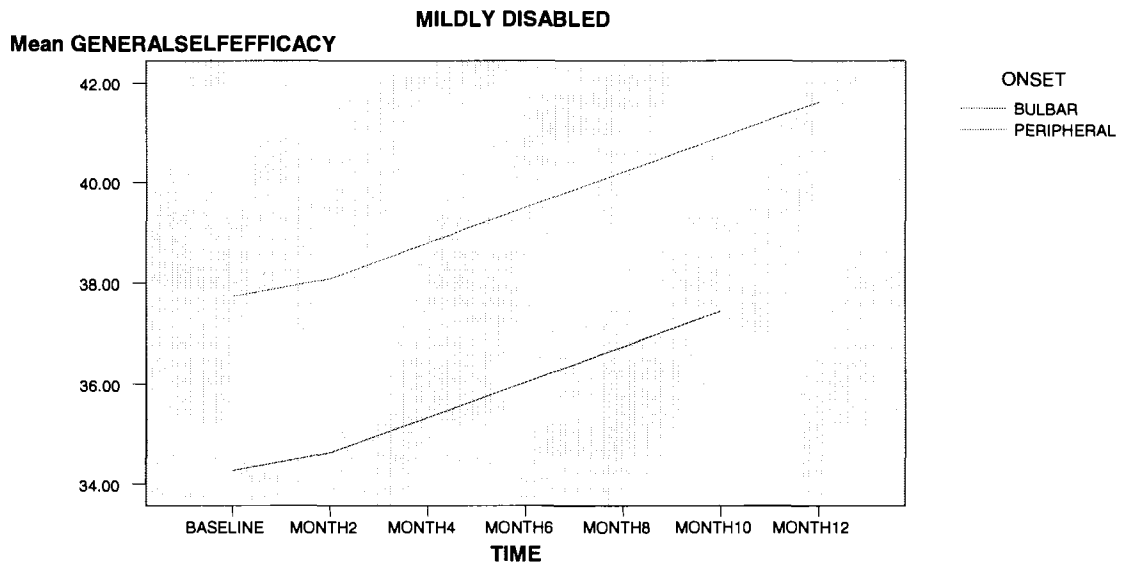


Figure 10



Caregiver self-efficacy was estimated to increase by 1.3 points on this scale for disease severity at levels 20, 30 and 40,  $F(1, 10) = 33.88$ ,  $PR > F < 0.001$  (See Tables 11 and 12). Indicating levels of caregiver self-efficacy were highest when patients were the

healthiest. Caregiver self-efficacy did not increase over the course of the mentor program or between the two groups of caregivers. Covariance Structure with Variance Components revealed best model (Fit Statistics: -2LL = 473.9 and AIC = 483.9) and used 61 (each subjects score at each time point) time points for the 12 caregivers during the study period with 23 missing information points.

Table 11

*Type 3 Tests of Fixed Effects for Caregiver Self-Efficacy*

Effect	Num DF	Den DF	F Value	Pr > f
Onset	1	10	2.02	0.1853
Disease Severity	1	47	33.88	<.0001
Time	1	47	1.62	0.2089

Table 12

*Solution for Fixed Effects for Caregiver Self-Efficacy*

Effect	Onset	Estimate	Standard error	DF	t Value	Pr >  t
Intercept		34.0317	9.4676	10	3.59	0.0049
Onset (bulbar)	1	-4.4659	3.1393	10	-1.42	0.1853
Onset (limb)	2	0	.	.	.	.
Disease Severity		1.2987	0.2231	47	5.82	<.0001
Time		0.6565	0.5153	47	1.27	0.2089

Figures 11, 12 and 13 plot Caregiver Self-Efficacy over time at each level of disease severity (including severely disabled, moderately disabled and mildly disabled) for caregivers caring for patients with bulbar onset and limb onset.

Figure 11

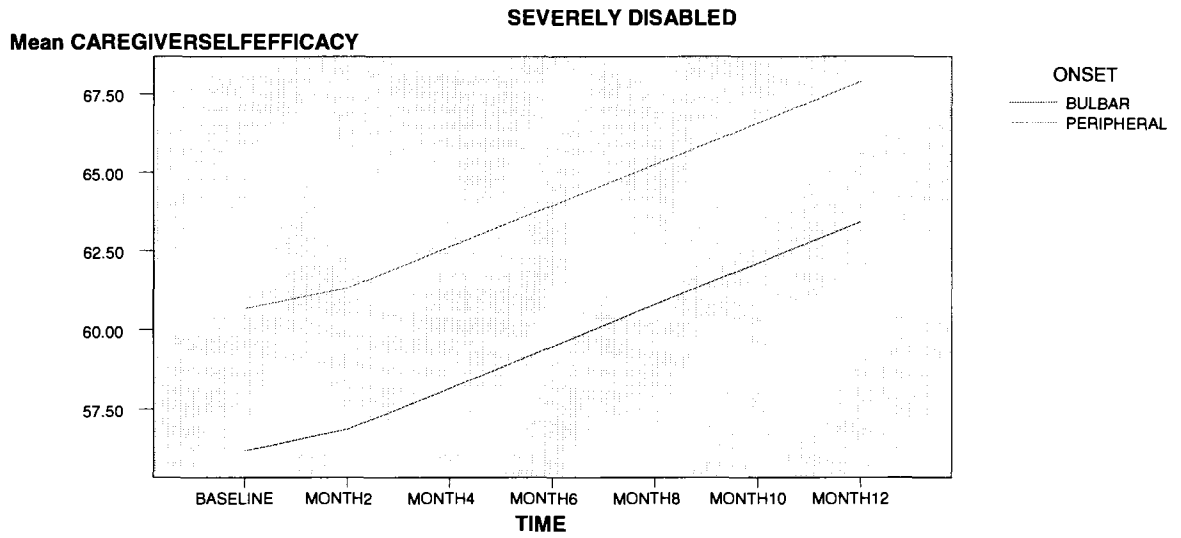


Figure 12

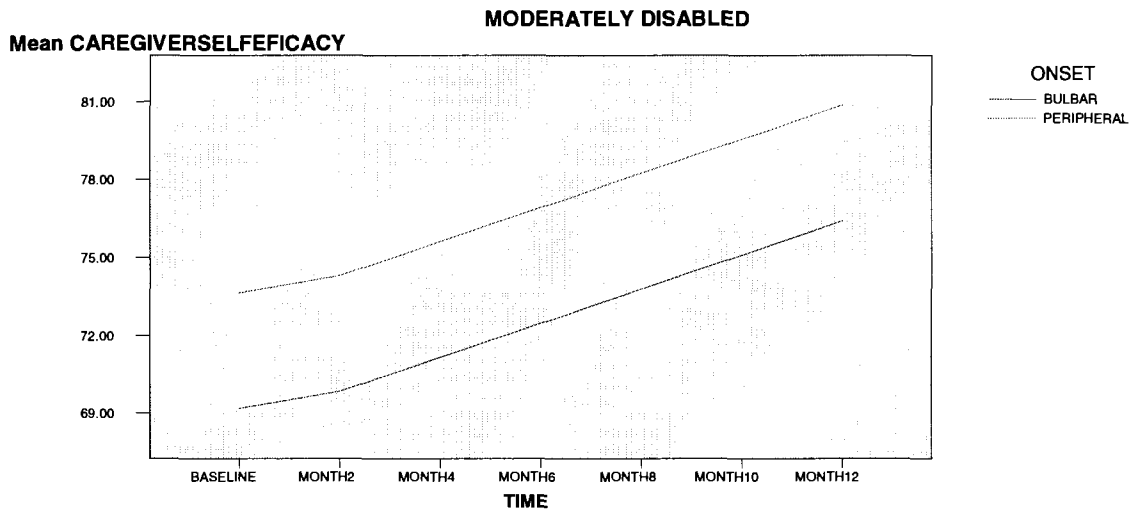
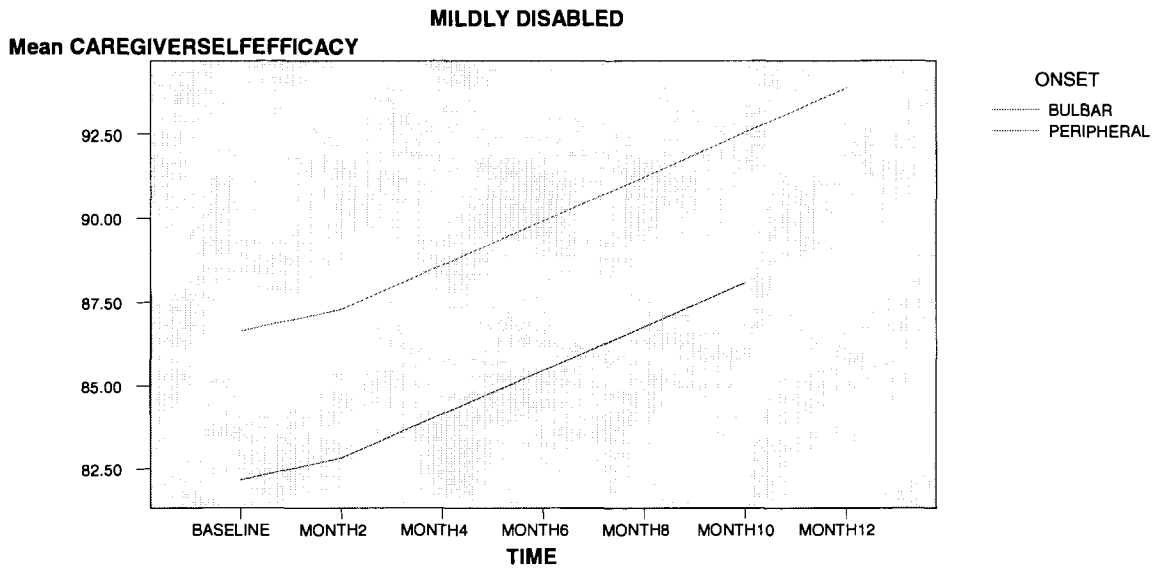


Figure 13



### Mentor and Caregiver Feedback

#### *Mentors Reports*

Tracking sheets were used by the mentors to record the topics discussed, duration and informal reports of how much time was spent providing emotional and informational support after each telephone contact. The length of conversations varied from time to time within each dyad and between dyads, lasting anywhere from 5 to 10 minutes to a maximum of 90 minutes. More regular contacts (once a week) seemed to be shorter than those occurring once a month. The topics of discussion varied considerably and included several key issues including: respiratory equipment, feeding tubes, home modifications, wheelchair accessible transportation, community resources, power of attorney, living wills, disease progression, ALS Society services and the patient's status. The caregivers also shared many intimate feelings with their mentors including disbelief, frustration,

sadness, fear, anxiety and loss of control. Interestingly, many of these emotions were expressed in discussions relating to how the caregiver thought he/she would cope in the future when the patient had died, rather than how he/she was coping with the current demands of caregiving. The majority of caregivers used their telephone contacts to compare and contrast their situation with those experienced by the mentor, which we learned later (during exit interviews) was both validating and comforting for the caregivers. Surprisingly, the majority of the conversations focused on normal, everyday occurrences including the details about parties that were attended, upcoming weddings and holidays, updates about family members and close friends, fundraising efforts, participation in social events such as church activities and bridge games and updates relating to visits by community health care professionals and to the ALS Clinic; suggesting a main function being filled by the telephone contacts was the need for emotional support and social contact. Finally, according to the mentors' informal reports, the type of support provided (emotional or informational) varied considerably from time to time within each dyad, but emotional support tended to be provided slightly more frequently than informational support over time and between dyads.

#### *Caregiver and Mentor Exit Interviews*

Although several questions were asked during the exit interviews the responses did not provide enough detailed information to conduct a full qualitative analysis. However, the responses did indicate that both the caregivers and mentors were satisfied with the program and thought the program was beneficial. Some examples of caregivers' statements follow:

- *“I think just being able to talk to someone who has gone through the same experience was beneficial. Just knowing, hearing how she handled different situations and just someone to talk to basically.”*
- *“The program was totally awesome because it not only gave me the support as I needed as far as getting things done or finding someone to ask questions of, but it gave me the support as a caregiver from someone who had actually through the process and to me that was very important.”*
- *“It made me feel a little less scared knowing exactly what to expect and my mentor was really good at doing that.....so I knew what was coming and it was a little less intimidating when it actually happened.....so you were already expecting it and you knew what to do.”*
- *“Being able to talk to someone and ask questions that you weren’t sure of what the next step was or what was going to happen next and he shared how he handled it. It was very good that way.”*

The mentors’ responses follow:

- *“I don’t remember any hard parts. I guess the hardest part was when the patient died. And when anything was difficult for her and I couldn’t do anything about....otherwise I thought it was totally rewarding.”*
- *“When I felt he was accepting my advice and doing something with it that made me feel good because I believed that I was helping.....a good feeling indeed that I was actually helping somebody to overcome some of the difficulties I had difficulty with when I was a caregiver.”*

- *“The best part was finally getting to use some of the information that I had accumulated with some pretty tough slugging.....I know I was able to pass it on to somebody so they don't have to go through what I went through. That was the best thing.”*



## Discussion

This is the first time a dyad support intervention has been tested in a population of caregivers caring for ALS patients. Although the purpose of this study was to assess the effect of the intervention on caregiver self-efficacy, it demonstrated the feasibility of providing support (using trained peers) to ALS caregivers devastated by the news that the family member has ALS. As a first and most important observation, the program was extremely well received by caregivers and mentors alike, although it is quite likely that the sources of satisfaction differed. Moreover, this study produced essential information necessary to standardize the delivery of this type of supportive care in the future. With the exception of social support groups the mentor program provides one of the only social support programs available to ALS caregivers. Based on feedback from exit interviews ALS caregivers by their own volition chose not to attend support groups because they are either not specific to ALS, not exclusive to ALS caregivers (and tend to include patients) and/or simply too difficult to attend (due to timing or lack of care for patient). Furthermore, the choice of caregivers and mentors to continue to connect after the research portion of the program ceased, coupled with the anecdotal evidence reported in the mentor tracking sheets and exit interviews illustrates not only the caregivers' appreciation and willingness to participate in this type of social support program, but the mentors' appreciation and willingness to share intimate details of their experiences with someone who initially was a stranger.

Given the extremely small sample size the following results need to be interpreted with care so not to assume causation. Future studies would need to be conducted with a larger sample in an effort to replicate these findings.

### *Social Support*

Even though social support did not increase over the course of the mentor program or as the disease progressed, higher levels of social support (specifically emotional support) were found among caregivers caring for patients with limb onset compared to caregivers caring for patients with bulbar onset. These caregivers also reported higher levels of general self-efficacy and satisfaction with the program. This suggests it is not the ongoing delivery of support as the disease progresses that is important but rather the perception that support is available during specific stages of the disease that is crucial. Patients with limb onset become physically disabled sooner than those patients with bulbar onset, requiring more physical care and equipment, such as walkers, wheelchairs, hospital beds, toilet seats and bath rails. Consequently, caregivers of patients with limb onset require more knowledge of community resources, equipment, home modifications and funding sources. Moreover, these caregivers require more emotional support as the disease begins to disrupt daily life, relationships, employment and finances and forces people to face the losses of hopes and dreams associated with this devastating disease. More importantly, as we had predicted, those caregivers higher in perceived social support were also those higher in self-efficacy suggesting the support provided enhanced the caregiver's sense of mastery and control in light of all the changes. Thus, it makes sense that caregivers who were more satisfied with the program were those reporting higher levels of perceived support (specifically emotional support)

provided by the mentors. Finally, these findings provide important information about the type of support to provide and when and to whom to offer the program, which will ensure the most cost-effective practices are used in future implementations of the mentor intervention. Based on the findings in this study, emotional support was a major component of the dyadic intervention and it would make sense to modify the current mentor program so as to focus on the provision of emotional support and select mentors who are comfortable providing this type of support.

### *Self- efficacy*

Both a Caregiver Self-Efficacy scale and a General Self-Efficacy scale were used in this study. Both scales indicated self-efficacy was lowest when the patient's disease was most severe, which is not what we had predicted. However, given the magnitude of care required to meet the physical and emotional needs of an ALS patient in the end stages of this disease it makes sense caregivers felt less efficacious as the disease worsened. Compared to caregivers caring for patients with bulbar onset, caregivers caring for patients with limb onset reported higher levels of General Self-Efficacy. Since these caregivers were the ones providing the majority of physical care (as stated earlier in this discussion) it would make sense that these caregivers by virtue of actively caregiving were improving their sense of self-efficacy and therefore reporting higher levels of self-efficacy than those caring for patients with bulbar onset. Interestingly, of the two self-efficacy measures, only General Self-Efficacy increased over time as predicted. The discrepancy in findings between these two scales suggests the self-efficacy scale specific to caregivers is not generalizable to all populations of caregivers and that the conditions and challenges faced by caregivers coping with different diseases.

Literature on self-efficacy (Fortinsky et al., 2002) indicates the best measure of self-efficacy is one that is specific to the task under examination. In other words, when measuring self-efficacy in for example, motherhood, cooking, gardening or in this case, caregiving, a self-efficacy measure with the specific task in mind should be used. The caregiver self-efficacy scale used in this study was originally designed for caregivers of patients with Alzheimer's disease, which requires a different kind of caregiving than occurs with ALS. According to Gauthier (2007) caring for ALS patients is unique and unlike another other caregiving experience. In those studies on dyadic interventions discussed earlier (Partin & Fortin, 2000; Weber et al., 2004) the self-efficacy scales used were specific to the disease in question and statements explored how the patient felt he/she would master the disease rather than their new role as a patient. The current results help provide support for an important point deserving of attention for future program design and implementation. Firstly, one should not assume that all caregiving requires the same types of tasks or requires the same level of knowledge. For example, those caring for patients with Alzheimer's disease might need to negotiate communication with someone losing their memory, while those caring for ALS patients need to learn to feed and toilet. Moreover, compared to a rare disease like ALS, information on Alzheimer's disease is more readily available and more people are aware of its existence; as such Alzheimer's caregivers might not need to learn as much about the disease. Secondly, self-efficacy scales designed with caregiving in mind should assess how the person feels he/she will master the disease rather than the role of caregiving. In other words, scales should not assess how well a person has adapted to the role of caregiving but rather how well he or she has been able to complete the tasks required to

care for a person with a specific disease. In the example of Alzheimer's disease, a scale might ask questions related to how well a caregiver felt he/she was able to negotiate communication with someone losing their memory rather than, how well he/she was able to find time to rest. Researchers assessing caregiver self-efficacy should be cautioned when selecting a self-efficacy scale designed specifically for caregivers.

#### *Limitations and Future Direction*

The data set was extremely small and more research is needed to explore the difference between the caregivers of bulbar and limb onset patients in relation to perceived social support and self-efficacy to better understand the underlying mechanisms of the mentor intervention. The differences between these caregivers can be understood as per our explanation above regarding the type of onset and level of disability. Alternatively, these differences could be understood on the basis of differences in levels of baseline social support and self-efficacy. Although those caregivers caring for patients with limb onset provided more care and are required to process large amounts of new information, they were also the caregivers who had a higher level of support and self-efficacy at baseline. The level of support and self-efficacy at baseline could have altered perceptions of support and self-efficacy increasing over the course of the program. In order to determine these effects future studies need to assess caregivers both high and low on support and self-efficacy caring for patients with limb onset as well as those high and low on support and self-efficacy caring for patients with bulbar onset.

Given the non-significant findings for changes in social support and satisfaction over the course of the program, it is recommended alternative measures be used in future

assessments of this intervention. The social support scale employed in this study asked caregivers to indicate the amount of support they were receiving in general and then asked them to name those people providing the support. Alternatively, a social support measure specifically asking caregivers about the type and amount of support being provided by their mentor could be more useful. In addition, a scale (or several scales) might be required to dissect structural aspects of social supports (such as marital status, community resources, finances, extended family) from the functional aspects of social support provided by the mentor. Similarly, a satisfaction scale asking more detailed questions about the level of satisfaction within each area of the mentor program would be more helpful than a single question about the overall level of satisfaction with the program.

Given the lack of significant findings in relation to caregiver self-efficacy we suggest using an alternative caregiver scale designed for caregivers other than Alzheimer's caregivers, in addition to incorporating more implicit training into the mentor program. According to the research on self-efficacy, self-efficacy can be enhanced in several different ways including vicarious learning, verbal persuasion, physiological and emotional states of arousal and performance experience (Maddux, 2002). Vicarious learning occurs as a function of observing, retaining and replicating behavior observed in others and as such, beliefs are influenced by observing other's behaviours and consequences of those behaviours. According to Parent and Fortin (2000), observing another individual mastering a situation can act as a source of efficacy information and raise one's expectations of mastering a similar situation. However, the success of learning through observation is dependent on the extent to which we are

similar to the person we are using as a comparison and how successfully we perceive the individual to have mastered the situation in question. Although the mentor program attempted to match mentors to caregivers based on similar demographics some of these factors might have been more poignant than others. Furthermore, it might have been beneficial to simply ask the caregivers to rate how similar they felt to their mentor and how successful they believed their mentors had been at caregiving. Verbal persuasion involves the formation of beliefs about one's abilities based on what others say to us about what we are capable of doing and is influenced by the "expertness" of the person giving the feedback. The mentors were encouraged to listen to the mentees and provide support but were not instructed to provide ongoing positive feedback to the caregivers about their abilities as a caregiver. The dyadic intervention was to enhance caregiver self-efficacy and as Parent and Fortin (2000) demonstrated through their intervention decrease anxiety, by matching new caregivers with experienced mentors. However, the impact of the ALS diagnosis may have been too great, overshadowing any of the positive impact of the mentorship, making it difficult to know the extent to which the program was working. Finally, the most powerful means to enhancing self-efficacy is through the ability to control one's environment and attribute these successes to one's own actions. In other words, people have to actually see themselves coping effectively to heighten their sense of mastery. Given the debilitating nature of ALS, the constant and ongoing adjustments required and the magnitude of care that is needed it is not surprising that caregivers might find it impossible to gain a sense of mastery and control over their environment. However, future studies might consider encouraging the caregiver to set

goals at the onset of the mentorship and track these as a means by which to monitor self-efficacy more directly.

Finally, given some of the promising results in this study, especially the difference in perceived social support between the 2 types of onset and the increase in general self efficacy over the course of the program, efforts need to be made to generate a larger sample in future assessments of this program in hopes of further understanding the impact of the mentor program on caregiver self-efficacy. Efforts to generate a larger sample could be accomplished by inviting other ALS clinics to participate in the study and /or by opening recruitment to all caregivers regardless of when the patient in question was diagnosed. This would also explore in greater detail the effect of the intervention on those caring for ALS patients through different stages of the disease.

### *Conclusion*

Many ALS caregivers are emotionally devastated when their family member is diagnosed with ALS and over time caregivers become physically exhausted attempting to keep up with the around-the-clock care a person with ALS requires. Although there is a great deal of evidence indicating social support programs help to improve physical and mental health and research supporting the theory that self-efficacy plays a crucial role in promoting psychological as well as physical health, this pilot project is one of the few attempts to assess whether a social support program based on supportive peer dyads could improve caregiver self-efficacy. Promising results in combination with positive feedback from both the caregiver and mentor interviews suggests this program provides crucial support to ALS caregivers and evidently, deserves further study. Furthermore, given the lack of social support resources available to ALS caregivers, it would be in the



best interest of these caregivers to enhance, modify and continue to assess the peer program in hopes of making it more effective and readily available to them.

Although we did not directly measure the impact of this program on the mentors, it is recommended future research on this program assess the mentors continued willingness to mentor and to attend monthly supervision meetings. The mentors not only continued to support their caregivers through bereavement, the majority of mentors have also agreed to be matched (to a new caregiver) for a second, and in some cases a third time. As such, future assessments need to explore the possible ways in which the mentors are benefiting from this program. In addition, it would be of great interest to further understand how these mentors cope with revisiting their personal experiences with ALS and whether sharing their stories aids or hinders their own grieving process. Furthermore, based on continued attendance at the monthly mentor supervision meetings it would be worth exploring these meetings to determine if they function, in part, as a “pseudo” support group for the mentors and aid in their grieving process.

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Appendix A

VOLUNTEER APPLICATION FORM

Name: \_\_\_\_\_

Address: \_\_\_\_\_ Apartment Number: \_\_\_\_\_

City/Town: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Phone Numbers Day: \_\_\_\_\_ Evening: \_\_\_\_\_

Other: ( \_\_\_\_\_ ) \_\_\_\_\_ Best time of day to call: \_\_\_\_\_

Email address: \_\_\_\_\_

Emergency contact: \_\_\_\_\_ ( \_\_\_\_\_ ) \_\_\_\_\_

Why do you wish to volunteer for the ALS Society of Ontario?

\_\_\_\_\_  
 \_\_\_\_\_

What skills or experiences do you feel you have to contribute or would like to use while volunteering for the ALS Society of Ontario?

\_\_\_\_\_  
 \_\_\_\_\_

Computer skills (please check all those with which you are proficient):

Microsoft Access      Microsoft Word      Microsoft Publisher  
 Microsoft Excel      Microsoft PowerPoint      Raiser's Edge

Which of the volunteer activities would you like to assist with: (Please check all boxes of interest):

Administration and Governance	Support Services	Public Awareness and Education	Fundraising
<input type="checkbox"/> Board Member	<input type="checkbox"/> Chair-Community Support Service	<input type="checkbox"/> Chair-Community Communications	<input type="checkbox"/> Chair-Community Fund Development
<input type="checkbox"/> Regional Representative	<input type="checkbox"/> Support Group Facilitator	<input type="checkbox"/> Media Relations Coordinator	<input type="checkbox"/> Walk for ALS-Committee Member
<input type="checkbox"/> Office Assistant	<input type="checkbox"/> Support Group Assistant	<input type="checkbox"/> Advocacy Coordinator	<input type="checkbox"/> Walk for ALS –Event Day Volunteer
<b>Community</b>	<input type="checkbox"/> Caregiver Group Leader		<input type="checkbox"/> Cornflower Sales-Coordinator
<input type="checkbox"/> President	<input type="checkbox"/> Community Equipment Volunteer		<input type="checkbox"/> Cornflower Sales – Event Volunteer
<input type="checkbox"/> Treasurer	<input type="checkbox"/> Education Volunteer		<input type="checkbox"/> Membership Coordinator

Other (Please Specify): \_\_\_\_\_

When are you available to volunteer?



	<u>Monday</u>	<u>Tuesday</u>	<u>Wednesday</u>	<u>Thursday</u>	<u>Friday</u>	<u>Weekends</u>
Morning						
Afternoon						
Evening						

I am only interested in volunteering on a per event basis.

How did you hear about the ALS Society of Ontario?

- ALS Society of Ontario website
- Charity Village website
- Volunteer Centre
- Newspaper ad (please specify which one): \_\_\_\_\_
- From someone living with ALS or their family/ friends
- From an ALS Society of Ontario Volunteer
- Ontario Works (Social Services)
- Other please specify: \_\_\_\_\_

As a volunteer you will be placed in a position of trust. Please provide contact information of at least two individuals who may be contacted for a reference. Please do not provide more than one family member as a reference.

\_\_\_\_\_  
 Name Relationship Phone Number

\_\_\_\_\_  
 Name Relationship Phone Number

\_\_\_\_\_  
 Name Relationship Phone Number

*Please do not hesitate to add any additional information, such as a resume or more detailed description of previous volunteer work, which would help with the processing of this application form.*

***To the best of my knowledge all information provided on this form is correct and I give permission to the ALS Society of Ontario to contact my references.***

Signature of volunteer applicant: \_\_\_\_\_

Date: \_\_\_\_\_

***Thank you for getting involved!!***

**For internal use only:**

Start Date: \_\_\_\_\_ End Date: \_\_\_\_\_

References checked by: \_\_\_\_\_ Date: \_\_\_\_\_

Date Police Check Sent: \_\_\_\_\_ Reviewed and Clear: \_\_\_ YES \_\_\_ NO

Reviewed By: \_\_\_\_\_

Driver's Abstract Reviewed and Cleared: \_\_\_ YES \_\_\_ NO Next review date: \_\_\_\_\_

Volunteer Program Referred to: \_\_\_\_\_

SCREENING INTERVIEW

**MENTOR PROGRAM – SCREENING FORM**

This form is to be completed by the interviewer at the orientation/screening session for volunteers interested in becoming a Mentor and is meant for internal use only. Please refer to program information for role definition and requirements.

Name of Mentor: \_\_\_\_\_

Referred by: \_\_\_\_\_

Mentor had been a primary caregiver for someone with ALS?

Yes             No

For how long?

Less than 1 year             1-2 years             2-3 years             3 yrs or more

How long since the client with ALS passed away?

Less than 1 year             1-2 years             2-3 years             3 yrs or more

**Screening Questions**

*Notes for interviewer is mentioned in italics after the question*

1. What was the most difficult part of adjusting to your role as a caregiver? *(effect on work, personal, social network)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. Were there any positive experiences as a caregiver? *(discover hidden strengths, emerged a stronger person etc)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. Did you find adequate support within family, friends and colleagues at work? *(look out for signs of negative experiences and unresolved issues)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. Did you find adequate support from your community health care system? *(look out for signs of negative experiences and unresolved issues)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

5. Did you find adequate support from your physician, neurologist, ALS clinic and/or ALS Society? *(look out for signs of negative experiences and unresolved issues)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

6. Did you find any support during/after your bereavement that proved helpful? (*look for social support, signs of moving along, coping with loss, developing new interests etc*)

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7. What support do you think you can provide caregivers of newly diagnosed clients as a Mentor? (*look for signs of wanting to take control, providing hands-on caregiving or advice, building friendships etc*)

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8. What do you think you will gain by becoming a Mentor? (*look for signs of using this role as a way of re-living their journey*)

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9. Describe briefly how you work:

a. Independently, with minimal supervision

---

---

b. Within a team, as a team member (i.e. with staff, other volunteers, on committees)

---

---

10. Describe briefly and specifically, how you handle situations where your views and opinions differ from:

a. Those in authority

---

---

b. Those with cultural, religious and education background that differ from you

---

---

c. Those with value systems that differ from yours

---

---

11. What do you feel are your greatest:

a. Strengths

---

---

b. Weaknesses

---

---

12. Briefly describe your own personal support system

---

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**Summary notes:**

1. In your opinion is this volunteer ready to take on the role of a mentor at present?

---

---

2. Is the volunteer aware of the roles, responsibilities and requirements associated with this position?

---

---

3. Is the volunteer ready and available to attend the next training session? If not, mention whether this volunteer should be considered for training at a later date.

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Please note:

1. Potential mentors need to commit to completing the initial training as well as being available for future training sessions as needed (subject to personal/work commitments).
2. Completion of the training program does not guarantee acceptance as a Mentor in this program. There will be an evaluation after the training, which will also allow them to decide whether this role is suitable for them.

## Appendix C

### CONSENT TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

**Study Title:** Implementation and Evaluation of a Social Support Program for ALS Caregivers Using Peer Mentors

**Principal Investigator:**

Scott Maitland 519 824 4120 extension 56156

**Family Dynamics and Human Relations Master's Candidate:**

Ishtar Gabriel 905 521 2100 extension 76870

**McMaster University Medical Centre Contact Person:**

Dr. John Turnbull 905 521 2100 extension 76365

You are invited to participate in a research study conducted by Ishtar Gabriel, from the ALS Clinic at McMaster University Medical Centre and from the Family Relations and Human Development Program at the University of Guelph. The results of this study will be used to evaluate a new social support program for ALS caregivers that will be offered to future caregivers through the ALS Clinic and the ALS Society and to complete the requirements of Ishtar Gabriel's Master's thesis at the University of Guelph.

**Purpose of the Study**

The purpose of this study is to implement and evaluate a social support program designed by the ALS Clinic at McMaster University Medical Centre and The ALS Society of Ontario to meet some of your needs as an ALS caregiver by providing informational and emotional support. You will be matched with an experienced and trained mentor (former caregiver). The mentor will help you navigate through information about the disease and prognosis, identify tools and resources, prepare for future stages and most importantly, help you establish your own support network outside the mentor program.

**Expected Duration and Number of Participating Subjects**

Your participation in the study will last approximately 12 months and will include 2 phases. The first phase (your phase) will include 12 new caregivers caring for someone newly diagnosed with ALS (not more than 12 months since diagnosis) and the second phase (starting the spring of 2006) will include 12 caregivers caring for someone with ALS (more than 12 months since diagnosis). As such, a total of 24 caregivers and 24 mentors will be recruited.

**Study Procedure**

In this study, you will complete 5 questionnaires at the initial visit and the same 5 questionnaires every 2 months (month 2, 4, 6, 8, 10, 12) for 12 months. The questionnaires include questions relating to 1) demographics, 2) patient progression, 3) social supports, 4) feelings about being a caregiver, 5) feedback about the program. The mentors will complete a tracking sheet after every phone contact with the caregiver

outlining the main issues and topics discussed and the amount of time spent providing emotional and informational support. At the end of 12 months you and each of the mentors will be asked to complete a brief interview to review the mentor program.

### **Initial Visit**

The initial visit will be arranged at a place and time most convenient to you and will include yourself, the patient, the mentor and the supervisor. This will give everyone a chance to meet face-to-face and discuss the program and the scheduling of the phone contacts. Once the initial visit is complete you and the mentor will schedule your first phone contact. The phone contacts will proceed as indicated in the caregiver information package (see attached). You will then meet with the research assistant to complete the first questionnaires (total of 5), which will take approximately 45 minutes.

### **Months 2, 4, 6, 8, 10, 12**

The research assistant will schedule a phone interview with you every 2 months (for 12 months) to complete 3 questionnaires. The questionnaires will take approximately 30 minutes.

### **Final Contact**

You will complete the questionnaires one last time approximately 3 months after the mentor program has come to completion, which will take approximately 45 minutes. A brief interview will also be conducted at this time and will take approximately 20 minutes.

### **Risks and Discomforts**

There is no anticipated risk associated with your participation in this study beyond the usual risks of everyday life (which could include some psychological discomfort in answering personal questions and/or providing support).

### **Potential Benefits**

The information from the study will help the ALS Clinic and the ALS Society develop a useful social support program for ALS caregivers.

### **Compensation for Study Participants**

You will not receive compensation for participating in this study.

### **Voluntary Participation/Right to Withdraw from the Study**

Your participation in this study is voluntary. If you volunteer to be in this study, you may withdraw at any time without consequence to you. Ishtar Gabriel's master's thesis will not be affected by your withdrawal from the study. You may exercise the option of removing your data from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. Dr. Turnbull may withdraw you from this research if circumstances arise that warrant doing so.

### **Confidentiality and Reporting of Results**

Completed questionnaires and interviews will be kept in a locked cabinet in a locked office at McMaster University Medical Center (which only the investigator has access to) and all personal identifying information will be coded (either by numbers or initials) which will keep all information confidential. Phone contacts may be discussed during mentor supervision in which case information will be presented without the use of personal identifying information. You will be given the opportunity to review the results once the study is complete.

### **Rights of research**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. The study has been reviewed and received ethics clearance through the Research Ethics Board at McMaster University Medical Centre and the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant contact:

Research Ethics Officer University of Guelph at 519 824 4120 ext 56606

Hamilton Health Sciences Patient Relations Specialist at 905-521-2100 Ext. 75240.

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### **Consent Statement**

I, \_\_\_\_\_ (print name) have read and understand all the preceding information describing this study and all my questions have been answered to my satisfaction. I have had time to consider entering into the study. I voluntarily consent to participate in this study.

\_\_\_\_\_  
Participant's Name (print)

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

I have explained the purpose of this study to the participant. To the best of my knowledge, she/he understands the purpose, procedures, risks and benefits of the study.

\_\_\_\_\_  
Person Obtaining Consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Appendix D

MENTOR TRACKING SHEETS

Date of Contact: \_\_\_\_\_, 2005. Type of contact: Phone € Visit €

**BEFORE calling the caregiver review your notes from last phone contact (especially step 7 where you have listed important issues and concerns you wanted to review)**

**STEP 1:** Indicate start time: \_\_\_\_\_ am/pm

**STEP 2:** briefly remind the CG of issues, concerns, problems, feelings discussed at last contact. Inquire about resolution. Check in to see how they are currently feeling about these issues.

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**STEP 3:** (immediately after contact or during if it does not infer with your ability to listen): Highlight issues discussed:

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**STEP 4:** arrange a time for the next contact.  
The next appt is \_\_\_\_\_ at \_\_\_\_\_

**STEP 5:** Indicate end time \_\_\_\_\_ am/pm

**STEP 6:** Indicate how much time was spent:

- Providing emotional support \_\_\_\_\_%
- Providing informational support \_\_\_\_\_%

**STEP 7:** List issues, concerns, feelings you would like to discuss at next contact

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**STEP 8:** List issues, concerns, feelings you would like to discuss at next supervision

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*Remember to check in with yourself and do something self-nurturing*

## Appendix E

### EXIT INTERVIEW FOR MENTOR

1. Overall, what type of support did you provide the most to the caregiver?
2. What was the hardest part about being a mentor?
3. What was the best part about being a mentor?
4. What was something you learned about being a mentor that you were not expecting?
5. Did you find the supervision helpful? Why? Why not?
6. Did you find the manual helpful? Why? Why not?
7. What are the strengths and weaknesses of the mentor program?
8. Was the duration of the program (12 months), the length of phone contacts and the number of phone contacts appropriate?

## Appendix F

### EXIT INTERVIEW FOR CAREGIVER

1. What demands did you experience as a caregiver during the 12 months of the program and how do think these demands were met by your mentor?
2. What was most beneficial about having a mentor?
3. What was least beneficial about having a mentor?
4. What things about the mentor program do you think need to be improved and why?
5. What things about the mentor program did you like the most and why?
6. Was the timing of the mentor program appropriate (highlight the time they were matched with mentor i.e. first 12 months since diagnosis)?
7. Was the duration of the mentor program appropriate?
8. Would you recommend the mentor program to other caregivers?

## Appendix G

### ALS FUNCTIONAL RATING SCALE (ALSFRS-R)

Participant ID#: \_\_\_\_\_ Date: \_\_\_\_\_ Month: \_\_\_\_\_

#### Instructions:

For each of the following please indicate the answer that best describes (*indicate patient's name*) current level of functioning.

#### SPEECH

4. Normal speech processes
3. Detectable speech disturbance
2. Intelligible with repeating
1. Speech combined with nonvocal communication
0. Loss of useful speech

#### SALIVATION

4. Normal
3. Slight but definite excess of saliva in mouth, may have nighttime drooling
2. Moderately excessive saliva; may have minimal drooling
1. Marked excessive of saliva with some drooling
0. Marked drooling; requires constant tissue

#### SWALLOWING

4. Normal eating habits
3. Early eating problems; occasional choking
2. Dietary consistency changes
1. Needs supplemental tube feeding
0. NPO

#### HANDWRITING

4. Normal
3. Slow or sloppy; all words are legible
2. Not all words are legible
1. Able to grip pen but unable to write
0. Unable to grip pen

#### 5a CUTTING FOOD AND HANDLING UTENSILS

(Subjects **without** *gastronomy*)

4. Normal
3. Somewhat slow and clumsy; but no help needed
2. Can cut most foods, although clumsy and slow, some help needed
1. Food must be cut by someone, but can still feed slowly
0. Needs to be fed

#### 5b. CUTTING FOOD AND HANDLING UTENSILS

(Subjects **with** *gastronomy*)

4. Normal
3. Clumsy but able to perform all manipulations independently
2. Some help needed with closures and fasteners
1. Provides minimal assistance to caregiver
0. Unable to perform any aspect of task

6. DRESSING AND HYGIENE

4. Normal function
3. Independent and complete self-care with effort or decrease in efficiency
2. Intermittent assistance or substitute methods
1. Need attendant for self-care
0. Total dependence

7. TURNING IN BED/ADJUSTING COVERS

4. Normal
3. Somewhat slow and clumsy, but no help needed
2. Can turn alone or adjust sheets, but with great difficulty
1. Can initiate, but not turn or adjust sheets alone
0. Helpless

8. WALKING

4. Normal
3. Early ambulation difficulties
2. Walks with assistance (any assistive device, including AFO's)
1. Nonambulatory functional movement only
0. No purposeful leg movement

9. CLIMBING STAIRS

4. Normal
3. Slow
2. Mild unsteadiness or fatigue
1. Needs assistance (including handrail)
0. Cannot do

10. DYSPNEA

4. None
3. Occurs when walking
2. Occurs with one or more of the following, eating, bathing, dressing (ADL)
1. Occurs at rest, difficulty breathing either sitting or lying down
0. Significant difficulty, considering using mechanical respiratory support

11. OTHOPNEA

4. None
3. Some difficulty sleeping at night due to shortness of breath: does not routinely use more than 2 pillows.
2. Needs extra pillows in order to sleep (more than two)
1. Can only sleep sitting up
0. Unable to sleep

12. RESPIRATORY INSUFFICIENCY

4. None
3. Intermittent use of Bi-PAP
2. Continuous use of BiPAP during the night
1. Continuous use of BiPAP, during the night and day
0. Invasive mechanical ventilation by intubation or tracheotomy

## Appendix H

### THE INVENTORY OF SOCIALLY SUPPORTIVE BEHAVIOURS

Participant ID#: \_\_\_\_\_ Date: \_\_\_\_\_ Month: \_\_\_\_\_

**Instructions:**

For the next several items please state how often you received the various forms of assistance in the past 2 months OR since you last completed this scale (Indicate time scales were last completed).

1 = not at all (in the past 2 months), 2 = once or twice (in the past 2 months), 3 = about once a week, 4 = several times a week and 5 = about every day.

ITEM	1	2	3	4	5
1. Looked after ( <i>indicate name of patient</i> ) when you were away. T					
2. Was available when you were in a stressful situation. E					
3. Provided you with a place where you could get away for awhile. T					
4. Did a chore to help you around the house. T					
5. Told you what he/she did in a similar situation. I					
6. Did something with you to help divert your thoughts. T					
7. Discussed (with you) some interest of yours. E					
8. Let you know that you did something well. E					
9. Suggested a contact for you of someone who could help. I					
10. Told you that you were doing okay. E					
11. Someone to chat with that you know would keep conversations confidential. E					
12. Assisted you in setting a goal. I					
13. Made it clear what was expected. I					
14. Complimented/validated a competency/strength of yours. E					
15. Gave you some information on how to do something. I					
16. Suggested some action you could take. I					
17. Gave you over \$25.00. T					
18. Comforted you by showing you compassion. E					
19. Gave you some information to help you understand a situation. I					
20. Provided transportation. T					
21. Checked back with you to see if you had followed some advice. I					
22. Gave you under \$25.00. T					
23. Helped you understand why something did not go well. I					
24. Listened to you talk about your private feelings. E					
25. Loaned or gave you something that you needed. T					
26. Validated your choices/decisions. E					
27. Explained something that made your situation clear. I					

28. Told you how she/he felt in a similar situation. E					
29. Let you know he/she will be available to help you if you needed it. E					
30. Expressed interest and concern in your well-being. E					
31. Told you that he/she feels close to you. E					
32. Suggested who you could see for assistance. I					
33. Told you what to expect in the future. I					
34. Loaned you over \$25.00. T					
35. Taught you how to do something. I					
36. Gave you feedback on how you were doing. I					
37. Did or said something to help cheer you up. E					
38. Did something to help assist you with (patient's name). T					
39. Pitched in to help you do something that needed to be done. T					
40. Loaned you under \$25.00. T					

*LEGEND: T = tangible support, I = information support, E = emotional support*

Appendix I

THE CAREGIVER SELF-EFFICACY SCALE

Participant ID#: \_\_\_\_\_ Date: \_\_\_\_\_ Month: \_\_\_\_\_

Instructions:

These questions apply to the past 2 months OR since you last completed this scale (*indicate time scales were last completed*).

For the next several items please indicate whether or not the item applies to you by stating “yes” it does apply or “no” it does not apply. If you stated “yes” please state how much of the time (in percentages).

Example:

If you have had a positive phone conversation every week in the past 2 months you would state “yes, 100% of the time”

If you have had a positive phone conversation 3 times in the past 2 months you would state “yes, about 30% of the time”

ITEM	Y/N	%
<b>Self Care Items</b>		
Positive phone conversation at least once a week.		
Positive phone conversation at least 2 or 3 times a week.		
Engage in a pleasant activity with care receiver.		
Some time for your own hobbies or enjoyable activities.		
Get 7 or more hours of sleep almost every night.		
Get out of the house, without care receiver, for an hour or more at least 5 days a week.		
Get out of the house, without care receiver, for at least 6 hours once a week.		
Keep positive attitude, get some personal satisfaction for life.		
<b>Problem Solving Items</b>		
Be clear and specific in look at caregiving problems.		
List possible solutions to a caregiver problem.		
Pick most effective method of solving this problem.		
Actually carry out the plan.		



Appendix J

THE GENERAL SELF-EFFICACY SCALE

Participant ID#: \_\_\_\_\_ Date: \_\_\_\_\_ Month: \_\_\_\_\_

Instructions:

These questions apply to the past 2 months OR since you last completed this scale (*indicate time scales were last completed*).

Please indicate how true these statements are in relation to your role as an ALS caregiver. 1 is not true at all, 2 is barely true, 3 is moderately true, 4 is exactly true

ITEM	1 not true	2 barely true	3 moderately true	4 exactly true
I can manage to solve difficult problems if I try hard enough.				
I can find the ways and means to get what I need.				
I am certain that I can accomplish my goals.				
I am confident that I can deal efficiently with unexpected events.				
I can solve most problems if I invest the necessary effort.				
I can remain calm when facing difficulties because I can rely on my coping abilities.				
When I am confronted with a problem, I can find several solutions.				
If I am in trouble I can think of a good solution.				
I can handle whatever comes my way.				
Thanks to my resourcefulness, I can handle unforeseen situations.				

Appendix K

SATISFACTION RATING

On a scale of 0 to 10 (0 being the lowest score and 10 being the highest score), please rate how satisfied you were with the mentor program in the past 2 months.

0    1    2    3    4    5    6    7    8    9    10