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Leslie Krongold

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The University of San Francisco

PROFESSIONAL AND LAY FACILITATOR'S PERCEPTIONS OF ROLES, GOALS,  
AND STRATEGIES TO PROMOTE SOCIAL SUPPORT AND SELF-  
MANAGEMENT IN FACE-TO-FACE SUPPORT GROUPS FOR ADULTS WITH  
MULTIPLE SCLEROSIS AND MYOTONIC MUSCULAR DYSTROPHY

A Dissertation Presented  
to

The Faculty of the School of Education  
Learning & Instruction Department

In Partial Fulfillment  
of the Requirements for the Degree  
Doctor of Education

by  
Leslie Krongold  
San Francisco  
May 2010

THE UNIVERSITY OF SAN FRANCISCO

Dissertation Abstract

Professional and Lay Facilitators' Perceptions of Roles, Goals, and Strategies to Promote Social Support and Self-Management in Face-to-Face Support Groups for Adults with Multiple Sclerosis and Myotonic Muscular Dystrophy

Chronic health conditions are on the rise and increase approximately 1% each year in the United States. Though this crisis can be cost prohibitive, there are economical treatment options available. One option is support groups for adults with chronic health conditions. Research has shown that social support experienced by group participants improves coping skills, lowers depression, and enhances quality of life. Another option for chronically ill people to help themselves is by participating in patient self-management programs. Patients taught self-management skills have improved their health status, made fewer physician visits, and have reduced hospital stays compared to control subjects. Unfortunately, these patient programs are often short-lived and limited to hospital settings.

The role of the facilitator is critical to the success of a support group achieving the goals of either social support or self-management. There is little research about support group facilitators promoting both goals of social support and self-management. The purpose of this study was to survey support group facilitators to determine their roles and strategies used to achieve the goals of social support and self-management behaviors. Transformative learning theory and goal-setting theory provided the theoretical underpinning for a conceptual model of support group facilitation.

A researcher-designed survey was used to gather descriptive data. Over 300 facilitators of support groups for adults with Multiple Sclerosis or Myotonic Muscular Dystrophy participated in the survey. Additionally, data were used to compare the strategies used by professionally-trained facilitators to strategies used by lay and peer facilitators.

Survey results revealed statistically significant differences in attitudes toward goal-setting; both professional and professional-peer facilitators responded more favorably to goal-setting. Peers and professionals differed on role perceptions as well as the strategies used to promote self-management health behaviors. Overall, facilitators chose to handle self-management topics with group conversation and made limited use of other collaborative strategies such as demonstration and participatory activities.

This dissertation, written under the direction of the candidate's dissertation committee and approved by the members of the committee, has been presented to and accepted by the Faculty of the School of Education in partial fulfillment of the requirements for the degree of Doctor of Education. The content and research methodologies presented in this work represent the work of the candidate alone.

Leslie Krongold

Candidate

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Similar to the *butterfly effect*, years ago a young woman working at the Muscular Dystrophy Association, asked me to facilitate a support group shortly after my diagnosis and brief attendance at the group. How this gesture influenced the course of my life events I'm sure she could not have imagined. I am grateful to her as this experience has enabled me to touch, and be touched by, the lives of so many diverse and interesting people.

I could not have done this study without the participation of three national health organizations – National Multiple Sclerosis Society, Multiple Sclerosis Foundation, and Myotonic Dystrophy Foundation. Thank you for reaching out to your support group facilitators and encouraging them to participate in the survey.

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## **CHAPTER I STATEMENT OF THE PROBLEM**

Seventy-five percent of each health care dollar spent in the United States goes to treat someone with a chronic health condition such as asthma, diabetes, lung disease, or other persistent ailments (Kanaan, 2008). Currently over 133 million Americans live with a chronic health condition; by 2030, this number is anticipated to grow 1% annually to approximately 171 million people (Chronic disease: The chronic care, 2009). Clearly, there is an escalating crisis.

While a person with a chronic health condition may have a medical regimen, they can enhance their treatment options by learning a set of behaviors to help them manage their own illness (Goodall & Halford, 1991). Generally, these behaviors are learned in one of three settings. First, hospitals typically offer self-management programs in a classroom setting for a limited number of sessions (Lorig, Ritter, Stewart, Sobel, Brown, Bandura, Gonzalez, Laurent, & Holman, 2001). A second setting for a person with a chronic health condition is to attend a face-to-face support group usually available at a variety of public venues (Schopler & Galinsky, 1993). A third possible setting is a support group that meets in an online environment. While self-management programs and online support groups are important, this study is about face-to-face support groups.

Support groups for adults with chronic health conditions meet face-to-face at hospitals, schools, churches, and public-access buildings, and are known to provide psychosocial benefits for their participants on a long-term basis (Davison, Pennebaker, & Dickerson, 2000). Research has established that the primary goal for support groups is providing social support for group participants (Brandl, Hebert, Rozwadowski, & Spangler, 2003; Collie, Kreshka, Ferrier, Parsons, Graddy, Avram, Mannell, Chen,

Perkins, Koopman, 2007; Mendelson, 2003; Mo & Coulson, 2008). Social support is associated with positive health outcomes such as improved coping skills (Schreurs, Colland, Kuijer, de Ridder, & van Elderen, 2003), lower depression (Lieberman & Goldstein, 2005), less stress and anxiety (Feld & Heyse-Moore, 2006), greater sense of well-being (Brooks, 2005), and enhanced quality of life (Gottlieb & Wachala, 2007).

There is also a body of research associating patient health behaviors with better physical and psychological health outcomes (Barlow, Turner, & Wright, 1998; Dongbo, Hua, McGowan, Yi-e, Lizhen, Huiqin, Jianguo, Shitai, Yongming, & Zhihua, 2003; Gallant, 2003; Lorig, Ritter, Villa, & Piette, 2008). Self-management includes a set of behaviors to help a person manage their own illness (Goodall & Halford, 1991). One longitudinal study with over 800 participants diagnosed with either heart or lung disease, stroke or arthritis, found those exposed to learning about self-management behaviors had maintained or improved their health status, made fewer hospital and physician visits, and reduced hospital stays compared to the control subjects (Lorig, Ritter et al., 2001).

While the majority of support group research is focused on the positive outcomes of social support, the support group literature has not explored the positive outcomes of self-management behaviors. Additionally, support group research has not examined to what extent self-management behaviors are promoted in the face-to-face support group setting. This study examines how face-to-face support groups for adults with chronic health conditions promote self-management behaviors.

The vast majority of support groups for adults with chronic health conditions are facilitated by professionals, lay persons, or persons who share the same disease as the participant (Davison et al., 2000). These support group facilitators may play a pivotal role

in guiding a recently diagnosed person from a place of confusion and bewilderment to a place of empowerment. However, little is known about the facilitator's role in face-to-face support groups. The limited research in this area is anecdotal. Many researchers have suggested a need to further explore the support group facilitator's role and the strategies used to achieve support group goals such as social support and self-management behaviors (Costello, 2007; Kirsten, Butow, Price, Hobbs, & Sunquist, 2006; Lekalakala-Mokgele, 2006; Lieberman, 2007; Lieberman, 2008; Owen, Bantum, & Golant, 2009). Consequently, the primary purpose of this study was to survey support group facilitators to determine their roles and strategies used to achieve the goals of social support and self-management behaviors.

There is a body of research comparing professional, lay, and peer support group facilitators with respect to their challenges and successes. Persons in health care occupations such as nurses, social workers, psychologists, physicians and individuals specialized in public health or mental health are considered professional facilitators (Hoey, Ieropoli, White, & Jefford, 2008). Several studies have explored the differences between facilitator types; for example, participants in a cancer support group rated their professional facilitators highly yet expressed greater satisfaction with the support they received from peers (Cella, Sarafian, Snider, Yellen, & Winicour, 1993). In another study with cancer support groups both professional and lay facilitators experienced challenges but the professionals had greater ease with managing the personal dynamics involved with support group facilitation (Kirsten et al., 2006).

The role of the peer support group facilitator has also been a line of research inquiry. A peer is considered a person who shares the same chronic health condition as

the support group participants (Hoey et al., 2008). Peers, either professional or lay facilitators, have been examined in a variety of chronic health support groups from cancer to Parkinson's disease to diabetes (Eysenbach et al., 2004; Lieberman & Goldstein, 2006). One study suggests peer leaders may have a greater influence on support group participants' psychosocial outcomes (Kendall, Catalano, Kuipers, Posner, & Charker, 2007). A secondary purpose of the study was to compare professional, lay, and peer facilitators regarding their role perceptions, support group goals, and strategies used to achieve goals.

### **Purpose of the Study**

Extensive studies have demonstrated efficacy for teaching self-management behaviors in hospital settings yet these settings reach a limited number of patients (Barlow, Turner, & Wright, 1998; Boldy and Silfo, 2006; Holman & Lorig, 2004). Support groups, a more accessible option for persons with chronic health conditions, are known to provide social support for their participants (Feld & Heyse-Moore, 2006; Gottlieb & Wachala, 2007; Lieberman & Goldstein, 2005; Schreurs et al., 2003). Little is known about the role of support group facilitators and their perception of the facilitative role in guiding support group participants toward goals of social support or self-management behaviors. Significant research has explored the challenges experienced by professional, lay, and peer facilitators in face-to-face support groups. But little research has examined the support group facilitators' perception of their role in promoting the goals of social support or self-management behaviors.

The purpose of this study was to describe support group facilitators' role perceptions, support group goals, and strategies used to achieve goals of social support

and self-management behaviors by comparing the strategies employed by professionally-trained facilitators such as psychologists, nurses, and social workers with the strategies used by lay and peer support group facilitators.

### **Significance of the Study**

This study is important for three reasons. First, face-to-face support groups offer an accessible and cost-efficient venue for adult education. Little is known about the role of support group facilitators; this study provides a deeper understanding of the similarities and differences between the perceived roles of facilitators. Second, the promotion of strategies for self-management behaviors potentially can increase the health and well-being of millions of Americans dealing with a chronic health condition. Self-management behaviors, cultivated and practiced in a support group setting, with the guidance of a facilitator, offer an effective enhancement to the necessary care for someone with a chronic health condition. Finally, this study addresses a noticeable gap in the research literature about facilitators of support groups for adults with chronic health conditions.

### **Theoretical Rationale**

Much of the research literature on support groups, from nursing and social work disciplines, is atheoretical (Kurtz, 1997). The current study, with two underlying theories, is conducted from an educational perspective with the support group facilitator viewed as an adult educator. Whether a chronically ill person attends a support group to hear from knowledgeable guest speakers, glean self-management behaviors, or commiserate with peers, learning and behavior changes inevitably occur. The support group leader is in a position to facilitate this learning practice for the participant. Transformative learning



theory (TLT), well researched in the field of adult education, is the predominant rationale for the study. It is a model for change and rooted in the communication process (Courtenay, Merriam, & Reeves, 1998; Taylor, 2007).

### **Transformative Learning Theory**

Transformative learning theory (TLT) evolved from Mezirow's research with women returning to college through reentry programs (Cranton, 1994). Initially conceived as a ten-stage linear process, TLT has expanded and is now considered more fluid and spiral (Baumgartner, 2001; Mezirow, 1981). Educational theorists have refined and modified the 10 developmental stages to articulate the meaning-making process adults undergo when faced with a *disorienting dilemma* (Mezirow, 1981). The disorienting dilemma may be a personal life crisis such as divorce, job loss, death of a loved one, or the diagnosis of a chronic health condition.

According to TLT, the first of three phases of the meaning-making process following the disorienting dilemma includes self-examination and dealing with unpleasant emotions (Christopher, Dunnagan, Duncan, & Paul, 2001; Mezirow, 1981; Moore, 2005). During this initial phase, learners question and realize that previous coping and problem-solving strategies for their life are no longer effective (Baumgartner, 2001; Moore, 2005). If a person recently diagnosed with a chronic health condition comes to a support group during this phase, he or she may still feel anger, frustration, or sadness. Facilitators may promote transformative learning by providing a safe and trusting space for participants to share their thoughts and feelings and together achieve mutual understanding (Taylor, 2007). Facilitators may also provide direct learning experiences that stimulate participant's reflection (Cranton, 1994). In the current study, support group

facilitators use different strategies when working with recently diagnosed group members, aware of their different needs.

The second phase consists of exploring new roles, planning a course of action, and learning the knowledge and skills necessary for following one's plan of action (Mezirow, 1991). This phase is marked by the learner's recognition that others have gone through a similar situation (Baumgartner, 2001; Christopher et al, 2001; Mezirow, 1981; Moore, 2005). Talking and listening to other individuals who have experienced the same dilemma is critical during this phase. In the current study, support group participants may learn of available options through their peers and the support group facilitator. By seeing others similar to them practicing self-management behaviors, support group participants build confidence that they too can achieve these goals (Moore, 2005). Facilitators can model behaviors appropriate for learning and growth and encourage dialogue in the support group (Cranton, 1994).

The final phase, or *perspective transformation*, is the eventual integration of the new-found self (Mezirow, 1981). Mezirow explains this phase as an empowered sense of self equipped with strategies and resources for functioning in a new way (1991). The perspective transformation is the outcome for transformed learners. In this study a perspective transformation would be the support group participant's practice and integration of self-management behaviors and social support cultivated by facilitators. New attitudes, beliefs, and behaviors are fully assimilated during this final phase of transformative learning (Moore, 2005).

Reflection, dialogue, relationships, and mentors are important throughout the entire transformative learning process (Baumgartner, 2001; Taylor, 2007). The support

group facilitator plays a key role in helping the support group participants examine their beliefs, feelings, and behaviors during the whole learning process (Moore, 2005). Support group facilitators use specific strategies to assist participants toward the goals of self-management and social support.

Over the last three decades TLT has been used as the primary theoretical framework in numerous empirical studies including medical education, environmental assessment, distance education, and business communication (Taylor, 2007). Most relevant is the longitudinal research with HIV-positive men and women (Baumgartner, 2002; Courtenay et al., 1998; Courtenay, Merriam, Reeves, & Baumgartner, 2000). Researchers sought to understand how HIV-positive men and women made sense of their experience once diagnosed with a chronic health condition. The original sample of 18 respondents came from four different community-based HIV-AIDS organizations in Atlanta, Georgia (Courtenay et al., 1998). Most of the sample worked or volunteered at AIDS service organizations and engaged in activities such as advocacy, peer counseling and education (Courtenay et al., 2000). Through qualitative interviews, respondents described a transformative learning process that indicated an initial reaction to their diagnosis period that lasted from six months to five years. External catalysts such as a family member, friend, or another HIV-positive individual in a support group, caused them to move out of this initial diagnosis period. Nearly all respondents mentioned that talking about their feelings was helpful.

Subsequent phases of the learning process included participants reevaluating their behaviors. Several sought alcohol and drug treatment as they realized the behaviors no longer served them well. Perspective transformation for most of the respondents included

self-care issues, heightened sensitivity to life, integration of their HIV-positive status, and wanting to be of service to others (Courtenay et al., 1998; Courtenay et al., 2000).

Mezirow (1991) suggests that once perspective transformation occurs, there is permanence. Transformed learners do not return to earlier beliefs and behaviors. Researchers tested this aspect of TLT by returning twice to the HIV-positive respondents. Although the original sample of 18 respondents had decreased, perspective transformation remained stable for the 11 remaining respondents over the four-year period (Baumgartner, 2002; Courtenay et al., 2000). Transformative learning theory alone may not adequately address how to foster a perspective transformation for a learner.

### **Goal-Setting Theory**

The second theory underlying the study is goal-setting, a cognitive motivation theory (Latham, 2000). Goal-setting theory is based on the premise that forming conscious goals impacts action (Locke & Latham, 2002). A goal is the aim of an action to achieve a specific standard or level of proficiency (Locke & Latham, 2002). Goal-oriented facilitators are more motivated to plan activities, and employ the appropriate strategies that focus attention toward achieving group goals. Locke and Latham found that when team leaders promote specific goals, there is a greater impact on team member's performance than when leaders suggest that members "do their best" (Locke & Latham, 2002).

Goal-setting theory also applies to support group participants. Research results have suggested a correlation between goal achievement and supportive supervisory behavior (Latham, 2000). Support group participants may be more likely to successfully attain goals when the group is facilitated by a supportive, goal-oriented leader. In this

study, when facilitators help participants establish proximal goals or perform easy steps toward a more distal goal, they are motivating them to increase their commitment toward attaining distal goals. Implicit in self-management is action planning for the chronically ill person. Establishing proximal goals is part of action planning. Creating action plans moves the support group participant toward the more distal goal of integrating self-management behavior.

TLT and goal-setting theories are appropriate for support group facilitator's behavior because they represent the motivation necessary for a support group facilitator to cultivate behavior change in support group participants. While TLT underlies the conceptualization of this study, the study is focused on the role of the facilitator and the goals and strategies employed by facilitators. The study does not focus on the transformative learning process although this theoretical rationale provides the constructs for the study.

Figure 1 introduces the model of support group facilitation. The squares in the figure represent the roles, goal-setting, and strategies used by the different facilitator types. Goal-setting serves to motivate facilitators' use of strategies to guide participants toward goals of self-management behavior and social support. This study focuses on the left side of the figure. The ellipses, on the right side of the figure, represent the participants' phases of the transformative learning process. People with chronic health conditions engage in a meaning-making process soon after they receive their health diagnosis. Figure 1 illustrates what happens once the person joins a support group. The transformative learning process suggests that if strategies used by the facilitator are effective, the participant may move through the meaning-making phases of reflection,

dialogue, and eventually achieve a perspective transformation. The arrow moving from the right to the left side of the model represents a transformative learning feedback process in which facilitators modify strategies based on the participant's meaning-making phase. Goal-setting theory helps to explain how support group facilitators meet the challenge of working with participants at different phases of the meaning-making process.

Transformative learning theory and goal-setting theory form a conceptual model for the study. Goal-oriented facilitators employ specific strategies to motivate support group participants toward the practice and integration of self-management behaviors such as exercise, nutrition and diet, medications, breathing techniques, and symptom management for fatigue, pain, stress, and emotions (Lorig, Holman, Sobel, Laurent, Gonzalez, & Minor, 2000). These strategies are sensitive to the participant's placement in the transformative learning stage.

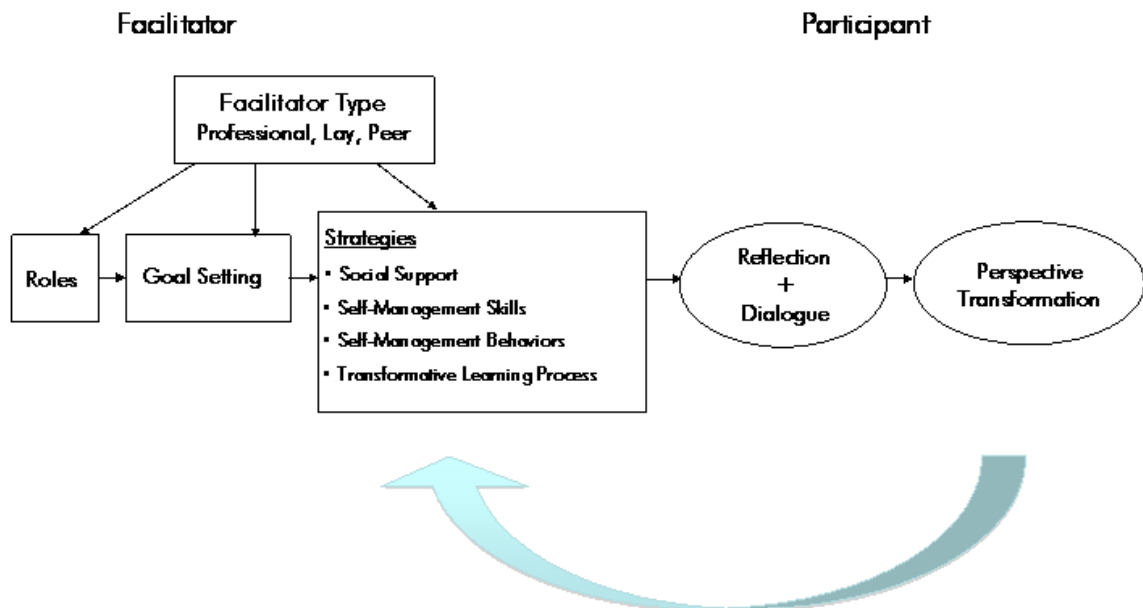


Figure 1. Model of Support Group Facilitation

## **Background and Need**

Chronic illnesses are responsible for 70% of deaths each year in the United States. In total, 1.7 million people annually succumb to a chronic health condition such as heart disease, cancer, or diabetes (Chronic disease: The chronic care, 2009). Once diagnosed, a person with a chronic health condition spends the rest of his or her life managing the illness. About 20% of Americans have some type of disability or chronic health condition (Fox, 2007). Chronic health conditions are both common and expensive. These illnesses escalate healthcare costs, and impact the daily lives of millions of people. A chronic health condition requires permanent lifestyle changes and accommodations (Shaw, 2001). Depending on the type and stage of the condition, there is need for continuous re-evaluation.

### **Chronic Health Conditions**

The four features of chronic health conditions include: onset, course, outcome, and incapacitation (Rolland, 1994). The onset of a chronic health condition may have an acute beginning such as a heart attack or stroke, or as with Alzheimer's and Parkinson's disease, there may be a more gradual onset. Course, the second feature, also has variability. The course of a chronic health condition can be progressive with symptoms increasing in severity or the symptoms may be stable. For example, a paralyzed person's symptoms tend to stabilize while someone with Myotonic Muscular Dystrophy experiences increasing muscle wasting and weakness. Some chronic health conditions have a relapsing course; examples include certain types of cancer, asthma, and Multiple Sclerosis. During a relapse the medical management of the condition, or intervention by healthcare professionals, may be paramount. The third feature is outcome. Many chronic

health conditions, such as arthritis, are nonfatal. Some chronic health conditions are unequivocally fatal, such as Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease. Other conditions such as diabetes tend to shorten a person's life span. The final feature of Rolland's typology is incapacitation. To what extent does the chronic health condition lead to additional disability? The inability to perform functions of daily living may range on a spectrum from mild to moderate to severe. Chronic health conditions such as a neuromuscular disease may necessitate the use of a cane, walker, or wheelchair. More severe forms of a chronic disease require use of a feeding tube or mechanical ventilation for breathing.

Many people with chronic health conditions have hidden disabilities, but make accommodations in their lives to compensate for what they can no longer do. A hidden disability is any type of impairment that impacts normal functioning and restricts lifestyle but may not be readily apparent to others (Taylor & Epstein, 1999). Arthritis, migraines, lupus, asthma, and chronic fatigue syndrome are some examples of hidden disabilities. People struggling with these chronic illnesses may appear normal and healthy yet spend significant time managing their illness so they can accomplish activities of daily living.

When first diagnosed with a chronic health condition, there is the crisis stage (Courtenay et al., 1998). Reactions during this stage vary from denial of the news to practicing unhealthy behaviors. Moving from diagnosis to action can take months, years, or decades. Research suggests that social support has been particularly effective in helping people move faster during this transitional period (Davison et al., 2000).

Researchers of HIV-positive men and women found that one catalyst for breaking out of



this reaction period is often initiated by talking to friends, family, or support group members (Courtenay et al., 1998).

### **Support Groups**

One type of support group includes a gathering of people who share the same problem or health condition. Support groups offer more than just a space to discuss personal experiences (Davison et al., 2000; van Uden-Kraan, Drossaert, Taal, Shaw, Seydel, & van de Laar, 2008b). People may join support groups to form community (Buchanan & Coulson, 2007; Kurtz, 1997; Lieberman & Russo, 2001-2002), share coping strategies (Cella et al., 1993; Kurtz, 1997), exchange information about health treatments and medication side effects (Butler & Beltran, 1993; Davison et al., 2000; Im & Chee, 2008; Kurtz, 1997; Lieberman & Russo, 2001-2002; Merrill, 1993), achieve a sense of empowerment (Buchanan & Coulson, 2007; DeCoster & George, 2005; Kurtz, 1997; van Uden-Kraan et al, 2008b), or escape social stigma associated with their health condition (Davison et al., 2000). Support groups can meet face-to-face or on the Internet. They may have a closed, fixed membership and meet for a designated length of time or they may have an open, drop-in membership. Some support groups exist as interventions by health care professionals or researchers in an effort to test a specific technique, treatment, or psycho-educational program. Other support groups are led by non-professionals or people without backgrounds in nursing, social work, or counseling. Many of these lay people have the same health condition as the support group participants and are referred to in the literature as peers (Davison et al., 2000).

People with chronic health conditions may attend support groups for increased knowledge of their condition, self-disclosure, camaraderie, and inspiration to move

forward with their lives (Merrill, 1993; Miller, 1998; Sarnoff Schiff, 1996). It is estimated that at least 40% of Americans belong to some type of support group that meets on a regular basis (Wuthnow, 1994). Face-to-face support groups may meet at a hospital, church, senior center, health organization's office, or someone's living room.

There is a distinction among different types of support groups: self-help, treatment, and support. Self-help groups are generally initiated by professionals, have a sponsoring organization, and rely on leaders with personal experience of the life crisis (Schopler & Galinsky, 1993). Treatment groups are usually led by professionals who do not share the personal life crisis and guide the group's progress. Situated midway is the support group whose leadership is either voluntary or professional but the participants' personal experiences and input often guide the group. Not all groups comply with this delineation. The majority of face-to-face support groups have a leader or facilitator, either professional or lay. Professional facilitators tend to have backgrounds in psychotherapy, nursing, social work, or public health. Lay facilitators may be volunteers or have the same chronic health condition as the group's participants. In this study, support groups refer to face-to-face meetings consisting primarily of participants sharing a neurological health condition. The group is facilitated by either a professional or lay person, either of whom may also share the same condition with the group participants.

People come to support groups with different expectations but the positive outcomes from regular attendance can be quite significant. One positive outcome is social support, a general term used to describe practical or instrumental, informational, and/or emotional support received in a social setting (Doronn, 2002; Mo & Coulson, 2008). High levels of social support have been associated with better physical health and fewer

symptoms of depression (Beaudoin & Tao, 2007; Davison et al., 2000; DuPertuis, Aldwin, & Bosse, 2001). Psychosocial interventions, with cancer patients and persons with HIV/AIDS, have been common for the last 25 years. Support group interventions for persons with HIV/AIDS suggest benefits of diminished pain and distress as well as a decrease in high-risk sexual behavior (Martin, Riopelle, Steckart, Geshke, & Lin, 2001; Walch, Roetzer, & Minnett, 2006). Positive effects for cancer patients include enhanced emotional and functional adjustment, and effective treatment of disease-related symptoms (Hoey et al., 2008; Meyer & Mark, 1995). Participating in a support group encouraged healthy behaviors, enhanced coping mechanisms, and provided information that assisted the positive outcomes (Hoey et al., 2008; Meyer & Mark, 1995).

### **Role of the Facilitator**

The research literature exploring the efficacy of support groups for adults with chronic health conditions generally focuses on the participants although there are a few studies centered on facilitators. Many studies attribute the support group's success to the facilitator (Dickerson, Posluszny, & Kennedy, 2000; Lieberman & Golant, 2002; Walsh, Hewitt, & Londeree, 1996). Yet compared to the number of studies focused on support group participants, there has been limited research centered on support group facilitators. The role of facilitator, or group leader, has been examined more extensively in some disciplines. For example, in psycho-therapeutic research on groups, the leader helps the group meet its needs and accomplish the group's goals (Clawson, Bostrom, & Anson, 1993; Keltner, 1989; Thomas, 2006). The individual and group goals deal with psychological or emotional issues. Studies with group leaders in business, government, and academia suggest that effective leaders establish goals, plan and cultivate the right

conditions to achieve goals (Galanes, 2003; Kickul & Neuman, 2000; Marta, Leritz, & Mumford, 2005).

The role of the facilitator is discussed in the behavioral sciences with respect to health interventions, but is often limited to the steps facilitators use to conduct the intervention (Marziali, Donahue, & Crossin, 2005). Several studies specific to health care and support groups have defined the parameters of the role of the nurse or social work facilitator (Martin & Smith, 1996; Kane, 2006). Much of what has been written about nurse support group facilitators falls into the realm of articles offering tips on how to recruit participants to their groups (Walsh et al., 1996) or proposing lists of therapeutic hints for effective group leadership (Scheick, 2002).

### **Facilitators and Self-Management**

In one health intervention designed to improve self-management techniques, nurse facilitators expressed difficulty dealing with participant's negative emotions as well as problems with helping people set goals (Schreurs et al., 2003). After receiving additional training, the nurses practiced their own goal-setting and followed action plans. Once nurses established the practice of goal-setting in their own lives, they found goal-setting and action plans to be powerful tools in the support groups.

One study explored the integration of self-management skills in a face-to-face peer-led support group called The Diabetes Club (DeCoster & George, 2005). A professional social worker initiated the group with the explicit goal of helping participants make positive lifestyle changes and transitioning group leadership to participants. Members generated their own self-care challenges. There was a statistically

significant increase in diabetes self-efficacy as well as positive physical manifestations of weight loss and a decrease in A1C (blood glucose) levels.

Integrating self-care behaviors into participant's daily lives has been successful in diabetes, arthritis, asthma, lung and heart disease face-to-face support group interventions (Barlow et al., 1998; Boldy & Silfo, 2006; DeCoster & George, 2005; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001; Schreurs et al., 2003; Steed, Cooke, & Newman, 2003). Many chronic health conditions can be managed by making lifestyle changes such as medical management, weight control and exercise programs, diet modifications, and alternative modalities. Patients receiving information on self-management techniques through support groups have demonstrated positive health outcomes (Escoffery, Powell, Englesakis, Rizo, & Stern, 2008). A study implementing self-management techniques for stroke survivors suggested different outcomes for participants based on whether their group leader was a peer or professional (Kendall et al., 2007). There is a body of literature associating successful self-management of a chronic condition with better physical and psychological health outcomes (Gallant, 2003).

### **Facilitator Types**

Several studies have addressed differences between professional and lay facilitators yet there is no consensus as to which type of facilitator may be more effective. In three studies, peer-led support groups were rated by support group participants as more beneficial than professionally-facilitated groups (Cella et al., 1993; Lieberman & Golant, 2002; Ussher et al., 2008). Kendall, Catalano, Kuipers, Posner, Buys, and Charker (2007) suggest that peer leaders may have more influence on psychosocial outcomes such as

mood and confidence however professional facilitators may have more impact on functional outcomes for participants such as energy level, speaking ability, or mobility.

Additional research is needed exploring the role and goals of support group facilitators (Costello, 2007; Dickerson, et al, 2000; Eysenbach et al., 2004; Kirsten et al., 2006; Lieberman & Russo, 2001-2002; Price, Butow, & Kirsten, 2006). Study findings with both professional and lay facilitators in face-to-face and online support groups have demonstrated that promoting self-management behaviors, coupled with social support, are associated with more positive physical and psychological outcomes for people with chronic health conditions. Providing information about self-management behaviors may not be enough to motivate people. The support of peers, a facilitator, and making specific plans to meet self-care goals is critical (Boldy & Silfo, 2006; Schreurs et al., 2003). To date, no studies have been identified that examine how support group facilitators perceive their roles in promoting self-management behaviors, especially for adults with neurological chronic health conditions.

Costello (2007) disseminated strategies nurses use in diabetes support groups with the primary goal of promoting self-management behaviors. Twenty strategies in four areas were identified such as emotionally connecting with participants, exchanging information, managing group dynamics, and promoting problem-solving. Yet only six nurses were interviewed. To date, no studies have been identified that look at the strategies used by facilitators of support groups for adults with neurological health conditions to promote self-management behaviors.

Several studies have explored the differences between professional and lay facilitators of support groups for adults with cancer, Parkinson's disease, mental illness,

and stroke. The findings have been inconsistent. To date, no study has been identified that has explicitly explored strategies used by professional and lay support group facilitators for adults with neurological health conditions. There has been passing mention of lay, or peer, facilitators sharing the same health condition as the support group participants. No studies have considered whether strategies used by facilitators differ when the facilitator shares the chronic health condition. The current descriptive research study described how support group facilitators perceive their role and the strategies used to promote the goals of social support and self-management behaviors in two groups of chronic health conditions.

Neurological chronic health conditions such as Multiple Sclerosis (MS) and Myotonic Muscular Dystrophy (MMD) are diseases that benefit from medical management and self-management (Betts, 2008; Cup, Pieterse, ten Broek-Pastoor, Munneke, van Engelen, Hendricks, van der Wilt, & Oostendorp, 2007). It is estimated that 400,000 people in the United States have MS, and approximately 200 people are diagnosed with the disease each week (FAQs about MS, 2009). People with MS exhibit diverse symptoms that often increase in severity or diminish between relapse periods; some symptoms include muscle weakness and loss, slurred speech, bladder problems, and fatigue. Leading a sedentary life for a person with MS can lead to obesity and/or cardiovascular disease (Betts, 2008; Hartley, 2009). MMD is the most common form of muscular dystrophy for adults and affects approximately 40,000 people in the United States and 1 in 8,000 people worldwide (Facts about myotonic muscular dystrophy, 2009; Harper, 2009). MMD is a slowly progressive disease that also has variable symptoms

including muscle wasting and weakness, gastrointestinal problems, heart palpitations, fatigue, and difficulties swallowing or breathing.

### **Research Questions**

This study addressed the following questions:

1. How do different support group facilitators (professional, lay, peer) perceive their role?
2. What are the attitudes toward goal-setting among the different facilitator types (professional, lay, peer)?
3. Does the promotion of social support strategies vary among the different facilitator types?
4. Does the promotion of self-management skill strategies vary among the different facilitator types?
5. What strategies are used to promote self-management behaviors and do they vary among the different facilitator types?
6. Does the promotion of transformative learning vary among the different facilitator types?

### **Definition of Terms**

Chronic Health Condition: any of a number of diseases or health conditions that require permanent lifestyle changes and accommodations (Shaw, 2001). Chronic health conditions vary according to their onset, course, outcome, and degree of incapacitation (Rolland, 1994) and include such conditions as diabetes, heart and lung disease, Multiple Sclerosis, arthritis, Parkinson's disease, and neuromuscular diseases.



Face-to-Face Support Group: a group that meets in person at a hospital, church, senior center, health organization's office, or other public facility. The group may have a closed, fixed membership and meet for a designated length of time or may have an open, drop-in membership. In this study, a face-to-face support group is an open, drop-in group with regular monthly meetings.

Facilitator: In this study, a facilitator is the support group leader, either a professional or lay person. Professional facilitators tend to have backgrounds in psychotherapy, nursing, social work, or public health. Lay facilitators may be volunteers or have the same chronic health condition as the group's participants.

Neurological Health Condition: In this study, a neurological health condition refers to either Multiple Sclerosis or Myotonic Muscular Dystrophy. The National Institute of Neurological Disorders and Stroke explains that most people with Multiple Sclerosis:

...experience muscle weakness in their extremities and difficulty with coordination and balance. These symptoms may be severe enough to impair walking or even standing. In the worst cases, MS can produce partial or complete paralysis. Most people with MS also exhibit paresthesias, transitory abnormal sensory feelings such as numbness, prickling, or "pins and needles" sensations. Some may also experience pain. Speech impediments, tremors, and dizziness are other frequent complaints. Occasionally, people with MS have hearing loss. Approximately half of all people with MS experience cognitive impairments such as difficulties with concentration, attention, memory, and poor judgment, but such symptoms are usually mild and are frequently overlooked. Depression is another common feature of MS. (NINDS Multiple Sclerosis Information Page, 2009)

The National Institute of Neurological Disorders and Stroke defines Myotonic Dystrophy as:

...the most common adult form [of Muscular Dystrophy] and is typified by prolonged muscle spasms, cataracts, cardiac abnormalities, and endocrine disturbances. Individuals with myotonic MD have long, thin faces, drooping eyelids, and a swan-like neck (NINDS Muscular Dystrophy Information Page, 2009).

Online Support Group (OSG): a group that makes use of computer-mediated communication tools that are either synchronous, where people communicate with each other in real time, or asynchronous, where people post messages to be read and responded to at different times. In this study, an OSG refers to a facilitated group using synchronous textual communication tools on the Internet.

Self-Management: is a set of behaviors to help a person manage their own illness. In this study, self-management refers to behaviors that help a person with either Multiple Sclerosis or Myotonic Dystrophy manage their illness.

Social Support: In this study, social support refers to any of five types of support: information support, tangible assistance, esteem support, network support, and emotional support (Cutrona & Suhr, 1992; Mo & Coulson, 2008). Information support is any communication offering suggestions or guidance, referral to an expert, book, or website, or sharing personal experience. Tangible assistance is any communication or act providing direct or indirect tasks, a loan, or willingness to assist in some capacity. Esteem support is any communication offering a compliment, validation, or relief of blame. Network support is any communication providing access to other support group participants. Emotional support is any communication or act expressing care and concern.

Strategy: A plan of action intended to accomplish a specific goal. In this study, strategy refers to any technique employed by a support group facilitator to promote the goals of participant self-management and/or social support.

Support Group: In this study, the term refers to a face-to-face group meeting consisting primarily of participants sharing a neurological health condition. The support group will be facilitated by either a professional or lay person, either of whom may also share the

same condition with the group participants. The support group may or may not be sponsored by a non-profit health organization.

## **CHAPTER II REVIEW OF LITERATURE**

The literature for this study pertains to three settings – self-management hospital programs, online support groups, and face-to-face support groups. While the current study focuses on the last setting, there is relevant information about the first two settings that is discussed and clearly identified. The self-management hospital programs and online support groups are different environments and may or may not generalize to face-to-face support groups.

This review of the literature includes two sections. The first section presents key studies exploring the most researched dimensions of support groups. These dimensions have been approached from a variety of disciplines including nursing, social work, public health, and behavioral medicine. The second section examines research on self-management behaviors for people with chronic health conditions. Although most of these studies were done in the context of hospital settings or health care interventions, the self-management skills and behaviors are relevant to support groups.

### **Support Group Dimensions**

The term support group has a fluid definition and is often interchangeable with other terms such as mutual aid and self-help group. Mutual aid refers to a group where its members help each other by listening, sharing, and offering advice (Schopler & Galinsky, 1993). Schopler and Galinsky (1993) operationalized these terms but the boundaries are often blurred. Self-help groups have primarily focused on life problems such as drug and alcohol addiction, eating disorders, or gambling (Adamsen, 2002). One study defined self-help as a group that meets on a regular basis with participation costs that do not

exceed eight dollars (Davison, Pennebaker, & Dickerson, 2000). For the purposes of this study, a support group refers to a face-to-face group meeting facilitated by either a professional or lay person. The support group may or may not be sponsored by a non-profit health organization (Schopler & Galinsky, 1993).

The last four decades have experienced a groundswell in the evolution of both face-to-face and online support groups (OSG). The current study focused on face-to-face support groups. When relevant, studies involving OSGs are discussed. There are three dimensions to support group research that have been identified in the field of social work (Galinsky & Schopler, 1995; Schopler & Galinsky, 1993). This section is organized according to these three dimensions. The first dimension includes group conditions which refer to the goals and expectations of the support group participants, facilitators, and any sponsoring organization. The second dimension is the characteristics of both group participants and leaders, or facilitators. Aspects of this dimension include the size and composition of the group and whether or not the facilitator is a professional, lay person, or peer. The third dimension addresses support group outcomes including the positive or negative effects experienced by the participants, facilitators, and/or sponsoring organization.

### **Group Conditions: Goals**

The first dimension of support groups, group conditions, refers to the goals and expectations of the support group participants, facilitators, and any sponsoring organization. The vast majority of support groups have a primary goal of providing psycho-social support for group participants (Brandl, Hebert, Rozwadowski, & Spangler, 2003; Collie et al., 2007; Mendelson, 2003; Mo & Coulson, 2008). Studies have linked

psycho-social support to increased psychological well-being, enhanced quality of life, and diminished feelings of depression for people with chronic health conditions (Steed, Cooke, & Newman, 2003). Diabetes support groups have been found to share the goal of psycho-social support but tend to include an educational component (Costello, 2007). Other groups either explicitly make advocacy a goal or gradually evolve to having it as the group's main function (Gray, Fitch, Davis, & Phillips, 1997). Schopler and Galinsky (1993) interviewed a small sample of support group facilitators who all said the major purpose of their group was to provide emotional support and information; two-thirds of the facilitators also mentioned problem solving as a significant pursuit.

Alley and Brown (2002) described a support group for diabetics using a task-centered problem-solving model. The researchers co-facilitated the group and formally applied the model to teach participants about problem-solving strategies with the ultimate goal of participants applying strategies to their own goals. After meeting twice monthly for one year, the support group participants completed a survey. The researchers failed to provide samples of the survey items. After participating in the support group, participants were now able to identify problems to work on as well as the appropriate solutions to the problems.

A community-based project, aimed at providing social support to women with breast cancer who live in rural areas, used videoconferencing technology to emulate a face-to-face support group (Collie et al., 2007). The support group was facilitated by a social worker. The eight sessions were transmitted to four different locations using a split screen; participants at each location could see and hear the social worker and other participants. The intervention was considered a success based on interviews with the

facilitator, participants, project coordinators, and survey results. Two of the three psychosocial measures had statistically significant improvements. Participants reported a decrease in depressive symptoms at posttest ( $t(16) = 2.44, p < 0.02$ , two-tailed) and a decrease in post-traumatic stress disorder symptoms ( $t(16) = 4.24, p < 0.05$ , two-tailed).

One means of evaluating social support is the *social support behavior code* developed by Cutrona and Suhr (1992). The *social support behavior code* consists of five main categories of social support: informational support, tangible assistance, esteem support, network support, and emotional support. Informational support is any communication offering suggestions or guidance, referral to an expert, book, or website, or sharing personal experience. Tangible assistance is any communication or act providing direct or indirect tasks, a loan, or willingness to assist in some capacity. Esteem support is any communication offering a compliment, validation, or relief of blame. Network support is any communication providing access to other support group participants. Emotional support is any communication or act expressing care and concern. Researchers have used the *social support behavior code* to analyze the content of posted text messages in OSGs. In two studies, one for people with Huntington's disease (Coulson, Buchanan, & Aubeeluck, 2007) and the other for persons with HIV/AIDS (Mo & Coulson, 2008), researchers examined the type of social support offered in self-directed OSGs. Both studies found informational support as the primary type of social support offered and emotional support as the secondary type of social support.

The Diabetes Club pursued a different support group goal (DeCoster & George, 2005). A pilot test intervention was organized by professionals with the purpose of empowering diabetic senior citizens to improve both their self-care behaviors and

glycemic control, or blood-sugar level. Social workers established a framework where their role and presence at support group meetings gradually diminished as participants assumed more power and responsibility for the group's maintenance. Meetings focused on problem-solving, sharing self-care techniques, and assessing improvements in health and behaviors. The intervention used a pre-post design and analyzed outcomes prior to the study and after six months of participation. The four outcomes were self-management behaviors, self-efficacy, member's weight, and A1C or blood-sugar level. Statistically significant improvements were found on all outcomes except for weight loss. The researchers discussed the limited power of the significance due to the convenience sample; participants were recruited from a senior citizen center. It is possible that this population represented a more active or engaged population than the general population of people with diabetes. Also noted by the researchers was the intervention's cost effectiveness and how it might impact participants with fewer hospital and clinic visits. As participants of The Diabetes Club assumed more control of the group, researchers observed their enthusiastic behavior. The participants appreciated the attendance of a newly diagnosed member so they could share their knowledge and support with them.

This study, as well as others reviewed, suggests that social support has been the dominant goal of support groups for adults with chronic health conditions. Other goals include advocacy, problem-solving, and self-management behaviors. In this dissertation, both goals of social support and promotion of self-management behaviors were investigated. The *social support behavior code* (Cutrona & Suhr, 1992) helped guide the development of the survey instrument for the study.



### **Group Characteristics: Facilitator Types**

Evaluating support group characteristics has been the focus of considerable research with a concentration on the characteristics of participants rather than facilitators. This literature review concentrates on the group characteristics related to facilitators. The main facilitator characteristic of interest is the facilitator type. This refers to whether the facilitator is a health care professional, lay person, or peer. Health care professionals include nurses, social workers, psychologists, physicians, and individuals specialized in public health or mental health. Lay facilitators include anyone without a background in health care. A peer is an individual that has personal experience with the health condition or problem associated with the support group (Hoey, Ieropoli, White, & Jefford, 2008). Both health care professionals and lay people may be considered peers.

Facilitators of support groups for adults with cancer are discussed in the literature more frequently than other chronic health conditions. Cella, Sarafian, Snider, Yellen, and Winicour (1993) conducted a comprehensive process and outcome evaluation of community-based cancer support groups facilitated by mental health professionals. Seventy-seven support group members completed a survey. They found support group participants expected a facilitator to intervene in any difficult group dynamic such as arguments or domineering group members.

In Gottlieb and Wachala's (2007) review of empirical studies on professionally-facilitated cancer support groups, two types of activities for meetings were presented. The first activity was any type of education or training provided by a professional. The second type of activity involved participants sharing experiences and facilitated by the

professional leading the group. Of relevance to the current study was the assessment that most cancer patients preferred physician or nurse-led support groups.

In a study addressing the challenges for cancer support group leaders, researchers found challenges faced by both professional and lay leaders (Kirsten, Butow, Price, Hobbs, & Sunquist, 2006). A significant challenge was dealing with a support group participant's declining health as well as his or her eventual death. Although both types of facilitators expressed difficulty dealing with some communication and behavior styles of participants, it was especially troublesome for facilitators who lacked training in group dynamics. The study recommended future research to gain a better understanding of effective support group leaders.

Another systematic review looked at peer facilitators of support programs for people with cancer (Hoey et al., 2008). Five types of peer groups were identified in this literature review: (a) one-on-one peers meeting face-to-face, (b) one-on-one peers on the telephone, (c) group support meeting face-to-face, (d) group support meeting on the telephone, and (e) group support meeting online. Hoey, Ieropoli, White, and Jefford spent considerable time rating studies for research quality and program description. Overall the quality of the studies was not highly rated and numerous studies did not include adequate detailed information about the peer support program. There was a high level of participant satisfaction reported in the studies as well as some perceived psycho-social benefits associated with peer support. Significant psycho-social functioning improvements were described in two of the five types of peer support groups – one-on-one meeting face-to-face and online group.

Over 60% of face-to-face groups identified as self-help are actually facilitated by some type of health care professional (Davison et al., 2000). Carlsen (2003) explored the collaborative relationship of professionals and lay people involved in a Chronic Fatigue Syndrome self-help group. Carlsen spent close to two years observing the support group, conducting in-depth interviews with hospital-based social workers and peer facilitators, and found the two groups often had conflicting goals. The peer support group participants believed their experience was of value to the professionals and had a process-oriented approach to group facilitation. The health professionals were more goal-oriented with a bio-medical approach. Because of these style differences, the collaboration was not successful.

The most significant study looking at both professional and peer support group facilitators was conducted with older women, many of whom had physical and/or emotional problems (Segrist, 2008). Three types of groups met for a year. One type was facilitated by licensed social workers (n=13) who were staff members for a non-profit organization providing services for older women (K.A. Segrist, personal communication, March 9, 2009). The second type of group was peer facilitated (n=22). The third type was a comparison group of women (n=9) not involved in a support group. The purpose of the study was to determine if facilitator type influenced the women's sense of well-being and incidence of depression. Segrist found that women in the peer-facilitated support group had significantly lower scores on the depression measure than the comparison group ( $p = .009$ ). She also found that participants in the peer-run group had a larger social network and believed participant's religious affiliation may have been an intervening variable. Unfortunately, group membership was confounded by race; the peer-run group

participants were 44% African-American while the staff-run group participants were predominantly Caucasian.

The issue of facilitator burn out, or dissatisfaction, often leading to the group's closure, has been mentioned in several studies exploring cancer support groups. Both peer and professional facilitators have difficulties with leading support groups; difficulties include dealing with low participant attendance, handling challenging participant behaviors, discussing sensitive issues such as death, and not receiving recognition and credibility of support groups by physicians (Butow, Ussher, Kirsten, Hobbs, Smith, Wain, Sandoval, & Stenlake, 2005; Kirsten et al., 2006). However, statistically significant differences were found in difficulties experienced by professional, lay, or peer leaders of support groups (Butow et al., 2005).

The research does not lead toward a consensus as to whether support group participants prefer professional or lay facilitators. Although professional facilitators were highly regarded by participants of a cancer support group, they gave higher ratings to the support they received from fellow participants. Although cancer patients seemed to prefer groups facilitated by either physicians or nurses, it is unclear if this preference generalizes to groups with other chronic health conditions. In the current study, facilitator type was explored in regard to the roles, goals, and strategies used by support group facilitators.

### **Outcomes: Social Support and Self-Management**

The final dimension of support groups, outcomes, refers to any positive or negative effects for the support group participants, facilitator, or sponsoring organization. The literature tends to focus on positive effects derived from participation in either

existing support groups or health interventions offering group support. The only negative effect discussed in a study with social work support group facilitators was the tendency toward leader burnout (Schopler & Galinsky, 1993). Schopler and Galinsky also found that successful group experiences tend to be the only ones documented and few groups conduct evaluations to gauge the group's effectiveness. There may be a publication bias as only statistically significant results were reported in their meta-analysis of psycho-social interventions for breast cancer (Zimmerman, Heinrichs, & Baucom, 2007).

Positive effects are generally communicated by self-report psycho-emotional measures or through interviews. Participants of both face-to-face, online support groups and health interventions have demonstrated statistically significant, improvement in coping skills (Brandl et al., 2003; Cella et al., 1993; Marziali et al., 2005; Schreurs, Colland, Kuijer, de Ridder, & van Elderen, 2003), lower depression (Collie et al., 2007; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Lieberman & Goldstein, 2005), less stress and anxiety (Buchanan & Coulson, 2007; Feld & Heyse-Moore, 2006), greater sense of well-being (Barlow, Turner, & Wright, 1998; Brooks, 2005; Owen, 2003), feelings of empowerment (van Uden-Kraan et al, 2008b) and enhanced quality of life (Gottlieb & Wachala, 2007). For support group interventions to have an impact on participant's psycho-social well-being, the intervention must be at least three-months in duration (Gottlieb & Wachala, 2007) but is more efficacious if it lasts more than six months (Hoey et al., 2008).

There has been considerable research investigating the psycho-social outcomes for participants of cancer support groups, specifically women with breast cancer. In a study using text analysis of posted messages in a breast cancer OSG, researchers found

that women who used more negative emotion words experienced greater psychological benefits than their peers using more positive emotion words (Han et al., 2008).

Zimmerman et al. (2007) conducted a meta-analysis of psycho-social interventions for breast cancer patients and identified three potential moderator variables: type of cancer, type of intervention, and type of practitioner. Intervention types included psycho-educational, cognitive-behavioral, supportive and relaxation. Most group interventions were led by psychologists. The overall effect size ( $d = 0.26$ ) confirmed that psycho-social interventions have a low positive effect. The effect size decreased if the intervention was educational and led by a psychologist. The most effective intervention for women with breast cancer was psycho-educational, led by a person with medical expertise, and occurring right after diagnosis and before surgery.

Another study looking at moderator variables examined the relationship between a support group's norms and participant outcomes (Lieberman, Golant, & Altman, 2004). Group norms are the unspoken rules or the social contract for a support group. The group norms may be conveyed by the group leader and may differ with the participants' perceptions of the group norms. Participants in cancer support groups reported better outcomes on quality of life and depression measures when their idea of the group norms more closely represented those of their group leader.

Gottlieb and Wachala (2007) conducted a review of empirical studies on cancer support groups that resulted in a number of findings. Most of the outcome studies focused on group member's disease knowledge, psycho-social functioning, and quality of life. Of particular interest are the five studies that included survival rate as an outcome measure. Three of the studies had statistically significant increases in survival rates.

Other positive effects experienced by support group participants were found in a study for HIV-positive men (Martin, Riopelle, Steckart, Geshke, & Lin, 2001). Baseline data were collected from study participants as well as three months into the peer-led support group meetings. Comparison data were collected from HIV-positive men who were not participating in any type of support group. Support group participants reported less unprotected sex than control subjects ( $F(1, 65) = 4.37, p < .05$ ). The support group meetings were not educational in nature and researchers believed that community norms were a factor for the HIV-risk behavior change.

Lieberman and colleagues have been exploring support groups and their leaders for many years, predominantly the relationship of the leader intervention to the participant outcomes. Most of these studies have been with participants in The Wellness Center (TWC) – a national non-profit organization providing various services to people with cancer. Based on a previous study suggesting a relationship between group leader's behavior and patient outcomes, a model representing five basic dimensions of leader behavior was created (Lieberman, Yalom, & Miles, 1973). According to the model, all leaders expressed behaviors, with varying intensity and frequency, of evoke-stimulate, executive-management, meaning attribution, uses of self, and support-caring. In a study with 287 cancer patients that were currently participating in TWC support groups facilitated by licensed psychotherapists, two of the leader behaviors – executive-management and meaning attribution -- were found to be strongly associated with self reports of lower depression and fewer physical problems (Lieberman & Golant, 2002). The executive-management functions include establishing group rules, discussing the group's goals with participants, managing time, as well as managing the group's

dynamics. Meaning attribution refers to providing a cognitive framework for the group and includes explaining, summarizing, and seeking feedback from participants.

In a different study, group norms of support groups were examined along with their relationship to the participant outcomes (Lieberman, Altman, & Golant, 2004). Group norms are the implicit and explicit agreements about the group's characteristics. Group norms were assessed separately with a researcher-developed measure; a norm was defined as agreement by at least 75% of the 53 facilitators queried. The norms were categorized as intensity of emotional expression, boundaries, aggression-confrontation, counterdependence-dependence, and peer control. Close to 300 TWC support group participants responded to the group norms measure as well as measures for quality of life and level of depressive symptoms. Participant group norm scores were compared to those of their group's facilitator. As researchers hypothesized, the greater the fit between the participant's and leader's group norms, the better the participant's outcomes were for quality of life and level of depression. Another interesting finding was the diminished positive outcomes for participants that perceived their facilitators approving of aggressive and confrontational behaviors.

Costello (2007) in a dissertation study used a descriptive exploratory design to identify the roles and strategies employed by nurses facilitating support groups for adults with diabetes. Her intention was to distinguish ways that nurses, through support groups, can assist diabetics with their self-management of the chronic condition. Purposive sampling as well as a snowball approach was used to identify six nurses with the knowledge and experience of facilitating support groups for adults with diabetes. The six Registered Nurses were all Caucasian women over 40 years of age. All of the nurses had



personal experience with diabetes or another chronic health condition. Each nurse facilitator was interviewed on two separate occasions, asked to write a reflective narrative, and participate in a group interview. Few of the nurses completed the writing assignment and only four of the women were available for the group interview. Four research questions guided the data analysis of this study.

Only three of the four research questions addressed in this study are relevant. Results for the study's first research question exploring the participant's perception of their role as a facilitator reflected four major areas:

1. A philosophy of shared authority and group ownership;
2. A conception of diabetes as a highly complex disease which is interconnected with all aspects of one's life;
3. A focus on quality of life; and
4. A recognition of perfectionism as neither possible nor desirable in self-managing diabetes (p.89).

The nurses spoke of their facilitative role as having evolved over time. They each considered their educational backgrounds as having a significant influence on their support group facilitative role as well as their own experiences with chronic health conditions. Half of the women had been participants in a support group prior to facilitating a group.

The second research question explored strategies used by the facilitators. As presented in Table 1, the researcher identified 20 strategies organized into four major types of strategies. These strategy types reflected elements of both goals of social support and self-management. Although specific to diabetes support groups, and captured from a small sample of interviews, the strategies resonate of those discussed in the support group and self-management literature.

Table 1

| Diabetes Support Group Facilitator Strategy Types            |   |   |  |
|--|---|---|--|
| Connecting   | Information Sharing and Exchange  | Managing Group Dynamics   | Promoting Problem-Solving  |
| Fostering connections among participants                     | Sharing, interpreting, and applying information                                       | Creating the environment: <ul style="list-style-type: none"> <li>• Making a safe place</li> <li>• Attending to the space</li> <li>• Fostering a positive milieu</li> </ul>  | Talking through real experience  |
| Fostering connections between participants and the community | Connecting misinformation<br><br>Selective, goal-directed facilitator self-disclosure | Coordinating flow: <ul style="list-style-type: none"> <li>• Filtering out</li> <li>• Pulling in quiet/toning down gregarious participants</li> <li>• Dealing with a negative presence</li> </ul> Fostering group rules: <ul style="list-style-type: none"> <li>• Enabling peer mentoring</li> <li>• Pulling it together</li> <li>• Developing the cast</li> <li>• Holding back</li> </ul> | Practicing skills<br>Shopping for groceries<br>Eating out<br>Choosing at a “potluck” |

*Note.* From “Roles and Strategies of Nurses Facilitating Diabetes Support Groups: An Exploratory Study” by J.F. Costello, 2007 by Dissertation Abstracts International (UMI No. 3276978). Reprinted with permission.

The final research question sought to identify enhancers and barriers to using the aforementioned strategies. The first of three enhancers/barriers discussed by the nurses was the homogeneity of the support group. Strategies were more effectively used in homogeneous groups, where group participants were close in age, had similar levels of

education, shared a similar socioeconomic status, and were at a similar stage of diabetes progression. The next enhancer/barrier was accessibility to diabetes education. Support group facilitators felt their effective use of strategies were enhanced when individual and group education and counseling opportunities were available to their support group members. The third enhancer/barrier was access to quality health care.

During the group interview the facilitators agreed they could each benefit from group process skills training. They commiserated about the lack of on-going training and support for support group facilitators. Costello suggested continued research on the connection of social support and integration of diabetes self-management into participant's lives, the need to test the identified facilitator strategies using a questionnaire, and a desire for nurses to have a set of best practices for support group facilitation. Obvious limitations to this study are the small sample, the lack of diversity amongst the small sample, and the researcher's familiarity with four of the six participants. In the current study, a large sample of professional, lay, and peer facilitators of face-to-face support groups were studied using a descriptive research design.

### **Summary**

This first section of the literature review looked at three dimensions of support group research. The first dimension, group conditions, discussed the goals and expectations for support group participants, facilitators, and sponsoring organizations. The second dimension, group characteristics, established the facilitator types: healthcare professionals, lay persons, and peer volunteers. The third dimension, outcomes, covered both the positive and negative effects of support group participation with an emphasis on social support and self-management of a chronic condition.

The research literature provides great breadth to the proliferation of face-to-face support groups. Evident in much of the research conducted with cancer support groups is the fact that challenges exist for both professional and peer facilitators. It is unfortunate that little effort has been made to delve deeper into the significant challenges faced by support group facilitators. Attempts at producing a guide to best practices for facilitators have been limited to superficial lists lacking research-based evidence. Support groups clearly provide social support to persons dealing with a chronic health condition yet little is known about the strategies used to achieve this goal. The *social support behavior code* identifies five types of social support (Cutrona & Suhr, 1992). The *social support behavior code* was used to assess social support strategies in the current study's survey instrument.

Figure 2 illustrates the five types of social support that may be promoted by support group facilitators. A more comprehensive figure was introduced in chapter one representing facilitator's promotion of both social support and self-management strategies. An additional version of the figure is presented at the end of the next section in this chapter.

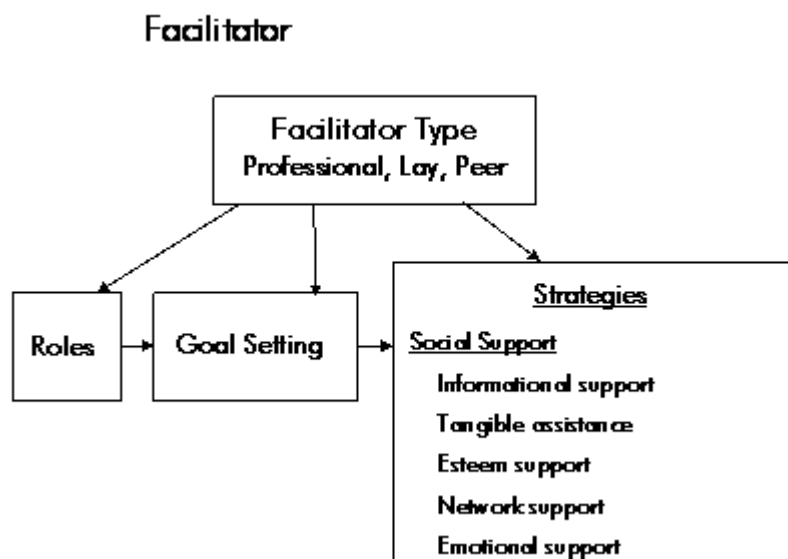


Figure 2. Social Support Strategies

While Costello's study addresses facilitators' perceptions of their role in support groups and identifies strategies used by facilitators, the study was limited to anecdotal evidence reported by only six nurses, four of whom have personal relationships with the researcher. More promising is the research on support group leader behaviors conducted by Lieberman and colleagues. The two leader behaviors -- executive-management functions and meaning attribution -- were associated with support group participant's self reports of psycho-social and physical health improvements. Executive-management functions included the establishment and discussion of group goals, thus supporting this study's emphasis on goal-setting. Meaning attribution refers to the support group leader's ability to explain, summarize, and seek feedback from participants. This leader behavior is relevant to transformative learning theory. Support group facilitators helped participants examine their beliefs, feelings, and behaviors during the transformative learning process and guide them toward a perspective transformation.

The vast majority of support group research has centered on health conditions such as cancer, diabetes, and HIV/AIDS. Chronic neurological health conditions such as Myotonic Muscular Dystrophy and Multiple Sclerosis represent two increasingly common chronic conditions experienced by Americans.

In the current study, professional, lay, and peer facilitators were surveyed regarding their role perceptions, support group goals, and strategies for promoting social support and self-management behaviors in face-to-face support group settings. Finally, this study addressed a noticeable gap in the research literature about facilitators of support groups for adults with chronic neurological health conditions.

### **Self-Management Behaviors**

While the first section of the literature review is about face-to-face support groups, this second section examines relevant information about strategies used to promote self-management behaviors in settings outside of support groups. Although much of the research studies are done in the context of patient self-management programs in hospital settings, the strategies used to promote self-management behaviors may have implications for face-to-face support groups.

The term *self-management* derives from a review of the literature addressing the daily regimen for patients dealing with diabetes (Goodall & Halford, 1991). The set of behaviors diabetics engage in to manage their blood glucose levels was previously referred to as *compliance* but Goodall and Halford suggested self-management has a less authoritative tone. A similar term, self-care, is often used to distinguish what the patient can do to treat their condition as compared with the medical care provided by a team of health care professionals (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

In the self-management literature there is often a distinction between the self-management skills and the practicing of self-management behaviors. For the purposes of this study, self-management refers to a set of behaviors used by a person with a chronic health condition to relieve any symptoms related to their condition. When appropriate, self-management skills are identified as separate from self-management behaviors.

This section of the literature review is organized into three sub-sections. The first sub-section, diabetes, discusses the role of self-management interventions in diabetes care. The second sub-section, chronic health conditions, highlights studies about self-management programs and interventions for a variety of chronic health conditions. Chronic care model, the third sub-section, addresses studies exploring self-management as they relate to a specific model of health care.

### **Diabetes**

Type II diabetes, with onset during adulthood, requires vigorous management by patients to monitor their blood glucose level (glycemic control), control their diet and exercise, and take either oral or injected medication. Self-care for diabetics has been a part of clinical management since the 1930s (Norris, Engelgau, & Narayan, 2001). Depending on the severity of the disease, a patient may need to add special tasks for the care of their eyes, feet, and gums. This chronic condition is the 6<sup>th</sup> leading cause of mortality in the United States (Heron, Hoyert, Murphy, Xu, Kochawuek, & Tejada-Vera, 2009).

Due to escalating health care costs, three types of health care interventions have been practiced in the past few decades. The first type of patient program is geared toward providing self-management information to increase diabetes knowledge, however,

research has shown that this type of program does not have a significant impact on patient's long-term glycemic control, the major outcome measured in diabetes self-management interventions (Goodall & Halford, 1991). A second type of program provides skills training with individualized feedback. These interventions have been shown to be more effective but participant drop out has been high with longer lasting interventions; few studies have been longitudinal and none have had long-term follow-up to check the efficacy of glycemic control. The third type, a more intensive behavioral intervention, is targeted toward weight loss. In addition to advocating for longitudinal studies, researchers have suggested that social support may be a critical factor in successful diabetes self-management. In the current study, self-management behaviors were examined in the context of support groups.

A robust review of randomized controlled trials (RCTs) – experiments commonly used to test the effectiveness of healthcare services – found five types of outcome measures for self-management skill training (Norris et al., 2001). In addition to glycemic control, RCTs looked at measures such as knowledge and attitudes, lifestyle behaviors and quality of life, cardiovascular disease risk factors, and use of health care services. Intervention components varied in terms of information and skills training presented but could be classified as primarily didactic or collaborative. Patients were passive recipients in didactic presentations while collaborative trainings included group discussions, hands-on practice, and other interactive training techniques. Didactic self-management interventions had no effect on patient weight loss, mixed results on their glycemic control and blood pressure, and positive effects on patient's diabetes knowledge. Collaborative self-management interventions had positive effects on patient's glycemic control and



mixed results for patient weight loss and blood pressure. Although few of the studies reviewed had follow-up periods longer than one year after the intervention, researchers found collaborative interventions that were ongoing and repetitive tended to have more positive results.

Steed et al. (2003) reviewed diabetes studies with one of three types of interventions: general education, self-management, or psychological. Each intervention included a quality of life or psychological well-being outcome measure. Self-management interventions showed a greater improvement in self-reports for quality of life compared to educational interventions; psychological interventions did not include a measure for quality of life. Compared with educational and self-management interventions, psychological interventions showed greater improvements in self-reports for depression. Although the researchers established a relationship between self-management behaviors, such as glycemic control and psychological well-being, it is still unclear if one influences the other. Due to limited descriptions of interventions and small samples, Steed et al. chose a discursive approach for this review as opposed to a meta-analysis.

### **Chronic Health Conditions**

In the early 1990s a team of researchers at Stanford University unveiled the Arthritis Self-Management Program that underscored the central role for the patient in managing their illness (Holman & Lorig, 2004). This program served as a prototype for future self-management programs directed toward persons with HIV/AIDS, chronic back pain, and other chronic conditions. The program content is taught in six two-hour sessions over a period of six weeks by trained peer instructors. Studies conducted by the

Stanford team found arthritis patients participating in the program reported a pain level 17 % below their baseline reports, a 9 % increase in physical activity, and 40% fewer visits to the doctor (Barlow et al., 1998).

The Stanford program of self-management has evolved to include five core skills that a chronically ill patient must practice (Lorig & Holman, 2003). The first skill is basic problem-solving where several potential solutions to a problem can be generated and evaluated for the best option. The second skill is decision making. The third self-management skill is resource utilization. This refers to any type of community or health resource that helps someone manage their health condition. Forming a partnership with a health care provider is the fourth self-management skill. Since a chronic health condition is not acute, a unique type of relationship can be fostered with health care providers. The final self-management skill is taking action by setting attainable, short-term goals. To teach these skills effectively the researchers investigated what prompted patients to make health behavior changes. Program participants overwhelmingly claimed the program helped them feel more in control of their condition.

A British program to improve exercise self-care for adults with Multiple Sclerosis (MS) was started in a hospital setting for a brief time period and continued in a non-clinical exercise center (Hartley, 2009). The program's focus was meant to combat the fatigue and symptoms of disability experienced by MS patients. Significant improvements were reported for participant's self-reports on quality of life ( $p = 0.0375$ ) as well as their walking speed ( $p = 0.006$ ). Program participants were generally satisfied with the program but expressed a preference for attending a program with people at the same level of disability.

A literature review addressing self-efficacy enhancing interventions for reducing chronic disability found study participants that were successful with their action plans increased their self-belief which empowered them to make behavior changes (Marks, Allegrante, & Lorig, 2005). These self-management behavior changes resulted in better overall health. The authors devised a list of seven strategies to enhance self-efficacy for people with chronic conditions.

1. Use a variety of learning strategies including lectures, discussions, brainstorming, demonstrations, goal setting, contracting, modeling, mental practice, homework, recall-enhancing methods, workbooks, texts, and videotapes, and provide mutual aid and support.
2. Involve significant others, such as spouse or family members, and encourage collaboration with other health care providers and self-efficacy of caregivers.
3. Foster self-management of exercise, food selection, weight control, fear, pain, depression and anxiety, and related self-monitoring strategies in small steps.
4. Apply encouragement, persuasion, and direct or indirect support for the desired changes.
5. Foster self-appraisal of emotional and physiological responses, decision-making, and the necessary knowledge, skills, and problem-solving ability to deal with disease-related issues across different domains.
6. Use trained educators, a detailed manual, and multicomponent teaching strategies with content drawn from both patients and practitioners.
7. Use both individual and small-group intervention approaches, especially collaborative and active participation strategies (p. 152).

A Dutch self-management intervention had smaller, disease-specific groups of participants led by nurse specialists (Schreurs et al, 2003). The researchers developed the program with an emphasis on personal goal-setting. Eighty-three men and women were organized into groups based on their chronic health condition of asthma, diabetes, or

heart failure. The program content for five sessions was the same for each group covering self-management tasks such as daily medication regimen, acting upon symptoms, and maintaining a healthy lifestyle. Participants chose their own goals, rehearsed their desired behavioral goal through role-playing scenarios, and wrote about their goal attainment process. Seventy-two percent of the participants were satisfied with the program sessions, though 23% acknowledged wanting additional sessions once the program ended. As far as program components, participants gave higher ratings for goal-setting strategies over homework assignments ( $t(57) = 3.98, p < 0.01$ ). Participants with more years of formal education tended to give a lower rating for the overall program ( $r = -0.36, p = 0.004$ ). Most of the nurse specialists leading the groups felt participants learned the most from their peers. Of the nine nurse specialists, four felt they needed more training to adequately lead the groups.

An Australian self-management intervention, *HealthPartners*, aimed at individuals with diabetes and/or cardiovascular disease, focused on an action-planning process (Boldy & Silfo, 2006). *HealthPartners*, facilitated by two nurses, included several different programs (exercise, nutrition, healthy living education with peer support, and self-management) for participants. The core of the intervention was the development of the action plan between the facilitator and participant. Together they identified relevant health issues, set goals, and agreed on action steps to meet the goals. The group of 127 participants generated 314 health issues. The most common issue identified was understanding symptoms/treatment (21%). Over 300 goals were set during a 14-month period; the most common goal was to improve understanding of symptoms/treatment (29%). The second most common goal was to increase exercise

(17%). To gauge the overall impact of the action-planning process participants identified a stage of success for each of their goals as identified by the stages of change model by Prochaska, DiClemente, and Norcross (1992). Stages were designated as pre-contemplation, contemplation, preparing, action, and maintaining. Thirty-eight percent of the goals were at a different stage by the end of the project, and approximately half of this group at the maintenance stage. Goals related to improving an understanding of symptoms/treatment proved easier to achieve than specific health maintenance goals (62% compared with 47%). Boldy and Silfo (2006) advocate for establishing self-management initiatives within a peer support framework.

Several studies on self-management suggest that including a social support component is critical to the successful practice of self-management behaviors. Patient education programs promoting the practice of self-management behaviors tend to produce better results when their duration is of a longer rather than shorter term. In the current study, self-management behaviors were identified as breathing techniques, exercise, fatigue, nutrition and diet, medications, pain management, relaxation and emotion management (Lorig, Holman, Sobel, Laurent, Gonzalez, & Minor, 2000). Both didactic and collaborative strategies used by support group facilitators were examined. In addition, the five core self-management skills identified by Lorig and Holman (2003) as being critical for all chronically ill people to practice were used in the survey instrument.

### **Chronic Care Model**

The Chronic Care Model (CCM) is a framework meant to guide quality improvements in clinical settings to meet the concerns for the increasing population of patients with chronic health conditions (Wagner, Austin, Davis, Hindmarsh, Schaefer, &

Bonomi, 2001). The CCM focuses on the healthcare system but fully supports a shift toward empowering the patient. One of the six elements of the CCM specifically concerns more interactive and less didactic patient self-management practices. The CCM encourages primary care clinics to integrate collaborative goal setting, action planning, and problem solving into their practice. Activities such as role-playing and skills demonstrations are promoted.

Researchers examined the relationship of Type 2 diabetes patients' self-management behaviors at primary care clinics with implementation of the CCM (Parchman & Kaissi, 2009). Over 600 participants responded to a survey, distributed at 20 primary care clinics, inquiring about the patient's stage of change for self-care behaviors: diet, exercise, blood glucose monitoring, and adherence to medication regimen. Stages of change refer to a patient's readiness for practicing a self-care behavior; they are either in the pre-contemplation, contemplation, preparation, action, or maintenance stage (Prochaska et al., 1992). The study also looked at patient risks for cardiovascular disease; clinics provided patient's latest lab results for A1C level, blood pressure, and LDL cholesterol. Health care providers responded to surveys assessing the clinic's compliance with the CCM components. Twenty-five percent of the patients reported being at the maintenance stage for the four self-care behaviors. Thirteen percent of the patients had good control of the three cardiovascular risk factors. The probability of patient's control for cardiovascular risks increased with the maintenance stage of change for all four self-care behaviors. There was also a relationship between patient's good control for cardiovascular risks with the clinic's links to the community.

Community linkages, one of the CCM components, refer to the diabetes specialists, health educators, and educational resources accessible to the patient at the clinic.

Another study examined the effects of two self-management approaches for diabetic patients and the correspondence to the CCM (Schillinger, Handley, Wang, & Hammer, 2009). Over 300 study participants were randomly assigned into one of three groups: usual care, automated telephone support with nurse follow-up (ATSM), and monthly group visits with a physician and health educator (GMV). The ATSM phone call lasted 6-10 minutes; the monthly group session was 90-minutes long and took place over a period of nine months. Both the ATSM and GMV participants worked on action plans. Most participants had limited English proficiency and had poorly controlled diabetes. The primary outcome studied for this intervention was self-management behavior but functional and metabolic outcomes were also studied. After one year the ATSM treatment participants showed statistically significant improvements in physical exercise, interpersonal communication, self-management behaviors such as foot care, and significant reductions in days spent in bed or in lost time preventing them from daily activities. Though there were improvements for GMV participants, the ATSM findings were more dramatic.

A more recent study, with heart failure patients, sought to identify factors influencing the self-management process (Meyerson & Kline, 2009). Nurse interventionists met with 27 study participants at their homes to practice mutual goal setting, a procedure where both nurse and patient agree on and prioritize goals. Nurses maintained anecdotal records from patient visits. Researchers used content analysis to identify four themes related to patient goals: dealing with competing priorities, self-

efficacy related to self-management, return to previous level of activity, and psychosocial adaptation. The study did not address the participants' level of success with goal attainment; researchers stressed the importance of nurses understanding the participant's perspective as well as their willingness to adopt positive health behaviors.

In the current study, support group facilitators for adults with neurological health disorders were studied to identify strategies they use to achieve goals of promoting self-management behaviors and social support.

### **Summary**

This second section of the literature review has examined studies related to self-management programs and behavioral health interventions focused on self-management for adults with a chronic health condition. The first sub-section, diabetes, introduced studies discussing self-management interventions for one of the leading causes of American mortality. Outcome measures such as glycemic control and weight loss were addressed. Collaborative self-management interventions were found to be effective but a call for longer-lasting interventions was made from researchers. A series of best practices for self-management programs evolved with goal-setting as a key behavior toward health change. The second sub-section, chronic health conditions, highlights the progress made by Stanford University researchers in developing a series of highly-structured classes for people with chronic health conditions. The peer-taught course emphasizes five core self-management skills recommended for chronically ill individuals. Numerous studies have found statistically significant results for patients engaging in self-management programs and interventions; these include improvements in health care status, decrease in health resource utilization, and increased self-management behaviors. The third sub-section,



chronic care model, briefly established an institutional framework promoting self-management practices for those with chronic health conditions. Researchers advocated for more interactive, collaborative activities such as action planning, role-playing, and skills demonstration.

The robust studies on self-management programs and interventions using randomized controlled trials is convincing evidence that persons with chronic health conditions can benefit from learning self-management skills and practicing self-management behaviors. Though many researchers, and study participants, have argued for longitudinal studies and more frequent program sessions, there has been no formal practice of integrating self-management into the support group paradigm. Social support has been shown to be a critical component of successful diabetes and cardiovascular disease self-management programs. Support groups are known to provide social support for participants. In the current study, the perceptions of professional, lay and peer support group facilitator's role in promoting self-management behaviors were investigated along with the strategies used to promote self-management in face-to-face support groups.

The stages of change model (Prochaska et al., 1992) for self-care behaviors parallels the meaning-making process articulated by the transformative learning theory. The model suggests a chronically ill patient experiences varying degrees of readiness for making health behavior changes. The transformative learning process offers a more suitable model for this study because of its more explicit description of behavioral changes which a support group facilitator can identify.

Earlier in this chapter Figure 2 presented the five types of social support that may be promoted by support group facilitators. Figure 3 represents strategies support group

facilitators may use to promote the goals of self-management skills and self-management behaviors. Both the five core self-management skills (Lorig & Holman, 2003) and description of self-management behaviors (Lorig, Holman, Sobel, Laurent, Gonzalez, & Minor, 2000) informed the current study's survey instrument.

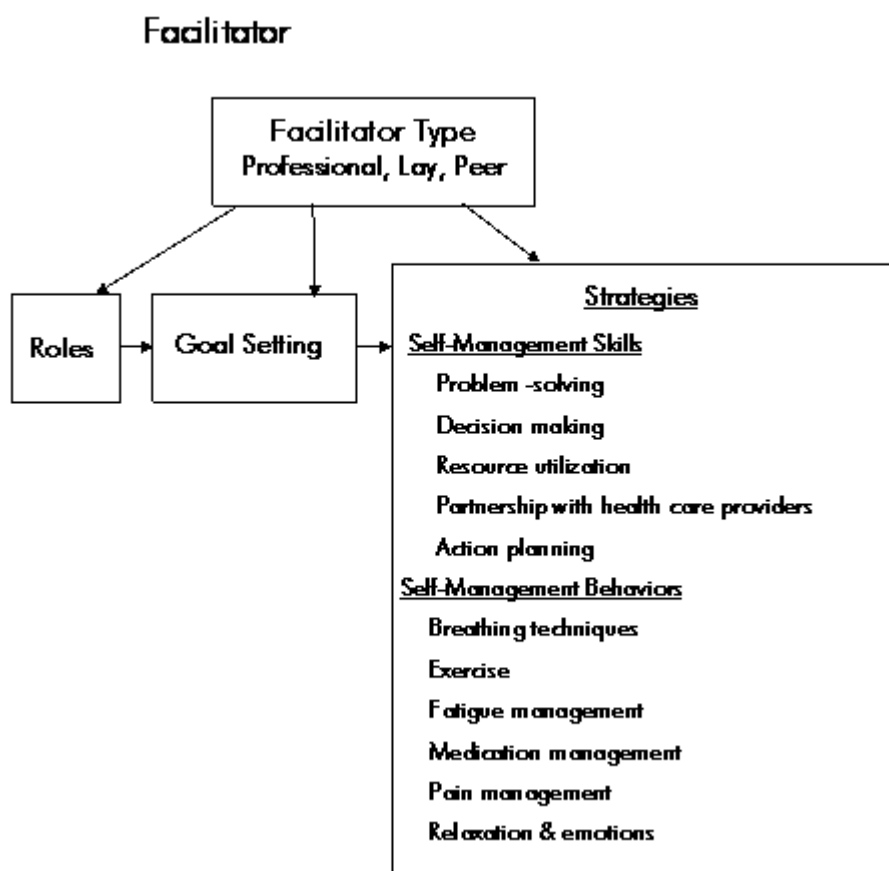


Figure 3. Self-Management Skills and Self-Management Behaviors

### **CHAPTER III METHODOLOGY**

This chapter presents the study methodology. Included in the section is the research design, sample, protection of human subjects, instrumentation, pilot test, procedures, and data analysis.

The primary purpose of the study was to explore how support group facilitators for adults with chronic neurological health conditions perceive their role in promoting social support and self-management behaviors and what strategies they use to achieve these goals. The study investigated the following research questions:

1. How do different support group facilitators (professional, lay, peer) perceive their role?
2. What are the attitudes toward goal-setting among the different facilitator types (professional, lay, peer)?
3. Does the promotion of social support strategies vary among the different facilitator types?
4. Does the promotion of self-management skill strategies vary among the different facilitator types?
5. What strategies are used to promote self-management behaviors and do they vary among the different facilitator types?
6. Does the promotion of transformative learning vary among the different facilitator types?

#### **Research Design**

The study used a descriptive survey research design to assess the perceptions of support group facilitators for adults with either Myotonic Muscular Dystrophy (MMD) or

Multiple Sclerosis (MS). The design is appropriate for characterizing a given population (Isaac & Michael, 1997). Specifically, the study examined the perceived roles and goals of support group facilitators and the strategies used to fulfill these goals. Variables of interest included the type of support group facilitator (professional or lay), whether the facilitator shared the chronic neurological health condition as the group participants (peer), perceptions of role and goals (facilitator role, goal-setting, transformative learning), and strategies used to achieve goals (social support, self-management skills, self-management behaviors).

Participants had the option of receiving a printed version of the survey instrument through U.S. mail or taking a web-based version of the survey. The majority of survey respondents completed the online version hosted on a website by SurveyMonkey, a professional online survey company. Approximately 15% of the respondents opted to receive a hard copy version of the survey mailed to them. Administering an online survey is quite commonplace now that the majority of U.S. households have Internet access and many with high speed connections (Dillman, Smyth, & Christian, 2009). Using mixed-mode data collection is known to reduce survey costs and measurement error, improve timeliness, coverage, and response rates (Dillman et al., 2009). A German study administered a traditional written survey to a random sample of the German population and an online survey to a random sample of Internet users in the country (Bandilla, Bosnjak, & Altdorfer, 2003). Researchers found many differences but when compared by similar educational level, there were no statistically significant differences in mean scores between the written and online survey responses. Findings from another study with college students and alcohol use also provide evidence that web-based and

paper-based surveys produce comparable results (McCabe, Diez, Boyd, Nelson, & Weitzman, 2006).

Participation in the study was voluntary. Participants had the opportunity to mail a postcard or enter their email address in an online format, separate from the survey, for entry in a drawing for an Amazon.com gift certificate. The 245 participants providing their email address, or a mailing address, were sent a document, *Tips for Support Group Facilitators*, once the study commenced. The document is based on the research results of this study (Appendix B).

### Participation and Sample Demographics

The population of interest is facilitators of support groups in the United States for adults with chronic health conditions. The current study focused only on face-to-face facilitators for two chronic neurological health conditions, Myotonic Muscular Dystrophy (MMD) and Multiple Sclerosis (MS). The sampling frame for the study included facilitators for the 9 support groups for adults with MMD and facilitators for the approximately 1437 support groups for adults with MS. Table 2 identifies the 1437 known support groups by their organizational affiliation. The sample included both professional and lay facilitators with or without the chronic neurological health condition.

Table 2

| Sampling Frame                      |  |                           |
|-------------------------------------|--|---------------------------|
| Organization                        | Type of Support Group Facilitators       | Population                |
| National Multiple Sclerosis Society | Professional, Lay, and Peer Facilitators | ~1300<br>10% Professional |
| Multiple Sclerosis Foundation       | Peer Facilitators                        | ~120                      |
| MS Care Centers                     | Professional Facilitators                | ~ 174                     |
| Myotonic Dystrophy Foundation       | Professional and Peer Facilitators       | 9                         |

Sampling for this study occurred in two ways. First, convenience sampling involved contacting two national MS organizations. One organization, National Multiple Sclerosis Society, based in the Northeast, sponsors approximately 1,300 support groups across the United States. Approximately 10% of the facilitators are professionals with the remaining being lay persons or peers (J. Gibson, personal communication, September 4, 2009). The Multiple Sclerosis Foundation, based in the South, sponsors approximately 120 support groups across the United States. Each of these groups is peer facilitated and meets in face-to-face settings. Participants from both national organizations were recruited through an email message sent by the organization's support group coordinator to a majority of their support group facilitators. A personalized invitation letter from the researcher accompanied the email message (Appendix A).

Second, using a snowball sampling technique, additional participants were recruited from regionally-based Multiple Sclerosis Care Centers such as the Shepherd Center in the South. Telephone calls were made to 174 MS Care Centers throughout the United States. The vast majority of these Centers did not sponsor support groups and offered a referral to their local NMSS-sponsored support group in their respective community. The direct phone calls led to 17 additional facilitators, primarily professionals, not involved in either of the national MS organizations already identified. In addition, the Myotonic Dystrophy Foundation identified nine support groups for adults with MMD. These are located throughout the United States. Each of the MMD facilitators was contacted directly using a similar personalized letter from the researcher.

These two sampling procedures yielded a sample of 302 respondents. The National Multiple Sclerosis Society had 38 of their 55 national chapters participate in the

research study. The 38 chapters reached a total of 1,071 support group facilitators; approximately 260 of the respondents were affiliated with the NMSS. Both online and hard copy survey participants are accounted for in Table 3. Thirty-four participants chose the hard copy version of the survey, while 268 participants completed the online survey.

Table 3

| Online and Hard Copy Survey Participants |                         |                        |                            |
|--|-------------------------|------------------------|----------------------------|
| Organization                             | Online Surveys Received | Hard Copy Surveys Sent | Hard Copy Surveys Received |
| National Multiple Sclerosis Society      | 226                     | 39                     | 32                         |
| Multiple Sclerosis Foundation            | 19                      | 0                      | 0                          |
| MS Care Centers                          | 17                      | 3                      | 2                          |
| Myotonic Dystrophy Foundation            | 6                       | 1                      | 0                          |
| Total                                    | 268                     | 43                     | 34                         |

Therefore, 25% of the NMSS support group facilitators notified about the survey actually participated. NMSS was only able to provide demographic information for gender. Of the 1,071 support group facilitators, 205 (19%) are male. In Table 3 the percentage of male support group facilitators that participated in the study is 20.2%. Geographic representation can be assessed by the 245 of 302 respondents that chose to provide contact information to participate in both the Amazon.com gift certificate drawing and receive a copy of the document, *Tips for Support Group Facilitators*, based on this survey's results. At least 42 of the 50 United States were represented.

Table 4

## Demographic Information on Support Group Facilitators

| Variable               | Range                           | f   | %    |
|------------------------|---------------------------------|-----|------|
| Gender <sup>a</sup>    | Female                          | 227 | 77.7 |
|                        | Male                            | 59  | 20.2 |
| Age Range <sup>a</sup> | 20-30                           | 10  | 3.4  |
|                        | 31-40                           | 20  | 6.8  |
|                        | 41-50                           | 64  | 21.9 |
|                        | 51-60                           | 119 | 40.8 |
|                        | 61-70                           | 64  | 21.9 |
|                        | Over 70 years old               | 9   | 3.2  |
| Ethnicity <sup>b</sup> | African-American or Black       | 6   | 2.1  |
|                        | Asian                           | 1   | .3   |
|                        | European or White               | 259 | 88.7 |
|                        | Hispanic                        | 4   | 1.4  |
|                        | Native American                 | 3   | 1.0  |
|                        | Other                           | 8   | 2.7  |
| Education <sup>a</sup> | Less than high school education | 0   | 0    |
|                        | High school diploma or GED      | 38  | 13.0 |
|                        | Community college or AA degree  | 24  | 8.2  |
|                        | Some college                    | 68  | 23.3 |
|                        | Bachelor's degree               | 82  | 28.1 |
|                        | Master's degree                 | 49  | 16.8 |
|                        | Doctoral degree                 | 14  | 4.8  |
|                        | Other                           | 11  | 3.8  |

<sup>a</sup>n = 286. <sup>b</sup>n = 281.



### **Protection of Human Subjects**

The use of human subjects as research participants was approved by the University of San Francisco Institutional Review Board for the Protection of Human Subjects. The decision was based upon a review of the study's purpose, background and design, description of the sample population and research procedures, as well as the guarantee of participant confidentiality. The researcher complied with all guidelines to protect the confidentiality of research participants.

The National Multiple Sclerosis Society (NMSS) had its own research review process. Upon receipt of approval for this study by the University of San Francisco's Institutional Review Board (IRB), the researcher submitted a copy of the IRB consent form, IRB approval memo, researcher's letter to participants, study protocol, and copy of the survey instrument to the NMSS. Within one week the NMSS notified the researcher the study was approved.

### **Instrumentation**

A researcher-designed survey instrument was used for the study. The instrument was designed following the guidelines outlined by Dillman (1991). Based on social exchange theory, Dillman has accumulated evidence supporting a claim that his procedures improve survey response rates. For homogenous groups, such as the sample for this study, Dillman reports response rates of 60-80%.

Dillman proposed three design considerations. The first was to reduce the perception of participant's cost for completing the survey so that the survey appears interesting and simple. This is achieved through the question-writing principles, sequencing of question items, visual presentation, booklet format, and mailing

procedures. The second design consideration was to increase the perceived rewards for the survey recipient by making the questions interesting. The third design consideration was to increase trust by assuring confidentiality and having a known sponsorship affiliated with the survey. All three were followed in the design of this survey.

The *Support Group Facilitator Survey* (Appendix C) consisted of 59 items. Thirty-five of the items used a 4-point Likert scale from “Strongly Agree” to “Strongly Disagree”. All Likert items also included a “Does Not Apply” option set off from the 4-point scale. The remaining 24 items were closed-ended multiple response questions, some with an additional fill-in-the-blank response for “Other.”

The researcher-designed question stems were based on information derived from the research literature. Figure 4 represents the variables investigated and their linkage to the survey instrument. There were many background and substantive issues explored in the survey. For example, survey item 43 draws from the support group literature on facilitator role as well as structured telephone interviews with eight Multiple Sclerosis support group facilitators in Northern California. Items for the goal-setting variable were generated based on goal-setting theory and support group research. Items for the social support variable represent a variety of strategies used to promote the five types of social support (informational support, tangible assistance, esteem support, network support, emotional support) identified by Cutrona and Suhr (1992). Items for the self-management skills variable represent a variety of strategies used to promote the five core self-management skills (problem-solving, decision making, resource utilization, forming a partnership with a health care provider, action planning) identified by Lorig & Holman, 2003. Items for the self-management behaviors (breathing techniques, exercise, fatigue

management, nutrition and diet, medication management, pain management, relaxation and emotion management) variable represent both didactic and collaborative strategies discussed in self-management literature (Norris, Engelgau, & Narayan, 2001).

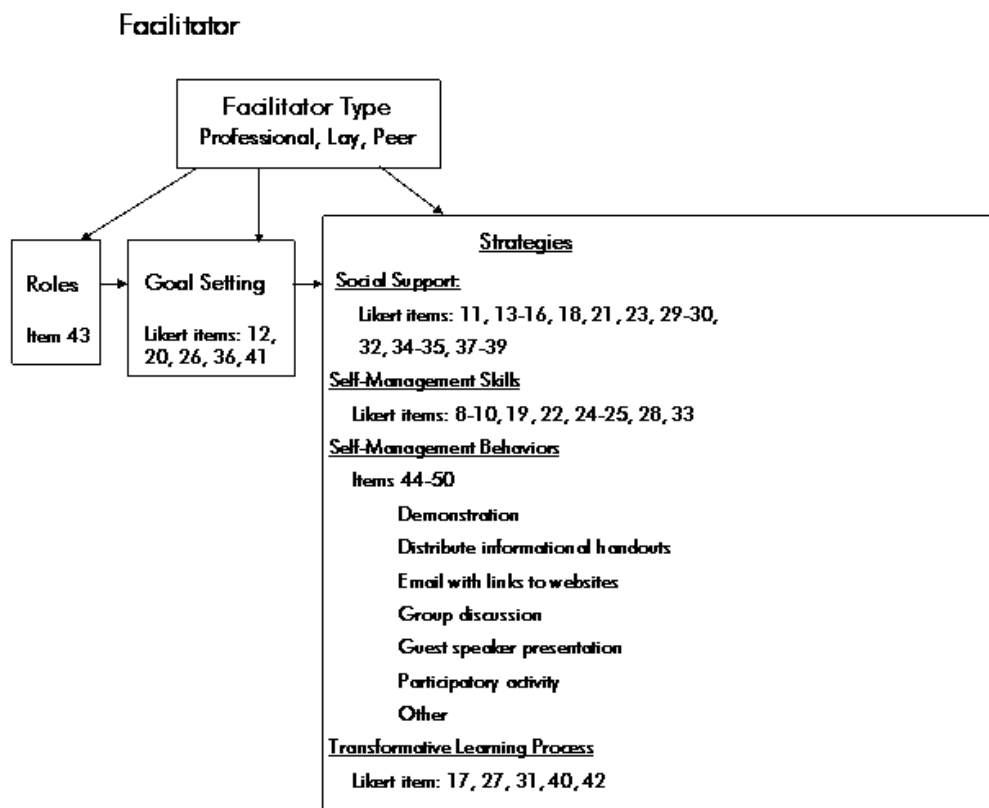


Figure 4. Survey Instrument Linkage to Model

The instrument was reviewed for content validity by two experts. The first expert was a psychologist with post-doctoral research experience as well as two years of face-to-face facilitation of a support group for adults with neurological chronic health conditions. The psychologist was provided with information about the proposed study's variables of interest and had reviewed an earlier version of the survey instrument. The psychologist noted an improvement over the earlier version of the instrument and verified that survey item content is appropriate for support groups for both Myotonic Muscular Dystrophy

and Multiple Sclerosis. The second expert was a practitioner with several years of experience facilitating face-to-face support groups for adults with Myotonic Muscular Dystrophy. This expert, a seasoned practitioner with little formal education, confirmed the appropriateness of the survey for the intended audience. She also commented that breathing techniques should be taught by a pulmonary specialist in response to item 44. No changes in the survey instrument were made since the item allows for a response of “guest speaker presentation” to address breathing techniques. Responses to item 43 initiated edits to the instructional text preceding the question.

An estimate of the reliability for all Likert scales was conducted. The Likert scales included goal-setting (Cronbach's  $\alpha = .458$ ), transformative learning (Cronbach's  $\alpha = .437$ ), self-management skills (Cronbach's  $\alpha = .702$ ), and social support (Cronbach's  $\alpha = .783$ ). Both the self-management skills and social support scales included several more survey items than the two other scales. Both the goal-setting (Cronbach's  $\alpha = .502$ ) and transformative learning (Cronbach's  $\alpha = .501$ ) scales reliability would increase if one item was deleted from each scale.

Table 5

## Variables Used in the Study

| Variable                        | Survey Item   |
|---------------------------------|---|
| Goal-setting                    | 12. I try to help members set realistic goals for themselves.<br>20. Support group activities are organized to guide the group toward optimal health.<br>26. Each year I identify goals for the support group.<br>36. It is difficult to predict how a group meeting will turn out.<br>41. I wish I had more control of the support group's direction.  |
| Transformative Learning Process | 17. I often try to help a member evaluate their beliefs or behaviors.<br>27. My role as the facilitator includes modeling healthy behaviors.<br>31. Members can learn valuable information from their peers in the group.<br>40. I believe that recently diagnosed members have different needs in the support group.   |
| Facilitator Role                | 42. I have witnessed remarkable changes with members over time.<br>43. Which two statements best describe your role as the facilitator for this support group?  |
| Self-Management Skills          | 8. When learning a new skill or technique, I encourage members to practice during the meeting.<br>9. Members frequently discuss what their short and long-term goals are.<br>10. The main purpose of this support group is to learn how to remain healthy.<br>19. As a group we often brainstorm possible solutions to a member's problem.<br>22. I coach members toward understanding a new way of thinking or doing things.<br>24. Practical skills such as operating an electronic wheelchair can be learned at this support group meeting.<br>25. I encourage members to form partnerships with their health care providers.<br>28. I regularly notify members of health or disability-related events in the community.<br>33. When I know a member has an important decision to make, I follow up with them at the next meeting. |
| Self-Management Behaviors       | 44. In the support group, how have you handled the management of breathing techniques?<br>45. In the support group, how have you handled exercise?<br>46. In the support group, how have handled the management of fatigue?<br>47. In the support group, how have handled the management of nutrition and diet?<br>48. In the support group, how have you handled the management of medications?<br>49. In the support group, how have you handled pain management?<br>50. In the support group, how have you handled the management of relaxation and emotions?  |
| Social Support                  | 11. I try to find a mentor, or role model, for new members.<br>13. If a member shares information I think may be incorrect, I follow up with a medical or health expert for accuracy.<br>14. When a member expresses a strong sense of self-blame, I try to encourage them to see things differently.   |

Table 5 (continued). Variables Used in the Study

|                         |  |
|-------------------------|--|
| Social Support          | <p>15. When a member has not attended a meeting for awhile, I make a point of contacting them.</p> <p>16. It is not appropriate for members to ask each other for any type of help outside the meeting.</p> <p>18. A list of support group members contact information is available to the group.</p> <p>21. My role is to help validate member's experience or feelings about having a chronic health condition.</p> <p>23. I have encouraged members to carpool to meetings.</p> <p>29. I have organized social events for members outside of the regular meeting time.</p> <p>30. I encourage members to make requests at meetings for help with some of the challenges they are dealing with.</p> <p>32. I encourage members to applaud others small or big personal successes.</p> <p>34. To help make a topic more meaningful to members, I break down the main points beforehand.</p> <p>35. There is nothing to do for a member with low self-esteem.</p> <p>37. During our meetings I encourage members to share personal experience that will provide helpful information to others.</p> <p>38. I discourage members from meeting outside of the assigned support group meeting time.</p> <p>39. I practice active listening by focusing on the speaker and suspending judgment.</p> |
| Co-Facilitation         | 1. Are you the only facilitator for this support group?  |
| Support Group Quantity  | 55. How many different support groups do you now facilitate?   |
| # of Years Facilitating | 2. How long have you been facilitating this support group?   |
| Meeting Frequency       | 3. How often does this support group meet?   |
| Group Membership        | 4. How would you describe the membership for this group?   |
| Membership Type         | 5. Is membership open?   |
| Meeting Attendance      | 6. How many people generally attend each support group meeting?  |
| Meeting Duration        | 7. How long is each support group meeting?   |
| Main Challenge          | 51. What is your main challenge with facilitating a support group?   |
| Previous Attendance     | 52. Have you ever been a participant in any support group prior to facilitating this group?  |
| Occupation              | 53. What is your occupation?   |
| Education               | 54. How many years of formal education do you have?  |
| Peer                    | 56. Do you share the same neurological chronic health condition as the support group participants?   |
| Gender                  | 57. What is your gender?   |
| Age                     | 58. What is your age?  |
| Ethnicity               | 59. What is your ethnic background?  |

### **Pilot Test**

The survey instrument was pilot tested with five Multiple Sclerosis support group facilitators, all located in Northern California. Two of the pilot test participants were given a hard copy of the survey. The remaining three participants completed the web-based version of the survey. Each of the participants was interviewed on the telephone after completing the survey.

Survey items 44-50 received minor edits based on the pilot-tested hard copies. Of particular importance was the amount of time necessary to complete the survey. Participants took anywhere from 10 to 30 minutes to complete either the online survey or hard copy versions though most completed the survey between 15-20 minutes.

Pilot test participants were questioned as to whether any part of the survey was confusing or irrelevant and whether they thought something was missing. Four of the five participants had favorable comments including “straight-forward,” “interesting,” and “a benefit” which caused one participant to think about her support group and what she might do at the next meeting. Another woman expressed confusion about negatively-worded questions such as the Likert item, “It is not appropriate for members to ask each other for any type of help outside the meeting.” No changes were made as only one of the five participants expressed difficulty with negatively-worded statements. Two participants suggested that Yes/No responses seemed more appropriate than simply agreeing or disagreeing with several of the Likert survey items. No changes were made as this would have dramatically altered the survey as well as the integrity of using Likert scales.

## **Procedures**

### **Data Collection**

Four organizations agreed to distribute the survey. The National Multiple Sclerosis Society (NMSS), based in the Northeastern part of the United States, has outreach to approximately 1,300 support groups. They agreed to distribute the researcher's invitation letter to all of their support group leaders. Once this study received Institutional Review Board (IRB) approval, a copy of the survey instrument and IRB approval letter was sent to the lead researcher at the NMSS organization.

The contact at the NMSS sent a communication to all NMSS chapter presidents about participation in the research study (Appendix D). Chapter presidents were instructed to contact the NMSS national headquarters for additional information. Additional information included the researcher's invitation letter in an email with a hypertext link to the survey instrument hosted on a website by SurveyMonkey, a professional online survey company. The letter also included the researcher's contact information to request a hard copy version of the survey.

The survey information was also posted to the NMSS list-serve. Thirty-eight of the 55 NMSS chapters participated in the outreach process; a total of 1,071 support group facilitators were contacted by email or a hard copy mailing from the NMSS national headquarters. Approximately five weeks later a second email communication was sent to the 1,071 support leaders with a direct link to the survey (Appendix E).

A more direct approach was used by the Multiple Sclerosis Foundation (MSF). The organization's coordinator emailed approximately 120 support group facilitators with a link to the online version of the survey instrument. The MSF coordinator decided that



an offer of hard copy surveys was not necessary; she also did not attempt a second communication with the facilitators. The researcher was not able to ascertain what prevented the offer of a hard copy version or a second communication. It was discovered during the data collection period that an overlap existed with support group affiliation. Apparently there are several support groups affiliated with both the NMSS and MSF. It is unclear how many groups overlap but it does not present a problem for this study's findings.

Originally the researcher contacted eight support group facilitators affiliated with the Myotonic Dystrophy Foundation (MDF) by email. Few responses to the survey occurred. Mid-way through the data collection period the MDF director sent an email supporting the research study (Appendix F).

A contact at the Shepherd Center suggested checking the website for The Consortium of Multiple Sclerosis Centers. Telephone calls were made by the researcher to 174 Multiple Sclerosis Care Centers, located throughout the country, to identify professional support group facilitators unaffiliated with the two national MS organizations. Thirty-five of the Centers had disconnected telephone numbers or no way to leave a recorded message. At least 42 of the Centers did not offer support group meetings and offered referrals to the local NMSS office. The researcher either left recorded messages about the survey or spoke with a support group facilitator at the remaining 97 Centers. Approximately twenty-two support group facilitators affiliated with the Centers completed the survey.

As soon as NMSS approved the study, the same procedures for the MS Foundation were followed for distribution of the invitation letter. The distribution of the

survey instrument to the Shepherd Center and Myotonic Dystrophy Foundation support group facilitators was more direct.

A total of 43 hard copy surveys were mailed yet only 34 were returned to the researcher. Email or telephone reminders were made to all hard copy recipients if they had provided the additional contact information. Forty of the hard copy surveys were requested by support group facilitators affiliated with the NMSS.

### **Data Cleaning**

All of the data for analysis came from the researcher-designed survey instrument, *Support Group Facilitator Survey* (Appendix C). The general strategy was to separate Likert items from closed-ended multiple response questions. The 35 Likert items represent four different scales; each scale's mean and standard deviation is presented as well as the frequencies and percentages of responses for each item. For analysis purposes, the responses were scored 1 to 4 with a lower score representing more agreement with the statement. The majority of Likert-type survey items had between 3-6 missing values. These values were replaced by the mean score based on all available cases.

The first step for the data analysis was the preparation and organization of the data set. Hard copy survey was manually entered into SurveyMonkey. Care was taken to confirm that participants hand written responses were correctly entered into the online format. When the data collection period ended the survey sample included 302 responses. All responses were exported from SurveyMonkey into an Excel spreadsheet document. Before bringing the data into the SPSS 15.0 for Windows Graduate Student Version statistical software application, short titles were given for each variable.

The raw SPSS data file was examined for (a) out-of-range responses, (b) checking for correct responses to prevent data entry errors, and (c) dealing with missing data. Missing data codes were entered for multiple responses, omitted responses, and the *Does Not Apply* option for all Likert items. Seven cases of missing data for items 8-42 were deleted. An additional three cases were deleted for missing 17, 20, or 29 Likert responses. Five Likert items (16, 35, 36, 38, and 41) were reverse coded.

As shown in Table 5 variables are organized into the four Likert scales: goal-setting, transformative learning, social support, and self-management skills. Research question one covers the goal-setting scale and the facilitator role variable. Research question two uses the social support scale. Research question three concerns the self-management skills scale. Research question four involves the self-management behavior variable. Research question five takes the transformative learning scale into account. The final research question addresses all of the previously mentioned variables, except for transformative learning, and also employs variables 53 and 56 to identify the facilitator types. Table 3 displays demographic data collected from variables 54, 57-59. Data from variables 1-7, 51-52, and 55 are reported in Appendix G.

An additional step before addressing the research questions included looking at the frequency distributions on all of the variables. A qualitative analysis for “other” responses was done on several survey items including demographics, role description, self-management behavior strategies, and facilitator challenges. An effort was made to examine the “other” response to see if it could fit in with one of the existing response categories. For example, item 59 on ethnic background included a response category, “European or White,” yet several participants wrote in Caucasian for the “other”

response. In this case, the “other” responses were counted as “European or White.” In several cases when someone wrote in synonyms for words in response categories, the response was re-coded as that category.

### **Data Analysis**

Data analysis was different for each of the research questions as described below.

#### **Research Question 1**

How do different support group facilitators (professional, lay, peer) perceive their role? To answer this question the frequency distribution for facilitator role was produced providing evidence as to which roles are most commonly perceived by support group facilitators. An additional frequency distribution was organized by facilitator type, providing evidence as to whether or not the facilitative role differs as perceived by the four facilitator types.

#### **Research Question 2**

What are the attitudes toward goal-setting among the different support group facilitator types? To answer this question the five Likert items making up the variable goal-setting were summed to create a scale. The means for goal-setting were produced, providing evidence as to what extent facilitators employ goal-setting strategies. To address the differences among facilitator types, an Analysis of Variance (ANOVA) was performed, providing evidence as to whether or not the facilitator types differ on goal-setting.

#### **Research Question 3**

Does the promotion of social support strategies vary among the different facilitator types? To answer this question the 16 Likert items making up the variable

social support were summed to create a scale. The frequency distribution and means for social support were produced, providing evidence as to what extent strategies are used by support group facilitators to promote social support. In this study, social support referred to any of five types of support: information support, tangible assistance, esteem support, network support, and emotional support (Cutrona & Suhr, 1992; Mo & Coulson, 2008). To address the differences among facilitator types, an Analysis of Variance (ANOVA) was performed, providing evidence as to whether or not the facilitator types differ on promotion of social support strategies.

#### **Research Question 4**

Does the promotion of self-management skill strategies vary among different facilitator types? To answer this question the 9 Likert items making up the variable self-management skills were summed to create a scale. The frequency distribution and means for self-management skills were produced, providing evidence as to what extent strategies are used by support group facilitators to promote self-management skills. In this study, self-management skills referred to problem-solving, decision making, resource utilization, forming a partnership with a health care provider, and action planning (Lorig & Holman, 2003). To address the differences among facilitator types, an Analysis of Variance (ANOVA) was performed, providing evidence as to whether or not the facilitator types differ on promotion of self-management skill strategies.

#### **Research Question 5**

What strategies are used to promote self-management behaviors and do they vary among the different facilitator types? To answer this question both the strategy and behavior were evaluated. There were 7 items making up the variable self-management

behaviors. Each item includes six strategies (demonstration, distribute informational handouts, email with links to websites, group discussion, guest speaker presentation, participatory activity). The number of strategies used for each behavior was calculated. It was important to look at to what extent the strategies used for each behavior was *didactic* or *collaborative*. Distributing informational handouts, emails with links to websites, and guest speaker presentations are considered more didactic strategies. Demonstrations, group discussion, and participatory activities are considered more collaborative strategies. In addition, the six strategies were compared with respect to how often they're used across all of the behaviors. The percentages and frequencies provided evidence for which strategies are most frequently used for each of the self-management behaviors as well as the answer to whether didactic or collaborative strategies are most often used for all of the behaviors. In this study, self-management behaviors were identified as breathing techniques, exercise, fatigue, nutrition and diet, medications, pain management, relaxation and emotion management (Lorig, Holman, Sobel, Laurent, Gonzalez, & Minor, 2000). To address differences for facilitator types, percentages of positive responses for each strategy and health behavior were calculated and organized by facilitator type, providing evidence as to whether or not there were strategy differences for the facilitator types.

### **Research Question 6**

Does the promotion of transformative learning vary among the different facilitator types? To answer this question the 5 Likert items making up the variable transformative learning process were summed to create a scale. The frequency distribution and means for transformative learning process were produced, providing evidence as to what extent

support group facilitators promote transformative learning. To address the differences among facilitator types, an Analysis of Variance (ANOVA) was performed, providing evidence as to whether or not the facilitator types differ on promotion of transformative learning. In this study, transformative learning process referred to strategies used by facilitators to encourage both reflection and dialogue for support group participants.

## CHAPTER IV RESULTS

The main purpose of this study was to describe support group facilitators' role perceptions, support group goals, and strategies used to achieve goals of social support and self-management behaviors. An additional purpose was to compare the strategies employed by professionally-trained facilitators such as psychologists, nurses, and social workers with the strategies used by lay and peer support group facilitators. This chapter presents results for each of the six research questions.

### Research Question One

Research question one, how do different support group facilitators (professional, lay, peer) perceive their role, was addressed by presenting frequency distributions. Based on the survey responses, support group facilitators have varying perceptions of their roles. A number of facilitators (37%) perceive their role to be one of making sure all support group participants have an opportunity to speak during the meeting. The second most frequently selected response (35%) regarding role description was one of arranging logistics which includes meeting set-up, managing publicity, etc.

Although both the online and hard-copy survey specified for item 43 that only two statements should be selected, at least 35 people selected more than two statements. All of these multiple responses were pulled out and are not represented in Figure 5. Fifteen respondents selected only one statement and are included in the frequency counts in Figure 5. If all multiple responses were left in, these two role descriptions still remain the most frequently selected responses.

Twenty-four respondents wrote in the *other* response so a qualitative analysis of *other* responses was done. Twelve of the *other* responses suggested that all of the listed



responses were reflective of their facilitative role and they could not limit themselves to two that were most representative. Five reiterated many of the response statements included in the survey item yet in different words such as “reach all our members,” and “listen objectively without judgment.” Three responses included “promote self-esteem” and “provide a safe and trusting environment.” Two responses focused on education; for example, the facilitator’s role is to “assess and facilitate learning.” One response concentrated on resource sharing, another by providing “a book and DVD, video library.” Finally, one response defied categorization and didn’t make sense, “facilitate group that has never met w/many needs, questions, etc.”

Facilitators perceive their role differently depending on their type. Facilitator types include professional, peer, lay, and professional-peer. Professional is operationalized as a respondent who identified their occupation for item 53 as a medical doctor, nurse, psychologist or social worker. Peer is operationalized as a respondent who identified sharing the same chronic neurological health condition as the support group members for item 56. Lay is operationalized as a respondent who identified their occupation for item 53 as *other* and specified something outside of the healthcare field and also responded negatively to item 56. Professional-peer is operationalized as a respondent who identified as a medical doctor, nurse, psychologist, or social worker and also identified positively for item 56. Of the 292 cases included in this study, 218 are part of the peer group.

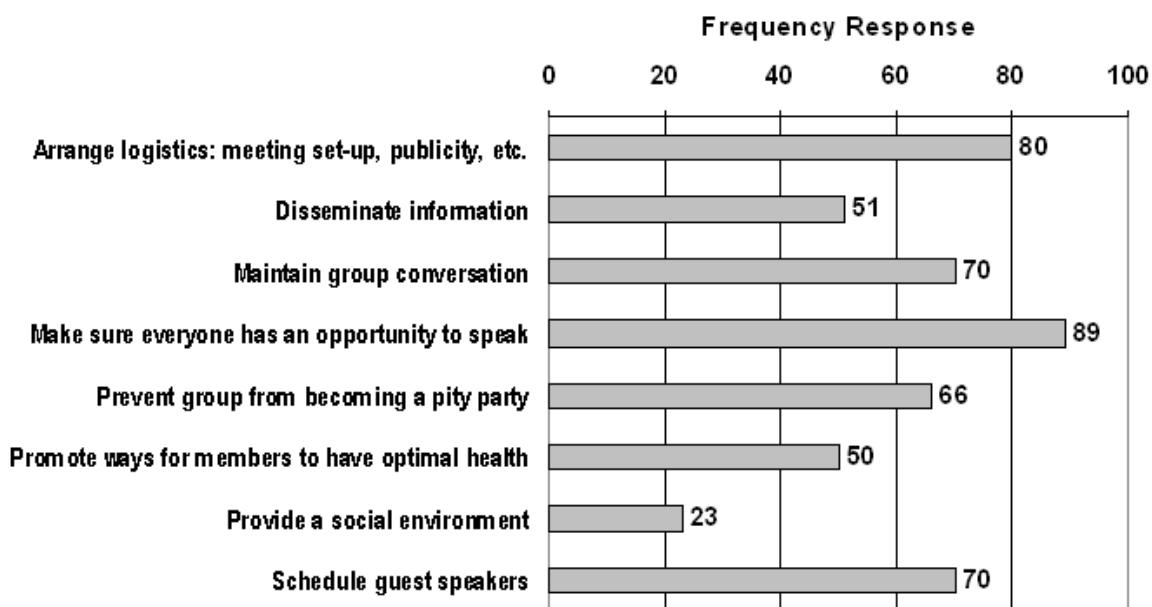


Figure 5. Frequency Response for Facilitative Role Description

Table 6 displays facilitator's responses to survey item 43 about role description organized by facilitator type. The most frequently selected statement varies for each facilitator type. The statement most frequently chosen by professional facilitators was "promote ways for members to have optimal health." This statement was not selected by one lay facilitator. The statement most frequently selected by lay facilitators was "prevent group from becoming a pity party." It is important to note the varying sample sizes for each facilitator type; percentages of responses are more revealing than the actual frequency of responses. The peer group consisted of 218 facilitators while the other three facilitator type sample sizes were between 22-28 individuals. Also of interest is the low response by all facilitator types for providing a social environment.

Table 6

## Percentages and Frequencies Responding to Role Perception by Facilitator Type

| Role Description   | Professional <sup>a</sup> | Peer <sup>b</sup> | Lay <sup>c</sup> | Professional +<br>Peer <sup>d</sup> |
|--|---------------------------|-------------------|------------------|-------------------------------------|
| Arrange logistics:<br>meeting set-up,<br>publicity, etc. | 25%<br>(7)                | 27%<br>(59)       | 32%<br>(7)       | 29%<br>(7)                          |
| Disseminate<br>information                               | 14%<br>(4)                | 19%<br>(41)       | 14%<br>(3)       | 12%<br>(3)                          |
| Maintain group<br>conversation                           | 32%<br>(9)                | 25%<br>(55)       | 28%<br>(5)       | 4%<br>(1)                           |
| Make sure<br>everyone has an<br>opportunity to<br>speak  | 32%<br>(9)                | 30%<br>(66)       | 28%<br>(5)       | 37%<br>(9)                          |
| Prevent group<br>from becoming a<br><i>pity party</i>    | 21%<br>(6)                | 23%<br>(50)       | 36%<br>(8)       | 8%<br>(2)                           |
| Promote ways for<br>members to have<br>optimal health    | 36%<br>(10)               | 15%<br>(32)       | 0                | 33%<br>(8)                          |
| Provide a social<br>environment                          | 4%<br>(1)                 | 8%<br>(18)        | 14%<br>(3)       | 4%<br>(1)                           |
| Schedule guest<br>speakers                               | 28%<br>(8)                | 22%<br>(49)       | 28%<br>(5)       | 33%<br>(8)                          |

<sup>a</sup>n = 28. <sup>b</sup>n = 218. <sup>c</sup>n = 22. <sup>d</sup>n = 24.

### Research Question Two

Research question two, what are the attitudes toward goal-setting among the different support group facilitator types, was addressed by performing an analysis of variance. Support group facilitators have differing attitudes toward goal-setting based on their facilitator type. Five Likert items were summated to create the goal-setting scale (mean = 2.12, standard deviation = .39). As presented in Table 7 nearly 85% of facilitators agree with the statement, “support group activities are organized to guide the

group toward optimal health,” while only a small percentage of them identified this as part of their facilitative role in research question one. With an overwhelming majority agreement (75.7%) for helping group members set realistic goals for themselves, there still were a significant number of facilitators that did not find this statement applicable to them.

Table 7

Frequencies and Percentages of Response Means (M) and Standard Deviations (SD) for the Goal-Setting Scale

|  | Strongly Agree | Agree          | Disagree       | Strongly Disagree | Does Not Apply | M    | SD   |
|--|----------------|----------------|----------------|-------------------|----------------|------|------|
| 12. I try to help members set realistic goals for themselves.                        | 24.3%<br>(71)  | 51.4%<br>(150) | 7.2%<br>(21)   | .7%<br>(2)        | 15.4 %<br>(45) | 1.81 | .609 |
| 20. Support group activities are organized to guide the group toward optimal health. | 29.1%<br>(85)  | 55.8%<br>(163) | 6.5%<br>(19)   | 1%<br>(3)         | 6.5%<br>(19)   | 1.77 | .614 |
| 26. Each year I identify goals for the support group.                                | 15.1%<br>(44)  | 43.2%<br>(126) | 26%<br>(76)    | 1.0%<br>(3)       | 13.7%<br>(40)  | 2.15 | .709 |
| 36. It is difficult to predict how a group meeting will turn out. <sup>a</sup>       | 11.6%<br>(34)  | 52.1%<br>(152) | 30.1%<br>(88)  | 3.1%<br>(9)       | 1%<br>(3)      | 2.74 | .696 |
| 41. I wish I had more control of the support group's direction. <sup>a</sup>         | 3.8%<br>(11)   | 12.7%<br>(37)  | 52.4%<br>(153) | 16.8%<br>(49)     | 12.3%<br>(36)  | 2.04 | .712 |
| Total  |                |                |                |                   |                | 2.12 | .39  |

<sup>a</sup> Survey items 36 and 41 were reverse coded.

To compare the four types of facilitators – Professional, Peer, Lay, and Professional + Peer – an Analysis of Variance (ANOVA) was performed. Using the SPSS software application, a random sample of 26 cases for the Peer group was taken to make the group samples more comparable. Results from a one-way ANOVA appear in Table 8. These results demonstrate a statistically significant difference between the four types of facilitators. Since the one-way ANOVA suggested differences among the four

facilitator types, a Bonferroni post hoc testing was done to identify where the difference occurred. The mean difference between the Professional group and the Peer group (-.266) is significant at the .048 level. The mean difference between the Professional + Peer group and the Peer group (-.288) is significant at the .037 level. Both the Professional and Professional + Peer groups were higher than the peer and lay groups. Although differences were found, this Likert scale did have low reliability.

Table 8

| Source         | df | Sum of Squares | Mean Squares | F Ratio | F Prob |
|----------------|----|----------------|--------------|---------|--------|
| Between Groups | 3  | 1.35           | .45          | 3.39    | .021   |
| Within Groups  | 96 | 12.74          | .13          |         |        |
| Total          | 99 | 14.09          |              |         |        |

### Research Question Three

Research question three, does the promotion of social support strategies vary among the different facilitator types, was addressed by performing an analysis of variance. Strategies used by support group facilitators to promote social support do not vary significantly between the different facilitator types. Sixteen Likert survey items were summated to create the Social Support Scale (mean = 1.78, standard deviation = .33). In Table 9 survey items are listed by each of the five types of social support. Overall, support group facilitators were more agreeable toward statements suggesting esteem support (group mean = 1.48) and less agreeable toward statements suggesting network support (group mean = 1.93). Of particular interest are several of the items with a high number of *Does Not Apply* responses such as “I have encouraged members to carpool to meetings” and “I try to find a mentor, or role model, for new members.”

A one-way ANOVA was performed and no statistical differences ( $F=1.31$ ,  $sig = .275$ ) were found in the mean scores for the four types of support group facilitators. Apparently support group facilitators do not differ in the strategies they use to accomplish this goal.

#### **Research Question Four**

Research question four, does the promotion of self-management skill strategies vary among different facilitator types, was addressed by performing an analysis of variance. Strategies used by support group facilitators to promote self-management skills do not vary significantly between the different facilitator types. To answer this question nine Likert survey items were summated to create the Self-Management Skills Scale (mean = 1.86, standard deviation = .37). Interesting to note in Table 10 is high agreement (76.3%) for statement, “the main purpose of this support group is to learn how to remain healthy.” Although support group facilitators also reported strong agreement with the statement, “support group activities are organized to guide the group toward optimal health,” in research question two, the majority of facilitators do not consider promoting optimal health as their role as presented in research question one.

Again, as evident in the Social Support Scale, there are a few items with frequent *Does Not Apply* responses such as “practical skills such as operating an electronic wheelchair can be learned at this support group meeting,” “when learning a new skill or technique, I encourage members to practice during the meeting,” and “members frequently discuss what their short and long-term goals are.”

Table 9

Frequencies and Percentages of Response Means (M) and Standard Deviations (SD) for the Social Support Scale

|  | Strongly Agree | Agree          | Disagree       | Strongly Disagree | Does Not Apply | M    | SD   |
|--|----------------|----------------|----------------|-------------------|----------------|------|------|
| <u>Tangible Support</u>  |                |                |                |                   |                |      |      |
| 16. It is not appropriate for members to ask each other for any type of help outside the meeting.                | 2.4%<br>(7)    | 6.8%<br>(20)   | 42.1%<br>(123) | 45.9%<br>(134)    | 1.7%<br>(5)    | 1.64 | .716 |
| 23. I have encouraged members to carpool to meetings.  | 5.1%<br>(15)   | 26.3%<br>(106) | 27.4%<br>(80)  | 5.8%<br>(17)      | 24.7%<br>(72)  | 2.45 | .734 |
| 30. I encourage members to make requests at meetings for help with some of the challenges they are dealing with. | 41.4%<br>(121) | 49.3%<br>(144) | 6.5%<br>(19)   | 0                 | 1.7%<br>(5)    | 1.64 | .601 |
| <u>Emotional Support</u>   |                |                |                |                   |                |      |      |
| 15. When a member has not attended a meeting for awhile, I make a point of contacting them.                      | 29.8%<br>(87)  | 49.3%<br>(144) | 13%<br>(38)    | 2.4%<br>(7)       | 4.8%<br>(14)   | 1.87 | .732 |
| 21. My role is to help validate member's experienced or feelings about having a chronic health condition.        | 30.8%<br>(90)  | 42.1%<br>(123) | 18.8%<br>(55)  | 3.1%<br>(9)       | 3.1%<br>(9)    | 1.93 | .798 |
| 39. I practice active listening by focusing on the speaker and suspending judgment.                              | 42.8%<br>(125) | 52.4%<br>(153) | 1.4%<br>(4)    | 0                 | 2.4%<br>(7)    | 1.57 | .520 |
| <u>Esteem Support</u>  |                |                |                |                   |                |      |      |
| 14. When a member expresses a strong sense of self-blame, I try to encourage them to see things differently.     | 43.8%<br>(128) | 45.5%<br>(133) | 1.4%<br>(4)    | 0                 | 7.5%<br>(22)   | 1.53 | .524 |

Table 9 (continued). Frequencies and Percentages of Response Means (M) and Standard Deviations (SD) for the Social Support Scale

|  | Strongly Agree | Agree          | Disagree       | Strongly Disagree | Does Not Apply | M    | SD   |
|--|----------------|----------------|----------------|-------------------|----------------|------|------|
| 32. I encourage members to applaud others small or big personal successes.   | 57.2%<br>(167) | 36.6%<br>(107) | 3.1%<br>(9)    | .3%<br>(1)        | 1.4%<br>(4)    | 1.45 | .573 |
| 35. There is nothing to do for a member with low self-esteem.  | 2.1%<br>(6)    | 1.4%<br>(4)    | 38.4%<br>(112) | 55.8%<br>(163)    | 1.4%<br>(4)    | 1.48 | .633 |
| <u>Network Support</u>   |                |                |                |                   |                |      |      |
| 11. I try to find a mentor, or role model, for new members.  | 14%<br>(41)    | 40.4%<br>(118) | 22.9%<br>(67)  | 2.4%<br>(7)       | 17.8%<br>(52)  | 2.17 | .735 |
| 18. A list of support group members contact information is available to the group.   | 30.8%<br>(90)  | 39.7%<br>(116) | 19.2%<br>(56)  | 3.8%<br>(11)      | 4.5%<br>(13)   | 1.95 | .825 |
| 29. I have organized social events for members outside of the regular meeting time.  | 19.9%<br>(58)  | 38.4%<br>(112) | 21.2%<br>(62)  | 3.8%<br>(11)      | 15.4%<br>(45)  | 2.10 | .809 |
| 38. I discourage members from meeting outside of the assigned support group meeting time.                                  | 2.4%<br>(7)    | 1%<br>(3)      | 38.4%<br>(112) | 50.3%<br>(147)    | 5.8%<br>(17)   | 1.51 | .648 |
| <u>Informational Support</u>   |                |                |                |                   |                |      |      |
| 13. If a member shares information I think may be incorrect, I follow up with a medical or health expert for accuracy.     | 24.3%<br>(71)  | 54.5%<br>(159) | 12%<br>(35)    | 1.7%<br>(5)       | 6.5%<br>(19)   | 1.90 | .673 |
| 34. To help make a topic more meaningful to members, I break down the main points beforehand.                              | 16.8%<br>(49)  | 47.3%<br>(138) | 17.8%<br>(52)  | 1.4%<br>(4)       | 14%<br>(41)    | 2.04 | .682 |
| 37. During our meetings I encourage members to share personal experiences that will provide helpful information to others. | 44.9%<br>(131) | 49.3%<br>(144) | 2.1%<br>(6)    | 0                 | 2.1%<br>(6)    | 1.55 | .534 |
| Total  |                |                |                |                   |                | 1.78 | .33  |

<sup>a</sup> Survey items 16, 35, and 38 were reverse coded.



A one-way ANOVA was performed and no statistical differences ( $F = 2.12$ ,  $sig = .10$ ) were found in the mean scores for the four types of support group facilitators. It seems that support group facilitators do not differ in the strategies they use to promote self-management skills.

### **Research Question Five**

Research question five, what strategies are used to promote self-management behaviors and do they vary among the different facilitator types, was addressed by presenting frequency distributions. Strategies used by support group facilitators, to promote the seven self-management behaviors, vary among the different facilitator types. The first step in addressing this research question was to cross the six strategies with the seven self-management behaviors as presented in Table 11. The strategy garnering the most overall responses for all facilitator types was group discussion. This means that group discussion is the most frequently selected strategy used to promote each of the six self-management behaviors. The study did not address with what frequency the strategies are actually used. The second most commonly selected strategy employed is the distribution of informational handouts. Guest speaker presentations are the third most frequently selected strategy. The strategy least selected for all self-management behaviors was demonstration.

Table 10

Frequencies and Percentages of Response Means (M) and Standard Deviations (SD) for the Self-Management Skills Scale

|   | Strongly Agree | Agree          | Disagree      | Strongly Disagree | Does Not Apply | M    | SD   |
|---|----------------|----------------|---------------|-------------------|----------------|------|------|
| <u>Problem-Solving</u>  |                |                |               |                   |                |      |      |
| 19. As a group we often brainstorm possible solutions to a member's problem.                                  | 31.5%<br>(92)  | 51.7%<br>(151) | 9.9%<br>(29)  | 2.4%<br>(7)       | 3.8%<br>(11)   | 1.82 | .708 |
| <u>Decision Making</u>  |                |                |               |                   |                |      |      |
| 33. When I know a member has an important decision to make, I follow up with them at the next meeting.        | 26.7%<br>(78)  | 63%<br>(184)   | 2.7%<br>(8)   | .3%<br>(1)        | 6.2%<br>(18)   | 1.74 | .516 |
| <u>Resource Utilization</u>   |                |                |               |                   |                |      |      |
| 20. The main purpose of this support group is to learn how to remain healthy.                                 | 31.8%<br>(93)  | 44.5%<br>(130) | 17.8%<br>(52) | .3%<br>(1)        | 4.5%<br>(13)   | 1.85 | .718 |
| 24. Practical skills such as operating an electronic wheelchair can be learned at this support group meeting. | 9.6%<br>(28)   | 35.6%<br>(104) | 25.7%<br>(75) | 5.5%<br>(16)      | 22.6%<br>(66)  | 2.35 | .786 |
| 28. I regularly notify members of health or disability-related events in the community.                       | 37.7%<br>(110) | 50.3%<br>(147) | 6.5%<br>(19)  | .3%<br>(1)        | 4.1%<br>(12)   | 1.67 | .611 |
| <u>Forming Partnerships</u>   |                |                |               |                   |                |      |      |
| 25. I encourage members to form partnerships with their health care providers.                                | 41.8%<br>(122) | 44.9%<br>(131) | 4.5%<br>(13)  | 0                 | 6.5%<br>(19)   | 1.59 | .576 |
| <u>Action Planning</u>  |                |                |               |                   |                |      |      |
| 8. When learning a new skill or technique, I encourage members to practice during the meeting.                | 24%<br>(70)    | 35.3%<br>(103) | 6.5%<br>(19)  | 1%<br>(3)         | 32.2%<br>(94)  | 1.76 | .678 |
| 9. Members frequently discuss what their short and long-term goals are.                                       | 12%<br>(35)    | 56.8%<br>(166) | 15.8%<br>(46) | .3%<br>(1)        | 13.7%<br>(40)  | 2.05 | .579 |

Table 10 (*continued*). Frequencies and Percentages of Response Means (M) and Standard Deviations (SD) for the Self-Management Skills Scale

|   | Strongly Agree | Agree          | Disagree      | Strongly Disagree | Does Not Apply | M    | SD   |
|---|----------------|----------------|---------------|-------------------|----------------|------|------|
| 22. I coach members toward understanding a new way of thinking or doing things. | 26.4%<br>(77)  | 47.9%<br>(140) | 15.1%<br>(44) | 3.1%<br>(9)       | 6.5%<br>(19)   | 1.94 | .757 |
| Total   |                |                |               |                   |                | 1.86 | .37  |

Table 11 also presents data for the frequency of strategies selected for each of the six self-management behaviors. Exercise attracted the most frequent number of various strategies used. Management of relaxation and emotions captured the second highest number of strategies. Capturing the least number of strategies was the management of breathing techniques.

The second step for answering this research question is to specifically address the differences between facilitator types and their use of strategies for self-management. Percentages of positive responses for strategies are presented in a table specific for each self-management behavior. No matter which type of facilitator, the most frequent strategy employed to promote all seven of the self-management behaviors was “Group discussion.” Seven self-management behaviors were explored in this study. Survey respondents had the opportunity to write in their own open-ended response in the *other* category for each self-management behavior. For these items, both quantitative and qualitative data are presented and when appropriate in the exact words of the respondents. The following paragraphs will present additional findings for each self-management behavior. It must be noted that the sample sizes vary for each facilitator type with the peer group generally consisting of 218 individuals and the other group sample sizes between 22-28 individuals.

Table 11

Percentages and Frequencies Responding to Each Strategy by Self-Management Behavior

| Self-Management Behavior                           | Demonstration  | Distribute informational handouts | Email with links to websites | Group discussion | Guest speaker presentation | Participatory activity |
|--|----------------|-----------------------------------|------------------------------|------------------|----------------------------|------------------------|
| Management of Breathing Techniques <sup>a</sup>    | 26.6%<br>(78)  | 28%<br>(111)                      | 26.4%<br>(77)                | 42.5%<br>(124)   | 39.7%<br>(116)             | 34.2%<br>(100)         |
| Exercise <sup>b</sup>                              | 53.4%<br>(156) | 78.8%<br>(230)                    | 53.4%<br>(156)               | 86.3%<br>(252)   | 72.3%<br>(211)             | 55.8%<br>(163)         |
| Management of Fatigue <sup>c</sup>                 | 26.7%<br>(78)  | 78.1%<br>(228)                    | 54.8%<br>(160)               | 90.1%<br>(263)   | 58.9%<br>(172)             | 31.5%<br>(92)          |
| Management of nutrition and diet <sup>d</sup>      | 33.9%<br>(99)  | 74.3%<br>(217)                    | 49.7%<br>(145)               | 83.9%<br>(245)   | 64.4%<br>(188)             | 31.5%<br>(92)          |
| Management of medications <sup>e</sup>             | 21.6%<br>(63)  | 72.6%<br>(212)                    | 56.2%<br>(164)               | 83.9%<br>(245)   | 65.1%<br>(190)             | 26.7%<br>(78)          |
| Pain management <sup>f</sup>                       | 23.6%<br>(69)  | 64.4%<br>(188)                    | 45.2%<br>(132)               | 78.4%<br>(229)   | 50.7%<br>(148)             | 23.3%<br>(68)          |
| Management of relaxation and emotions <sup>g</sup> | 50.7%<br>(148) | 69.2%<br>(202)                    | 44.9%<br>(131)               | 83.9%<br>(245)   | 59.9%<br>(175)             | 51%<br>(149)           |

Note. Sample sizes vary slightly due to missing responses.

<sup>a</sup>n = 274-277. <sup>b</sup>n = 284-286. <sup>c</sup>n = 281-283. <sup>d</sup>n = 282. <sup>e</sup>n = 280-282. <sup>f</sup>n = 272-275. <sup>g</sup>n = 279-282.

The self-management behavior, breathing techniques, had the lowest percentage of responses compared to the other health behaviors. Many support group facilitators apparently do not perceive breathing techniques as a relevant topic for group meetings. In Table 12 group discussion is the most frequently selected strategy by three of the four facilitator types; more professional + peer facilitators selected guest speaker presentation. Fewer facilitators selected email with links to websites as their strategy to handle breathing techniques. Professional facilitators responded with greater frequency to employing four of the six strategies – demonstration, distributing informational handouts, group discussion, and participatory activity.

Forty-three facilitators wrote in a response for the management of breathing techniques. Fifteen of the write-in responses felt the health behavior did not apply to their members. Nine additional people were inclined to say the topic has not been handled or discussed. Five responses suggested the topic would be covered at a future meeting. Six facilitators mentioned strategies such as “yoga,” “tai chi,” or inviting guest instructors of “Feldenkrais” or “Alexander Technique” to the support group meeting. The remaining eight responses were varied though half of them reported that their members select the topics to be discussed in the group while implying that breathing techniques had never been selected.

The self-management behavior, exercise, garnered a lot of attention. Although group discussion is clearly the more common strategy chosen to handle exercise, more professional + peer facilitators selected participatory activity than the other facilitator

Table 12

Percentages Responding to Each Strategy for Breathing Techniques by Facilitator Type

| Facilitator Type          | Demonstration | Distribute informational handouts | Email with links to websites | Group discussion | Guest speaker presentation | Participatory activity |
|---------------------------|---------------|-----------------------------------|------------------------------|------------------|----------------------------|------------------------|
| Professional <sup>a</sup> | 42.9          | 57.1                              | 25                           | 64.3             | 42.9                       | 42.9                   |
| Peer <sup>b</sup>         | 23.9          | 35.8                              | 27.1                         | 39.9             | 38.5                       | 33                     |
| Lay <sup>c</sup>          | 27.3          | 27.3                              | 18.2                         | 36.4             | 36.4                       | 31.8                   |
| Professional & Peer       | 33.3          | 45.8                              | 29.2                         | 45.8             | 50                         | 37.5                   |

<sup>d</sup>  
<sup>a</sup>n = 28. <sup>b</sup>n = 218. <sup>c</sup>n = 22. <sup>d</sup>n = 24

types as shown in Table 13. Both demonstration and email with links to websites are less frequently selected as strategies to promote exercise in a support group.

Thirty-one facilitators offered additional responses for this self-management behavior. Eight of the responses suggested activities organized outside of the regular support group meeting such as “MS aquatics class,” “weekly yoga lessons,” or “walking groups.” One of the eight facilitators wrote of planning outdoor activities that “encourage deep breathing, rhythmic movement and light weight lifting as well as tossing a large ball from person to person.” Four people mentioned multimedia such as “video” and “web cast,” while five others reiterated the use of guest speakers such as a “yoga guru” and “physical therapist.” Two facilitators said they plan to address exercise at a future support group meeting. Still there were five facilitators that responded to this self-management behavior as not applicable to their members due to it being a “medical issue” or members “declined to participate.” The remaining seven responses did not fit into categories; examples include one response, “access to wellness trainer for one on one discussions, email” to “lead by example.”

The management of fatigue is the third self-management behavior examined in this study. The strategy to promote the management of fatigue in a support group is most often handled with group discussion but professional + peer facilitators responded with the same frequency to the distribution of informational handouts. In Table 14 lay facilitators responded with the least frequency to all strategies except for group discussion.

Table 13

Percentages Responding to Each Strategy for Exercise by Facilitator Type

| Facilitator Type                 | Demonstration | Distribute informational handouts | Email with links to websites | Group discussion | Guest speaker presentation | Participatory activity |
|----------------------------------|---------------|-----------------------------------|------------------------------|------------------|----------------------------|------------------------|
| Professional <sup>a</sup>        | 42.9          | 82.1                              | 46.4                         | 89.3             | 60.7                       | 53.6                   |
| Peer <sup>b</sup>                | 55            | 79.4                              | 55.5                         | 85.3             | 72.9                       | 53.7                   |
| Lay <sup>c</sup>                 | 50            | 72.7                              | 50                           | 90.9             | 63.6                       | 63.6                   |
| Professional & Peer <sup>d</sup> | 54.2          | 75                                | 45.8                         | 87.5             | 87.5                       | 70.8                   |

<sup>a</sup>n = 28. <sup>b</sup>n = 218. <sup>c</sup>n = 22. <sup>d</sup>n = 24



Four of the 22 responses for additional strategies to manage fatigue mentioned multimedia including “DVDs,” “video,” and “teleconferences.” Four responses reiterated the use of guest speakers including “neurologists.” Three facilitators tied in “discussion about medications” for handling fatigue while five others offered “guided imagery” and “individual coping mechanisms discussed, patterned, exhibited” as additional strategies. One facilitator said the topic was not applicable. The remaining five responses were varied such as “fatigue is big” and “again another topic to be further explored.” A facilitator, perhaps misinterpreting the question, recommended a “break in the middle of meeting.”

Nutritional and diet management is another topic commonly covered in support groups. Professional + peer facilitators responded with the highest percentage to all strategies with the exception of group discussion and guest speaker presentations for handling nutrition and diet management as shown in Table 15. Participatory activity was less frequently selected by all but the lay facilitators. Demonstration was the least frequently selected strategy used by lay facilitators for the management of nutrition and diet.

Table 14

Percentages Responding to Each Strategy for Fatigue Management by Facilitator Type

| Facilitator Type          | Demonstration | Distribute informational handouts | Email with links to websites | Group discussion | Guest speaker presentation | Participatory activity |
|---------------------------|---------------|-----------------------------------|------------------------------|------------------|----------------------------|------------------------|
| Professional <sup>a</sup> | 28.6          | 82.1                              | 57.1                         | 89.3             | 67.9                       | 28.6                   |
| Peer <sup>b</sup>         | 27.5          | 77.1                              | 57.3                         | 89.4             | 57.8                       | 34.4                   |
| Lay <sup>c</sup>          | 9.1           | 68.2                              | 31.8                         | 95.5             | 54.5                       | 13.6                   |
| Professional & Peer       | 33.3          | 91.7                              | 50                           | 91.7             | 62.5                       | 25                     |

<sup>d</sup>  
<sup>a</sup>n = 28. <sup>b</sup>n = 218. <sup>c</sup>n = 22. <sup>d</sup>n = 24.

Nine of the 23 individuals providing an additional strategy to use for the management of nutrition and diet reiterated the use of “expert” guest speakers including a “dietician,” “nutritionist,” and “chef.” Five responses mentioned including “healthy snacks” or catering lunch at their support group meetings. Two facilitators mentioned using multimedia to handle the topic. The remaining seven facilitators offered a variety of different strategies. One of these strategies was to encourage “members to share recipes and ideas” while another subscribes to book lending. While some facilitators wholeheartedly found this behavior to be important enough to “attend an outside presentation,” two of the seven uncategorized responses thought the topic did “not apply to members” or was a “medical issue.”

The fifth self-management behavior, the management of medications, is a relevant issue for people with Multiple Sclerosis because 85% of the MS population is eligible for injections (For people with relapsing MS, 2010). Of those eligible, 43% are not on disease modifying therapy, or taking injections (K. Koch, personal communication, April 1, 2010). In Table 16 there are fairly low percentages for all facilitator types using either the demonstration or participatory activity strategies. The strategy with the highest percentage is, once again, group discussion.

Table 15

Percentages Responding to Each Strategy for Nutrition and Diet Management by Facilitator Type

| Facilitator Type          | Demonstration | Distribute informational handouts | Email with links to websites | Group discussion | Guest speaker presentation | Participatory activity |
|---------------------------|---------------|-----------------------------------|------------------------------|------------------|----------------------------|------------------------|
| Professional <sup>a</sup> | 21.4          | 67.9                              | 42.9                         | 85.7             | 67.9                       | 21.4                   |
| Peer <sup>b</sup>         | 35.3          | 74.3                              | 50.5                         | 82.6             | 61.5                       | 32.1                   |
| Lay <sup>c</sup>          | 18.2          | 68.2                              | 40.9                         | 95.5             | 77.3                       | 22.7                   |
| Professional & Peer       | 50            | 87.5                              | 58.3                         | 83.3             | 75                         | 45.8                   |

<sup>d</sup>  
<sup>a</sup>n = 28. <sup>b</sup>n = 218. <sup>c</sup>n = 22. <sup>d</sup>n = 24.

Of the 24 respondents that listed additional strategies to handle the management of medications, nine reiterated the use of guest speakers including a “neurologist” or “pharmacist” and nurses to “demonstrate injection techniques.” Five of the facilitators responded that the self-management behavior did not apply to their support group or was a “medical issue.” Three multimedia formats were offered for handling the management of medications such as a “web cast,” “teleconference,” or “slide presentation” each by a different facilitator. The remaining seven responses varied from a facilitator suggesting group participants “be open but consult their medical doctor” to “discussion about compliance only.” One person replied that the latest medication information was communicated in their group newsletter.

The management of pain is a health behavior that is a recurrent topic in support groups for adults with chronic health conditions. Facilitators often deal with support group participant’s discussion of the pain they are experiencing. Table 17 shows that each facilitator type selected group discussion with a higher percentage than other strategies. Both professional and lay facilitators selected demonstration less frequently than other strategies while peer and professional + peer facilitators selected participatory activity less frequently.

Table 16

Percentages Responding to Each Strategy for Medication Management by Facilitator Type

| Facilitator Type          | Demonstration | Distribute informational handouts | Email with links to websites | Group discussion | Guest speaker presentation | Participatory activity |
|---------------------------|---------------|-----------------------------------|------------------------------|------------------|----------------------------|------------------------|
| Professional <sup>a</sup> | 21.4          | 78.6                              | 42.9                         | 82.1             | 64.3                       | 32.1                   |
| Peer <sup>b</sup>         | 21.6          | 70.2                              | 57.3                         | 84.4             | 64.2                       | 26.1                   |
| Lay <sup>c</sup>          | 9.1           | 72.7                              | 50                           | 72.7             | 54.5                       | 18.2                   |
| Professional & Peer       | 33.3          | 87.5                              | 66.7                         | 91.7             | 83.3                       | 33.3                   |

<sup>d</sup>  
<sup>a</sup>n = 28. <sup>b</sup>n = 218. <sup>c</sup>n = 22. <sup>d</sup>n = 24.

Six of the 15 responses for this self-management behavior reiterated the use of guest speakers such as “massage therapist” or “acupuncture practitioners.” Two facilitators plan on handling this topic at a future meeting while one facilitator does not find the topic relevant to the group. Of the remaining six varied responses, one facilitator mentioned that referrals for “professionals specializing in pain management” are shared with support group members.

The final self-management behavior is the management of relaxation and emotions. Facilitators overwhelmingly use group discussion most often when handling this issue in a support group. All facilitator types also chose the same strategy used with the least frequency – email with links to websites. In Table 18 Professional + Peer facilitators make the most use of almost all the strategies for handling the management of relaxation and emotions.

Six of the 17 facilitators responded to this self-management behavior reiterating the use of guest speakers including a “social worker” and “neuro-psychiatrist.” Three facilitators felt the topic did not apply to their members or they had never addressed it. Two individuals mentioned compact discs of “relaxing and encouraging music” were available for loan to members. Of the remaining six varying responses, strategies for handling the management of relaxation and emotions included exercises or games “to illustrate importance of positive attitude,” DVDs, and making “gratitude journals.”

Table 17

Percentages Responding to Each Strategy for Pain Management by Facilitator Type

| Facilitator Type          | Demonstration | Distribute informational handouts | Email with links to websites | Group discussion | Guest speaker presentation | Participatory activity |
|---------------------------|---------------|-----------------------------------|------------------------------|------------------|----------------------------|------------------------|
| Professional <sup>a</sup> | 17.9          | 64.3                              | 35.7                         | 78.6             | 60.7                       | 25                     |
| Peer <sup>b</sup>         | 24.8          | 62.8                              | 47.7                         | 78.9             | 48.6                       | 23.9                   |
| Lay <sup>c</sup>          | 9.1           | 68.2                              | 31.8                         | 68.2             | 50.                        | 18.2                   |
| Professional & Peer       | 33.3          | 75.                               | 45.8                         | 83.3             | 58.3                       | 20.8                   |

<sup>d</sup><sub>n</sub> = 28. <sup>b</sup><sub>n</sub> = 218. <sup>c</sup><sub>n</sub> = 22. <sup>d</sup><sub>n</sub> = 24



Table 18

Percentages Responding to Each Strategy for Management of Relaxation and Emotions by Facilitator Type

| Facilitator Type          | Demonstration | Distribute informational handouts | Email with links to websites | Group discussion | Guest speaker presentation | Participatory activity |
|---------------------------|---------------|-----------------------------------|------------------------------|------------------|----------------------------|------------------------|
| Professional <sup>a</sup> | 60.7          | 78.6                              | 42.9                         | 89.3             | 67.9                       | 57.1                   |
| Peer <sup>b</sup>         | 48.6          | 67.4                              | 46.3                         | 83               | 56.9                       | 48.6                   |
| Lay <sup>c</sup>          | 50            | 59.1                              | 27.3                         | 77.3             | 59.1                       | 45.5                   |
| Professional & Peer       | 58.3          | 83.3                              | 50                           | 91.7             | 79.2                       | 70.8                   |

<sup>d</sup>  
<sup>a</sup>n = 28. <sup>b</sup>n = 218. <sup>c</sup>n = 22. <sup>d</sup>n = 24.

### **Research Question Six**

Research question six, does the promotion of transformative learning vary among the different facilitator types, was addressed by performing an analysis of variance. Based on the survey responses support group facilitators respond favorably to the promotion of transformative learning. To answer this research question five Likert survey items were summated to create the Transformative Learning Scale (mean = 1.78, standard deviation = .35). As shown in Table 19, nearly 82% of the facilitators witnessed remarkable changes in their group participants over time. Other tenets of promoting transformative learning theory are supported such as the facilitator's role modeling of healthy behaviors (83.3%) and group members learning from their peers (98.1%). Of particular note are the mixed results for facilitators helping members evaluate their beliefs and behaviors. Forty-seven percent of the facilitators agreed with this statement while over 38% disagreed and nearly 13% did not think the statement applied. No statistically significant differences were found between facilitator types and their promotion of transformative learning.

### **Summary**

The data results provided evidence that support group facilitators self-report strong agreement with statements reflective of promoting social support strategies and transformative learning. Additionally, the facilitators, in general, report fairly strong agreement with statements indicative of promoting self-management skills. However, there is evidence that a large number of support group facilitators report that some strategies for promotion of social support and/or self-management skills does not apply to

Table 19

Frequencies and Percentages of Response Means (M) and Standard Deviations (SD) for the Transformative Learning Scale

|  | Strongly Agree | Agree          | Disagree      | Strongly Disagree | Does Not Apply | M    | SD   |
|--|----------------|----------------|---------------|-------------------|----------------|------|------|
| 17. I often try to help a member evaluate their beliefs or behaviors.                    | 6.2%<br>(18)   | 41.1%<br>(120) | 31.2%<br>(91) | 7.2%<br>(21)      | 12.7%<br>(37)  | 2.46 | .742 |
| 27. My role as the facilitator includes modeling healthy behaviors.                      | 27.1%<br>(79)  | 56.2%<br>(164) | 9.6%<br>(28)  | 1%<br>(3)         | 5.1%<br>(15)   | 1.83 | .635 |
| 31. Members can learn valuable information from their peers in the group.                | 71.2%<br>(208) | 27.1%<br>(79)  | 0             | 0                 | .3%<br>(1)     | 1.27 | .444 |
| 40. I believe that recently diagnosed members have different needs in the support group. | 44.2%<br>(129) | 45.2%<br>(132) | 6.2%<br>(18)  | 1.4%<br>(4)       | 1.7%<br>(5)    | 1.63 | .662 |
| 42. I have witnessed remarkable changes with members over time.                          | 27.4%<br>(80)  | 54.5%<br>(159) | 8.6%<br>(25)  | 0                 | 7.5%<br>(22)   | 1.79 | .589 |
| Total  |                |                |               |                   |                | 1.78 | .35  |

their support group members. The study sample reported moderate agreement with statements indicative of a positive attitude toward goal-setting and overwhelmingly group discussion as the most frequently used strategy for promoting self-management health behaviors. The study findings also suggest differences between facilitator types and their attitude toward goal-setting and their use of didactic and collaborative strategies to promote self-management health behaviors.

The four main findings to be discussed in Chapter V include the following:

1. The four types of facilitators differed in the perception of their role as support group facilitators. As represented in Table 6, professional facilitators more often identified their role as promoting ways for participants to achieve optimal health

while lay facilitators more often viewed their role as preventing the support group from becoming a *pity party*.

2. The four types of support group facilitators differed in their attitudes toward goal-setting. This was found in the analysis of variance in Table 8. A statistically significant difference was found for the attitudes toward goal-setting among the four support group facilitator types; both professional and professional + peer facilitators are more inclined to establish goals for their support groups.
3. Apparently the four facilitator types are similar in the strategies they use to promote social support, self-management skills, and transformative learning in a support group. This was found in the three separate analysis of variance performed. No statistically significant differences were found among the four support group facilitator types.
4. Strategies to promote self-management behaviors do vary among different support group facilitator types. Both professional and professional + peer facilitators use a variety of strategies more frequently than peer and lay facilitators in addition to making more use of collaborative over didactic strategies. This can be found in Tables 12 – 18.

## **CHAPTER V**

### **SUMMARY, LIMITATIONS, DISCUSSION, AND IMPLICATIONS**

The chapter is organized into four sections. The first section summarizes the first four chapters of the study and presents the main findings of the study. The second section addresses the study's findings in light of the limitations. The third section discusses the findings as they pertain to the body of previous research. The final section addresses both the implications for future research and practice.

#### **Summary of Study**

Chronic health conditions, from asthma to diabetes to Multiple Sclerosis, are on the rise and increase approximately 1% each year in the United States (Chronic disease: The chronic care, 2009). Though this crisis can be cost prohibitive, there are economical treatment options available to Americans faced with a lifelong ailment.

One option for people with chronic health conditions are support groups. Support group meetings are held at hospitals, churches, and other publicly accessible locations, where people share their challenges and successes with one another (Davison, Pennebaker, & Dickerson, 2000). Research has shown that the social support experienced by support group participants enhances health from improved coping skills (Schreurs, Colland, Kuijer, de Ridder, & van Elderen, 2003) to lowering depression (Lieberman & Goldstein, 2005) and enhancing quality of life (Gottlieb & Wachala, 2007).

Another efficient and effective way for a chronic sufferer to help themselves is by participation in a patient self-management program. Self-management includes a set of behaviors to help a person manage their own illness (Goodall & Halford, 1991). Patient self-management behaviors are most often taught in hospital settings, yet these settings reach a limited number of people with chronic health conditions. Numerous studies have

shown that chronically ill people exposed to self-management programs maintain or improve their health status, make fewer hospital and physician visits, and have reduced hospital stays compared to control subjects (Barlow, Turner, & Wright, 1998; Dongbo, Hua, McGowan, Yi-e, Lizhen, Huiqin, Jianguo, Shitai, Yongming, & Zhihua, 2003; Gallant, 2003; Lorig, Ritter, Villa, & Piette, 2008; Lorig, Ritter, Stewart, Sobel, Brown, Bandura, et al, 2001).

While patient self-management programs occur in a classroom environment and are taught by one or two individuals, support groups are generally facilitated by professionals, lay persons, or peers who share the same disease as the participant (Davison et al., 2000). Although the role of the support group facilitator seems to vary, facilitators undoubtedly play a strategic role in guiding a recently diagnosed person from a place of confusion and bewilderment to a place of empowerment.

Prior research has suggested a need to further explore the support group facilitator's role and the strategies used to achieve support group goals such as social support and self-management behaviors (Costello, 2007; Kirsten, Butow, Price, Hobbs, & Sunquist, 2006; Lekalakala-Mokgele, 2006; Lieberman, 2007; Lieberman, 2008; Owen, Bantum, & Golant, 2009).

The primary purpose of this study was to describe support group facilitators' role perceptions and their support group goals of social support and self-management behaviors. The secondary purpose was to compare the strategies used by professionally-trained facilitators such as psychologists, nurses, and social workers with the strategies used by lay and peer support group facilitators.

This study's significance has both research and practical implications. The study addresses a gap in the research literature about support group facilitators for adults with neuromuscular health conditions. The significance of the study impacts the practice for support group facilitators by providing a deeper understanding of their perceived roles and the strategies they use to promote both social support and self-management skills and behaviors in a face-to-face support group environment.

The theoretical rationale for this study included both transformative learning theory (TLT) and goal-setting theory. TLT, a multi-stage developmental course for describing how adults learn, is a model for change and grounded in the communication process (Courtenay, Merriam, & Reeves, 1998). The theory identifies different stages an adult experiences after a *disorienting dilemma*, such as the diagnosis of a chronic health condition, to help make meaning of their new life situation. Much of the meaning is explored through talking and listening to others experiencing a similar disruption in their life.

Subsequent stages of transformative learning include exploring new roles, planning a course of action, and learning the knowledge and skills necessary for following one's plan of action (Mezirow, 1991). The final phase of the transformative learning process is the *perspective transformation*; this would be a support group participant's practice and integration of self-management behaviors and social support cultivated by facilitators.

Transformative learning theory does not fully address how a support group facilitator might cultivate a perspective transformation for a learner. Goal-setting theory, a cognitive motivation theory, focuses more attention on the facilitator than the support

group participant. Goal-setting theory is based on the idea that forming conscious goals effects action (Locke & Latham, 2002). Support group facilitators with the implicit intention of establishing both personal and group goals are more motivated to employ the appropriate strategies to promote social support and self-management skills and behaviors. Figure 6 presents a model for support group facilitation. On the left side is the facilitator, both professional, lay or peer, and on the right is the support group participant. The facilitator’s role and attitude toward goal-setting influence the type of strategies used to promote social support and self-management based on the participant’s phase in the transformative learning process.

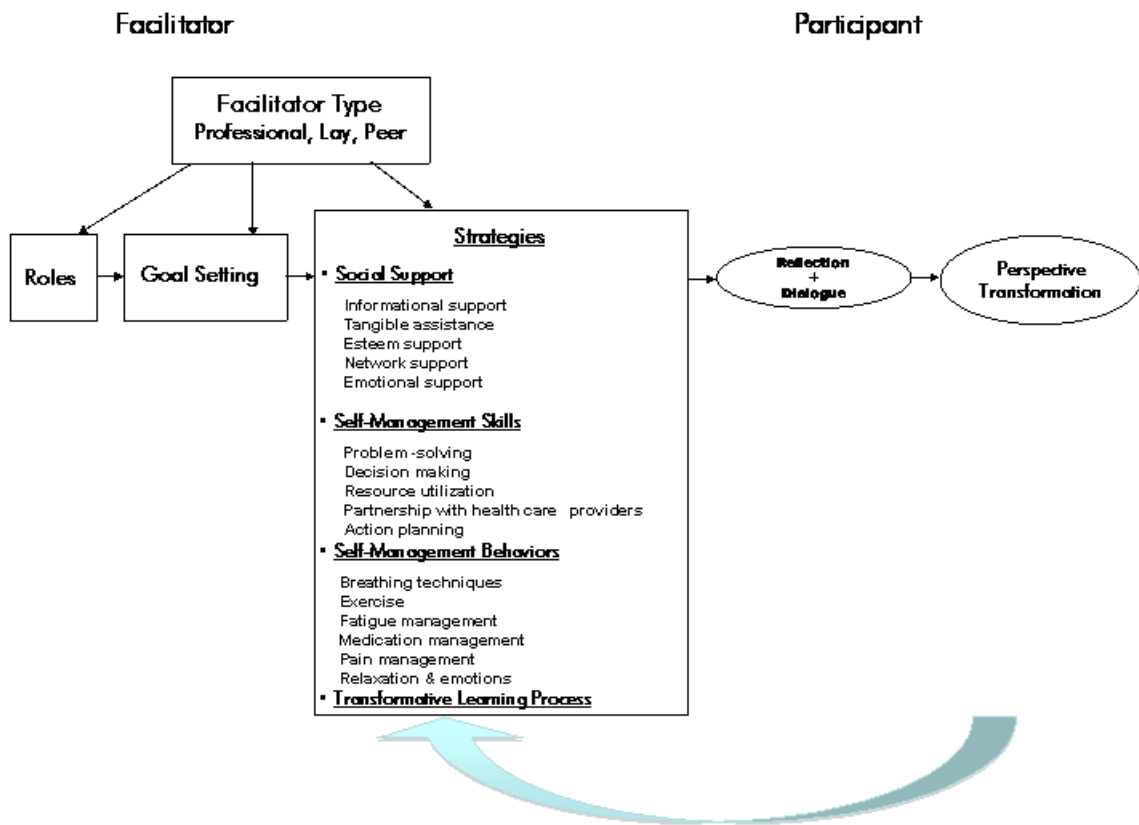


Figure 6. Model of Support Group Facilitation



The study's descriptive research design employed a researcher-designed survey instrument. The target population for this study was facilitators of support groups for adults with chronic health conditions; the sample included facilitators of adult support groups for adults with either Myotonic Muscular Dystrophy or Multiple Sclerosis. Survey respondents were accessed by one of four channels. Three channels were national health organizations sponsoring either Myotonic Muscular Dystrophy or Multiple Sclerosis adult support groups. The fourth channel involved the researcher making telephone calls to Multiple Sclerosis Care Centers, operated across the country, to identify support group facilitators unaffiliated with the national health organizations.

Survey items represented four Likert scales (Goal-Setting, Transformative Learning, Social Support, and Self-Management Skills) and multiple-response questions addressing either facilitator role description, strategies used to handle self-management behaviors, or facilitator demographics. Survey items were created based on the social support and self-management literature as well as generated from focus group meetings with local support group facilitators for adults with Multiple Sclerosis. The instrument was reviewed by two experts for content validity. Once the research study received Institutional Review Board approval, a pilot test was conducted with five support group facilitators. Two facilitators received the hard-copy survey while the other facilitators completed the online survey.

Data collection lasted approximately two months. The 59-item survey was completed, either online or with a hard-copy version, by 302 individuals. All hard copy surveys were manually entered into SurveyMonkey, the online survey application used for the web-based version of the survey. Data analysis included exporting data from

SurveyMonkey to an Excel spreadsheet file. After data were brought into the SPSS statistical software application and cleaned, ten cases were omitted due to missing data. All Likert scales were tested for reliability. Both quantitative and qualitative data were analyzed to address the following research questions:

1. How do different support group facilitators (professional, lay, peer) perceive their role?
2. What are the attitudes toward goal-setting among the different facilitator types (professional, lay, peer)?
3. Does the promotion of social support strategies vary among the different facilitator types?
4. Does the promotion of self-management skill strategies vary among the different facilitator types?
5. What strategies are used to promote self-management behaviors and do they vary among the different facilitator types?
6. Does the promotion of transformative learning vary among the different facilitator types?

The data analysis revealed four main findings. First, there were differences in role perception for professional, peer, lay, and professional + peer facilitators. As a whole, more facilitators selected “make sure everyone has an opportunity to speak” as best defining their role. Yet, looking at the data by facilitator type, a greater percentage of professional facilitators selected “promote ways for members to have optimal health.” This role description was not selected at all by lay facilitators. Lay facilitators selected “prevent group from becoming a *pity party*” with greater frequency than other role

descriptions. Second, a statistically significant difference was found with goal-setting for the different types of support group facilitators. Both the professional group ( $p = .048$ ) and the professional + peer group ( $p = .037$ ) had higher goal-setting mean scores than the peer group. The professional and professional + peer groups responded more favorably to goal-setting. Third, no significant difference was found in mean scores for social support ( $F = 1.31$ ;  $df = 3, 96$ ) and self-management skills ( $F = 2.13$ ;  $df = 3, 96$ ) with the four facilitator types. The fourth main finding from the data analysis is the differences in strategy use for the promotion of self-management behaviors. Overall, the highest usage of most didactic and collaborative strategies to promote all of the self-management behaviors was either by the professional or professional + peer support group facilitators. Lay facilitators had the least frequent use of most strategies for Breathing, Fatigue Management, Pain Management, and Medication Management. Overall, “group discussion” was the most frequently used strategy for all self-management behaviors. Generally there was low use of “demonstration” and “participatory activity” for most self-management behaviors except for “exercise.”

### **Limitations**

Three limitations were identified for this study. First, survey research has its own inherent limitations. A weakness of self-reported survey responses is the reliability and validity of the data (Burchinal, 2008). According to Isaac and Michael (1997), survey responses are reactive in nature and have the potential to produce misleading data. The risks include response bias and over- or under-rater bias. The use of Likert survey items perhaps adds to this limitation, especially because of the low reliability of the four Likert scales. To circumvent potential acquiescence bias, the tendency for respondents to avoid

using extreme response categories, Anderson recommends having an approximately equal number of both favorable and unfavorable worded statements (Anderson, 1988). In the current study, out of 35 Likert survey items, only five were worded unfavorable. Anderson (1988) advises using Guttman or Thurstone scales since they are more sensitive to assessing attitude change than Likert scales. In addition, increasing the number of items for both the goal-setting and transformative learning scales may have increased the scale's reliability (Carifio & Perla, 2007).

The second limitation for this study was administering the survey to facilitators representing only two types of chronic neurological health conditions. The results can not be generalized to the greater population of support group facilitators for adults with other varieties of chronic health conditions such as diabetes, HIV/AIDS, or cancer. In the interest of time and expense, the researcher limited the sample to two chronic health conditions rarely mentioned in the support group or self-management behavior literature.

The third limitation concerns the group of facilitators that responded to the email message sent by the health organization. There may be a disproportionate number of peer facilitators represented because they may be more emotionally invested in the survey than facilitators that do not share the health condition. If outreach to support group facilitators had been through a nursing, social work, or psychological professional organization, perhaps the professional facilitator response would have been larger. To make the comparisons between the four facilitator types, a random sample of the peer group was taken so the four group samples were more comparable.

## **Discussion of Findings**

Four main findings from this study are discussed. The primary purpose of this study was to survey support group facilitators about their perception of the role they play, their attitude toward goal-setting, and the strategies used to promote social support and self-management behaviors in the support group setting. The secondary purpose of this study was to look at the differences that may exist between facilitator types with the above-mentioned variables.

### **First Main Finding**

Research question one explored support group facilitators' perception of their role. Looking first at facilitators' perception of their role, there is little prior research exploring this variable for support group facilitators. Revenson and Cassel (1991) studied a group of 45 facilitators of support groups for adults with scoliosis and identified over 364 leadership activities encompassing the support group leader's role. The role with the greatest percentage of response was system maintenance at 49.7%. The current study explored role perception and identified "make sure everyone has an opportunity to speak" as the statement with the greatest frequency response. The statement "arrange logistics: meeting set-up, publicity, etc." had the second most responded frequency and is more similar to the scoliosis study. It is also noted that the facilitators in the scoliosis study assumed more organizational responsibilities than facilitators associated with the two national Multiple Sclerosis organizations. Somewhat different findings were revealed in the Costello (2007) study with six nurse facilitators of diabetes support groups. The qualitative study allowed for more in-depth discussion with the nurses about their roles so

that thematic responses such as a “philosophy of shared authority” and “focus on quality of life” were generated.

Numerous studies exist where comparisons are made between professional, lay, or peer support group facilitators (Butow et al., 2005; Carlsen, 2003; Kirsten et al., 2006; Owen et al., 2009; Segrist, 2008) but none explicitly examine differences in the facilitators’ perception of their role. Nurses assuming the support group facilitator role are known to help guide group participants with “discussion” and “structured teaching or resource materials” to address “individual’s and group’s needs” (Martin & Smith, 1996). Social workers assuming the support group facilitator role are expected to market the group and recruit members and assist members coping with issues (Walsh, Hewitt, & Londeree, 1996). The Revenson and Cassel study (1991) did include both professional, lay, and peer facilitators, the findings are not reported separately. Researchers used a technique, cluster analysis, to identify six different types of facilitators: health professionals with a mission, connected health professionals, career leaders, grassroots founders, obligated veterans, and connected grassroots leaders. In the current study, 36% of professional facilitators identified “promote ways for members to have optimal health” while only 15% of peer facilitators chose this statement to describe their role. None of the lay facilitators made this selection. Researchers noticed that major differences in studies addressed in their literature review tended to have different group leadership (Kendall, Catalano, Kuipers, Posner, Buys, & Charker, 2007). They surmised that peer support group leaders may have more influence on psychosocial outcomes such as mood and confidence while professional facilitators may have more of an impact on functional outcomes for support group participants such as energy level, speaking ability, or

mobility. Perhaps this conjecture is associated with professional facilitators perceiving their role differently? While positive psychosocial outcomes are clearly vital to the health of a person dealing with a chronic health illness, there is evidence that peer-led patient self-management programs can have a positive impact on both psychosocial outcomes as well as functional outcomes (Barlow et al., 1998; DeCoster & George, 2005; Lorig et al., 2001; Steed, Cooke, & Newman, 2003).

### **Second Main Finding**

Research question two examined facilitators' attitudes toward goal-setting. The tendency toward establishing and achieving goals is indicative of supportive behavior for group leaders (Latham, 2000) and bodes well for promoting short-term goals and action plans to assist support group participants with self-management behaviors. Again, little exists in the research specifically about support group facilitators and goal-setting, yet Lieberman and Golant (2002) found that professional facilitators of cancer support groups rated high with executive-management functions, such as establishing group rules and discussing group goals with participants, were positively associated with group participant positive outcomes such as lower depression, fewer physical problems, and better functioning. In the current study, facilitators were moderately agreeable to statements promoting goal-setting yet a significant number of respondents felt that helping group participants identify goals or identifying group goals themselves did not apply.

To better understand the significant number of *does not apply* responses, the researcher discussed the findings with contacts at the two national Multiple Sclerosis organizations. In the following paragraphs the professional judgments of these staff

people, cited as personal communications, offer a context for understanding the *does not apply* responses.

One Multiple Sclerosis staff member suggested that group leaders affiliated with their organization may see their main purpose as “information sharing” and not see “goal setting as something they would be involved in” (K. Koch, personal communication, April 1, 2010). The idea of goal-setting was perceived as part of “a therapy group” and not appropriate for support group meetings (MS coordinator, personal communication, April 2, 2010). This reaction from the health organizations is not surprising. The success of patient self-management programs and action planning has not yet merged with support and self-help groups. Patient self-management programs are taught by peers in a hospital setting and only available to individuals affiliated with that hospital. The concept of goal-setting and actions plans in terms of assisting people with chronic health conditions is more readily practiced and understood in the diabetes community.

Looking at the differences that may exist between facilitator types and their attitude toward goal-setting, the current study found a statistically significant difference – both professional and professional + peer support group facilitators have more favorable attitudes toward goal-setting than either the peer or lay support group facilitators. There is little in the literature to link the current study’s finding; Carlsen (2003), in a qualitative study, believed peer facilitators had a more process-oriented approach to group facilitation and professional facilitators were more goal-oriented with a bio-medical approach. While the current study did not explore the effectiveness of support group facilitators, there are studies with group leaders in business, government, and academia that suggest effective leaders establish goals, plan and cultivate the right conditions to



achieve group goals (Galanes, 2003; Kickul & Neuman, 2000; Marta, Leritz, & Mumford, 2005). The practice of goal-setting and assisting with action planning can easily be learned as researchers found in a study with nurse facilitators for groups of diabetic patients (Schreurs et al., 2003). After two half-day training sessions, nurses were able to offer more support to group members as well as implementing action planning in their own lives.

### **Third Main Finding**

The third research question asks if the promotion of social support strategies varies among the different facilitator types. No statistically significant differences were found in the promotion of social support strategies among the four facilitator types. Research has shown that social support is the main goal for the majority of support groups for adults with chronic health conditions (Brandl, Hebert, Rozwadowski, & Spangler, 2003; (Collie, Kreshka, Ferrier, Parsons, Graddy, Avram, et al, 2007; Mendelson, 2003; Mo & Coulson, 2008). For this study, social support is categorized according to the *social support behavior code* (Cutrona & Suhr, 1992). The *social support behavior code*, as characterized by Cutrona and Suhr, identifies five types of social support: tangible, emotional, esteem, network, and informational. Two previous studies have used the *social support behavior code* when analyzing posted text messages in online support groups (Coulson, Buchanan, & Aubeeluck, 2007; Mo & Coulson, 2008). Both studies found that informational support was the primary type of support offered with emotional support as secondary. The significant difference when looking at these studies and comparing them to the current study is that the online support groups did not have facilitators; the support gleaned from the text messages were from online

participants, not an online facilitator. The current study found esteem support to have the most favorable responses and network support with the least favorable responses. Support group leaders affiliated with one of the national Multiple Sclerosis organizations are trained to “encourage members to recognize, honor and celebrate successes” (K. Koch, personal communication, April 1, 2010). Esteem support is apparently stressed in another MS organization as “leaders want to empower a person. Encouraging, and having faith in them, shows a person the leaders and members do care about them (MS coordinator, personal communication, April 2, 2010).

The fourth research question asks if the promotion of self-management skill strategies vary among the different facilitator types. No statistically significant differences were found. The research on support groups for adults with chronic health conditions barely discusses the role of self-management with the exception of studies focused on diabetes support groups. Costello (2007) advocates that support groups are a viable method for integrating self-management into an adult diabetic’s life. The primary aim of her study was to elicit an account of strategies nurse facilitators use to promote self-management. Lorig and Homan (2003) recognized five core self-management skills for adults with chronic health conditions: problem-solving, decision-making, resource utilization, forming a partnership with health care provider, and setting short-term goals or action-planning. The current study addressed the promotion of self-management skills as defined by Lorig and Holman. Overall, the facilitators in the current study expressed favorable agreement toward promoting self-management skills. The most favorable response was encouraging support group participants to form partnerships with their health care providers. The least favorable responses concerned the practice of practical

skills as well as participants discussing their short and long-term goals. Turning to one of the national Multiple Sclerosis organization's leadership, it's noted that there is a "reluctance of group leaders to bring in speakers on topics that address more visible symptoms" (K. Koch, personal communication, April 1, 2010). Additionally, the support group leaders do not "see the meetings as a place to set goals."

The sixth research question asks if the promotion of transformative learning varies among the different facilitator types. No statistically significant differences were found. As anticipated, facilitators were generally in strong agreement with aspects of transformative learning especially in response to support group participants learning valuable information from one another. Results from this study support the claim that reflection and dialogue are important throughout the entire transformative learning process (Baumgartner, 2001; Taylor, 2007). In this study, over 83% of the respondents agreed that their role as the facilitator included modeling healthy behaviors. Ironically a much smaller percentage of facilitators identified their role in item 43 was to "promote ways for members to have optimal health." The high rate of *does not apply* responses for "helping members evaluate their beliefs or behaviors" may be indicative of many Multiple Sclerosis group leaders trained to hold "back with their personal beliefs when a member is expressing something different than what they believe" (K. Koch, personal communication, April 1, 2010). Unfortunately helping someone evaluate his or her beliefs or behaviors may be misinterpreted as telling someone what to do. One MS organization provides a manual to their support group leaders advising them to "refrain from giving personal interpretations, giving advice, sharing medication or offering recommendations" (Koch & Law, p. 10, 2008).

#### **Fourth Main Finding**

Research question five inquires as to the type of strategies used by support group facilitators to promote self-management behaviors and whether there are differences in strategy use among the facilitator types. While self-management *skills* and self-management *behaviors* may sound like they're one and the same, the difference between this research question and the fourth research question is the focus on specific health behaviors and the type of activity, or strategy, a support group facilitator employs. The self-management behaviors identified as applicable to most people with chronic health conditions include breathing, exercise, fatigue, nutrition and diet, medications, pain management, and relaxation and emotions (Lorig, Holman, Sobel, Laurent, Gonzalez, & Minor, 2000). A comprehensive review of diabetes self-management training for adults with diabetes type 2 revealed that collaborative activities were superior to didactic activities in terms of outcomes for study participants (Norris, Engelgau, & Narayan, 2001). Didactic self-management interventions, where a patient was a passive recipient of a presentation, had no effect on patient weight loss, mixed results for glycemic control and blood pressure, and positive effects on patient's diabetes self-knowledge. Collaborative interventions, which included group discussion, hands-on practice and other interactive techniques, on the other hand, had positive effects on patient's glycemic control and mixed results for patient weight loss and blood pressure. The Chronic Care Model stresses the importance of having more interactive and less didactic patient self-management practices (Wagner, Austin, Davis, Hindmarsh, Schaefer & Bonomi, 2001). Activities such as role-playing, action planning, and skills demonstrations are encouraged. In the current study, "group discussion" was the most frequently selected

strategy for all seven of the self-management behaviors. As promising as that sounds, the other two collaborative strategies, “demonstration” and “participatory activity”, were often the least frequently selected strategies. Also to take into consideration is the high number of *does not apply* responses for item 24 (“Practical skills such as operating an electric wheelchair can be learned at this support group meeting”), item 8 (“When learning a new skill or technique, I encourage members to practice during the meeting”) and item 9 (“Members frequently discuss what their short and long-term goals are”). In a literature review of interventions for reducing chronic disability, researchers found study participants successful with their self-management behavior changes when learning strategies included collaborative and active participation with demonstrations, goal setting, modeling, and the use of workbooks, texts, and videotapes combined with mutual aid and support (Marks, Allegrante, & Lorig, 2005). Unfortunately the notion of practicing new skills is deemed inappropriate for a support group meeting; a staff member from one MS health organization suggested “a meeting is not the time to practice a new skill; they are to take part in the meeting. Leaders know this,” (MS coordinator, personal communication, April 2, 2010). Again, much of the knowledge and success from peer-led patient self-management programs has not penetrated the support and self-help group model so firmly entrenched in many non-profit national health organizations.

While the current study found no statistically significant differences in facilitator types attitudes toward promoting social support and self-management skills, there is a difference in the amount and type of strategies used to promote self-management health behaviors by different facilitator types. Again, there is no prior research to specifically link the current study’s finding to except that using a variety of more collaborative

strategies is more effective in bringing about self-management behavior changes for people with chronic health conditions (Marks et al., 2005; Wagner et al., 2001). As to why professional facilitators more readily use collaborative strategies, it may be that their training and work experience has prepared them with these skills. It undoubtedly takes more time and initiative to facilitate a role-playing scenario for a group of people than it does to facilitate a group conversation but with appropriate training and tools, peer facilitators can easily learn more collaborative strategies and encourage *professional* guest speakers to engage more collaborative strategies.

In conclusion, the findings of the current study suggest there are differences in face-to-face support group facilitator types (professional, peer, lay) for adults with chronic neurological health conditions. These differences seem to be associated with the facilitator's professional experience in health care and when that experience is combined with a shared chronic health condition. The study did not attempt to gauge whether one facilitator type is more effective than the other type. Yet it can be assumed that using collaborative strategies to promote self-management health behaviors and social support will increase effectiveness if effectiveness is defined as support group participants achieving optimal health. Both professional and professional + peer support group facilitators tend to use more collaborative strategies than peer or lay facilitators.

### **Implications**

The research results will hopefully serve as a catalyst for researchers to better understand the significant role support group facilitators can have in the lives of people with chronic health conditions. Additional research is necessary to assess what makes a support group facilitator most effective in terms of guiding group participants toward

successful management of their chronic condition so they may achieve both optimal physical and mental health. This section explores the implications of this study for future research and practice.

### **Research**

This study's findings have implications for three areas of future research: refinement of the survey instrument, exploration of study variables within online support groups, and longitudinal studies exploring facilitator effectiveness.

One limitation in the current study was the reliability of the survey instrument's four Likert item scales. To increase reliability, the next iteration of the survey instrument requires additional items for both the goal-setting and transformative learning scales. Likert items for the four scales should be evaluated and re-written so an approximately equal number of both favorable and unfavorable worded items exist. The newer, pilot-tested survey instrument should be used with large samples of persons with other chronic health conditions.

The second implication for future research is with online support groups (OSGs). The current study was specifically limited to face-to-face support group facilitators yet approximately half of people with chronic health conditions go online to seek information and support for their condition (Fox, 2007). Thousands of commercial and non-profit OSGs exist (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Benefits to joining an OSG include anonymity and the accessibility of participating from the safety of one's own home rather than visiting a public facility. Members of certain cultural groups may be less inclined to disclose personal issues with face-to-face encounters (Gary, 2003).

It is impossible to gauge how many OSGs exist; these groups make use of computer-mediated communication tools that are either synchronous where people communicate with each other in real time, or asynchronous where people post messages to be read and responded to at different times. Several health organizations have synchronous chat tools available on their website but the majority of OSGs use asynchronous methods to communicate. For example, over 152,000 health and wellness groups were listed at one website, Yahoo! Groups, as of September 2009. This represents just a fraction of what is available from websites offering online support to people with chronic health conditions.

Countless studies have looked at the phenomenon of promoting social support and self-management in an online environment (Blank & Adams-Blodnieks, 2007; Eysenbach et al., 2004; Klemm, 1998; Lieberman & Goldstein, 2005; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008b; Weinberg, Schmale, Uken, & Wessel, 1996). Lieberman and Russo (2001-2002) found the vast majority of OSGs are not facilitated by professionals yet their study was limited to asynchronous modes of online communication. In a literature review of health OSGs and their impact on health and social outcomes, the researcher's recommendation for future research was to shift the focus from professionally-led health interventions to more consumer-led, self-help venues (Eysenbach et al., 2004).

After several studies showing the effectiveness of their self-management program, Stanford researchers developed a web-based version of their Chronic Disease Self-Management Program. The online course, similar to the face-to-face course, was taught in an interactive style intended to enhance self-efficacy (Lorig, Ritter, Laurent, & Plant,



2006). After one year of program completion, participants in the treatment intervention had statistically significant improvement in health status and stretching and strengthening exercise compared to the control group. No research has examined the current study's variables of interest with facilitators of online support groups.

The third implication for future research is to employ a longitudinal research study design to assess the effectiveness of different facilitator types and how they employ strategies to promote social support and self-management in both face-to-face and online support groups. Schopler and Galinsky (1993) found that successful group experiences tend to be the only ones documented and few groups conduct evaluations to gauge the group's effectiveness. Effectiveness should be measured by group participant outcomes related to their improved emotional and physical health. Prior research suggests that both social support and self-management can positively impact the life of a person with a chronic health condition.

Some researchers, whether their studies have explored participant outcomes in face-to-face groups or OSGs, believe that the group leader, or facilitator, has the ability to influence participant outcomes (Lieberman, Golant, & Altman, 2004; Ussher, Kirsten, Butow, & Sandoval, 2008). In the current study, findings suggest that there are no differences between facilitator types and their attitude toward social support and self-management skills yet there are differences in the strategies used to promote self-management health behaviors.

Costello suggested continued research on the connection of social support and integration of diabetes self-management into participant's lives, the need to test the

identified facilitator strategies using a questionnaire, and a desire for nurses to have a set of best practices for support group facilitation.

### **Practice**

Support group facilitators assume their role in a multitude of ways. The professional facilitators, people with health care experience such as nurses, social workers, or psychologists, have this responsibility as part of their job. Most peer facilitators are volunteering to lead their support group; some with the guidance of a non-profit health organization, while others create the group to fill a void in their community. Lay facilitators may assume the facilitative role because they are the caregiver for a chronically ill person. Whichever path these facilitators have traveled, they all face similar challenges. Research has explored these challenges. In cancer support groups both professional and lay facilitators had difficulties coping with participant's declining health as well as his or her eventual death and dealing with communication and behavior styles of participants (Kirsten et al., 2006). Nurse facilitators expressed problems handling group participant's negative emotions as well as struggling to help people with their goal-setting and action plans (Schreurs et al., 2003). Many researchers advised that support group facilitators, even nurses and social workers, are ill-equipped to handle support group personal dynamics and require additional training (Costello, 2007; Kirsten et al., 2006; Schreurs et al., 2003).

The current study's implications for practice speak to the need for training opportunities for all types of facilitators of support groups for adults with chronic health conditions. The training must emphasize strategies to promote both social support and self-management health behaviors as well as other helpful facilitator skills. Extensive

studies have proven efficacy for patient self-management programs and interventions yet the programs reach a limited number of patients, are expensive, and of short duration (Barlow et al., 1998; Boldy & Silfo, 2006; Lorig, Ritter, Stewart, Sobel, Brown, Bandura, Gonzalez, Laurent, & Holman, 2001; Marks et al., 2005). Support groups represent the natural evolution for promoting patient self-management and reaching a much wider audience.

Critical in diabetes self-management research has been the lack of follow-up for self-management programs and interventions (Fisher, Brownson, O'Toole, Anwuri, & Glasgow, 2005). In 2002 the Robert Wood Johnson Foundation established The Diabetes Initiative which led to the development of several self-management programs, and a shared model of best practices. Key features of this model include individualized assessment, collaborative goal-setting, self-management skill training, access to resources, and a continuity of clinical care. To address the issue of a stable link to clinicians is the role of the Community Health Worker (CHW). The CHW is not a professional health care provider but a community member serving as a bridge between peers and the health care providers (Davis, O'Toole, Brownson, Llanos, & Fisher, 2007). In a study with a small sample of diabetes patients assisted by CHWs, patients preferred the explanations and encouragement offered by CHWs over their health care providers, family, and friends. CHW contact with patients was primarily by phone (82%), rather than face-to-face (15%), and covered skills training related to healthy eating, physical exercise, and blood glucose monitoring.

If CHWs, non-professionals, can be trained to enhance self-management practices for people with diabetes, then support group facilitators can be trained as well. Boldy and

Silfo (2006) advocate for establishing self-management initiatives within a peer support framework. As health care costs escalate and the numbers of individuals with chronic health conditions increase, we must find ways to promote evidence-based strategies for the maintenance of optimal emotional and physical health.

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Appendix A

Invitation Letter from Researcher

Hello,

I am contacting you because of your role as a support group facilitator for adults with Multiple Sclerosis. Currently I am a doctoral student at the University of San Francisco; my dissertation is about support group facilitators. By participating in this research study, you can contribute to the currently limited research on support group facilitators. I am also a support group facilitator for adults with neuromuscular diseases.

In January 2010 I will begin conducting my study with support group facilitators throughout the country. You can participate in the study by completing a survey questionnaire. The survey is available on the [web](http://www.surveymonkey.com/s/xxx) (<http://www.surveymonkey.com/s/xxx>) or as a printed hard copy. You are welcome to choose whichever format is most suitable for you.

If you are interested in receiving a hard copy version of the survey instrument please contact me by phone (xxxxxx) or by email ([lkrongold@usfca.edu](mailto:lkrongold@usfca.edu)) as soon as possible. All of your responses are completely confidential and your name will not be associated with your responses.

As a token of my appreciation for your participation I will send you a copy of *Tips for Support Group Facilitators* based on my research. I anticipate completing this document before the summer of 2010. In addition, you can be entered into a drawing for a \$100 Amazon.com gift certificate.

Please contact me if you have any questions or concerns. I look forward to your participation.

Thank you,

Leslie Krongold

Appendix B

*Tips for Support Group Facilitators*

## Tips for Support Group Facilitators Research Study Results

Approximately 300 support group facilitators completed the research survey. There were a few Myotonic Dystrophy and mixed-neurological condition groups included but the vast majority were support groups for adults with Multiple Sclerosis.

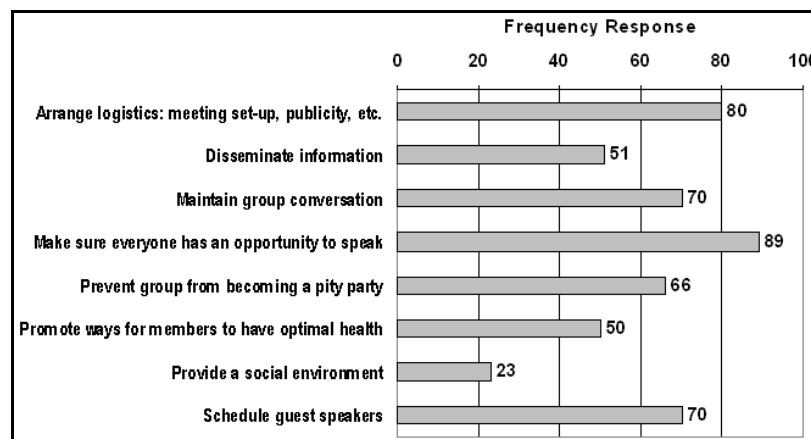
The research study I conducted sought to describe the support group facilitator's perception of their role and how they promote either or both goals of social support and self-management behaviors in their support group. By promoting these goals, I'm referring to the *strategies* used to achieve these goals such as group discussion, guest speakers, role playing, etc.

Prior research suggests that social support has helped people with chronic health conditions learn more coping skills, lower their depression, feel less stress and anxiety, achieve a greater sense of well-being, and enhance quality of life.<sup>1-5</sup>

Self-management is a set of behaviors to help a person manage their own illness in addition to what medical care provides.<sup>6</sup> Prior research suggests that promotion and practice of self-management behaviors for people with chronic health conditions have resulted in better functional outcomes such as increased physical activity, weight loss, and fewer hospital stays and physician visits.<sup>7-12</sup>

People come to the facilitative role from a variety of backgrounds. Some of us are *peers*, and share the chronic health condition, while others are *professionals* with a nursing, social work, or other healthcare experience. The facilitators responding to this study were predominantly peers; also participating were 28 professionals, 24 professional + peer, and 22 lay facilitators.

Facilitators' responses when asked to select the two statements best describing their role in the support group:



Although social support seems like a simple enough term to describe, previous researchers have broken it down into five different aspects of social support: information support, tangible assistance, esteem support, network support, and emotional support. Here are brief descriptions for each type of social support.

- Information support is any communication offering suggestions or guidance, referral to an expert, book, or website, or sharing personal experience.
- Tangible assistance is any communication or act providing direct or indirect tasks, a loan, or willingness to assist in some capacity.
- Esteem support is any communication offering a compliment, validation, or relief of blame.
- Network support is any communication providing access to other support group participants.
- Emotional support is any communication or act expressing care and concern.<sup>13</sup>

Based on survey responses, support group facilitators had more favorable responses toward promoting *esteem* support. The least favorable responses were for promoting *network* support.



*Evaluate where you might fall on the social support continuum and imagine how you might be able to promote more of a certain type of social support in your group.*

Research has found there are five essential skills that people with chronic health conditions can learn to help them manage their condition. These self-management skills are described below.

- Problem-solving: generating several potential solutions to a problem and evaluating the best option,
- Decision-making,
- Resource utilization: any type of community or health resource that helps someone manage their health condition,
- Forming a partnership with health care provider, and
- Establishing short-term, attainable goals and taking action.<sup>14</sup>

This research study revealed that support group facilitators responded more favorably to strategies promoting the self-management skill of forming partnerships with health care providers. The two self-management skills with the least favorable responses concerned resource utilization and the practice of practical skills as well as support group members discussing their short and long-term goals.



*If you wish to promote the practice of self-management skills in your support group, consider how you might implement these five essential skills.*

Numerous research studies of people with different chronic conditions – asthma, diabetes, cardiovascular disease, cancer, and HIV/AIDS – have identified specific areas of health behavior that can be managed by the patient. These self-managed



health behaviors include: exercise, nutrition and diet, medications, breathing techniques, and symptom management for fatigue, pain, stress, and emotions.<sup>15</sup>

This research study aimed to describe which strategies support group facilitators use to promote these health behaviors. The survey included the following strategies and survey respondents were given the option to write in their own strategy:

- ✦ Demonstration
- ✦ Distribute informational handouts
- ✦ Email with links to websites
- ✦ Group discussion
- ✦ Guest speaker presentation
- ✦ Participatory activity

The greatest response was for group discussion, a strategy used most for each of the self-management health behaviors. Both the use of demonstration and participatory activities were the least frequently selected strategies.

Research has found that certain strategies tend to be more effective than other strategies. A strategy that invites interaction, or collaboration, from support group participants enhances learning rather than a strategy that is more didactic, with the support group participant remaining passive.<sup>16-17</sup>

Strategies such as group discussion, demonstration, and any activity that engages the participation of support group participants would be more collaborative than didactic.



*Consider how you might encourage participants to learn about managing these healthy behaviors in a more participatory manner.*

While many facilitators had not previously thought of *breathing* as a support group topic, other facilitators mentioned strategies such as “yoga,” “tai chi,” or inviting guest instructors of “Feldenkrais” or “Alexander Technique” to the support group meeting.

*Exercise* garnered the most responses for the use of “participatory activity” strategy. One facilitator wrote of planning outdoor activities that “encourage deep breathing, rhythmic movement and light weight lifting as well as tossing a large ball from person to person.”

Several facilitators referred to the use of video, DVD, or teleconference for *fatigue management*. Two facilitators tied in “discussion about medications” for handling fatigue while others offered “guided imagery” and “individual coping mechanisms discussed, patterned, exhibited” as additional strategies.

When handling the topic, *management of nutrition and diet*, many facilitators discussed the use of “expert” guest speakers including a “dietician,” “nutritionist,”

and “chef.” To address this topic even further, a few facilitators also include “healthy snacks” or catering lunch at their support group meetings.

Some strategies for handling the *management of medications* in a support group setting included the use of guest speakers including a “neurologist” or “pharmacist” and nurses to “demonstrate injection techniques.” One person replied that the latest medication information was communicated in their group newsletter.

The topic of *pain management* generated several responses regarding the use of guest speakers such as “massage therapist” or “acupuncture practitioners.” One facilitator mentioned that referrals for “professionals specializing in pain management” are shared with support group members.

A topic clearly addressed by nearly all of the support group facilitators is the *management of relaxation and emotions*. Many facilitators suggested the use of guest speakers including a “social worker” and “neuro-psychiatrist.” Three individuals mentioned exercises or games “to illustrate importance of positive attitude.” Compact discs of “relaxing and encouraging music” were available for loan to members. One facilitator mentioned making “gratitude journals.”

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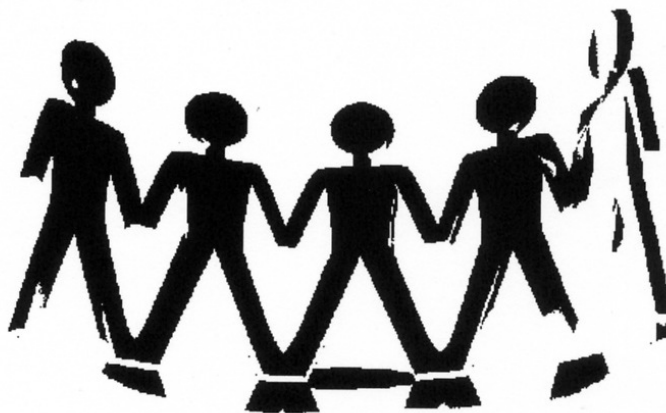
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Appendix C

Support Group Facilitator Survey

## Support Group Facilitator Survey (2010)

### 1. Support Group Facilitator Survey



### 2. Your Participation in this Research Survey

My name is Leslie Krongold and I am a graduate student at the University of San Francisco. I am doing a study on the roles, goals, and strategies used by support group facilitators for adults with chronic neurological health conditions. You are being asked to participate in this study because you are a facilitator of a support group for adults with a chronic neurological health condition.

If you agree to be in this study, you will complete a survey that asks about your experiences as a support group facilitator. To complete the web-based version of the survey, please click on the link below.

It is possible that some of the questions on the survey may make you feel uncomfortable, but you are free to decline to answer any questions you do not wish to answer, or to stop participation at any time. Study records will be kept as confidential as is possible. No individual identities will be used in any reports or publications resulting from the study. Study information will be coded and kept in locked files at all times. Only study personnel will have access to the files. Individual results will not be shared with personnel of your health organization.

While there will be no direct benefit to you from participating in this study, the anticipated benefit of this study is a better understanding of the roles, goals, and strategies used by facilitators of support groups for adults with chronic neurological health conditions.

There will be no costs to you as a result of taking part in this study. After participating in the survey you have the option of participating in a drawing for an Amazon.com gift certificate; one winner will be drawn. This is a potential benefit and compensation for participants.

## Support Group Facilitator Survey (2010)

If you have any questions about the research, you may contact the researcher at (510) 864-1190. If you have further questions about the study, you may contact the IRBPHS at the University of San Francisco, which is concerned with protection of volunteers in research projects. You may reach the IRBPHS office by calling (415) 422-6091 and leaving a voicemail message, by e-mailing IRBPHS@usfca.edu, or by writing to the IRBPHS, Department of Counseling Psychology, Education Building, University of San Francisco, 2130 Fulton Street, San Francisco, CA 94117-1080.

**PARTICIPATION IN RESEARCH IS VOLUNTARY.** You are free to decline to be in this study, or to withdraw from it at any point. Your health organization is aware of this study but does not require that you participate in this research and your decision as to whether or not to participate will have no influence on your present or future status with the organization.

### 3. Instructions

Thank you for taking this survey. Your responses are completely confidential. There may be questions or activities that are not relevant to your support group. The survey results will further a research understanding about facilitators of support groups for adults with neurological chronic health conditions.

Please focus only on one face-to-face support group when responding to the following questions. You can select your response by clicking on the circle next to your response.

#### 1. Are you the only facilitator for this support group?

- I am the sole facilitator.
- I co-facilitate with one other person.
- I co-facilitate with two or more persons.

#### 2. How long have you been facilitating this support group?

- Less than 1 year
- 1-2 years
- 2-5 years
- More than 5 years

#### 3. How often does this support group meet?

- Weekly
- Monthly
- Every other month
- Quarterly
- Other (please specify)

**Support Group Facilitator Survey (2010)****4. How would you describe the membership for this group?**

- Everyone has the same neurological health condition.
- Members have different neurological health conditions.

**5. Is membership open?**

- Open membership or drop-in
- Closed membership

**6. How many people generally attend each support group meeting?**

- Fewer than 5
- 5 - 9
- 10 - 14
- 15 - 19
- 20 or more

**7. How long is each support group meeting?**

- Less than 1 hour
- 1 hour
- 1-2 hours
- More than 2 hours

**4. Agree or Disagree?**

The next section presents a series of statements. Click in the circle to represent how much you agree or disagree with the statement related to how you facilitate the support group.

**8. When learning a new skill or technique, I encourage members to practice during the meeting.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**Support Group Facilitator Survey (2010)**

**9. Members frequently discuss what their short and long-term goals are.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**10. The main purpose of this support group is to learn how to remain healthy.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**11. I try to find a mentor, or role model, for new members.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**12. I try to help members set realistic goals for themselves.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply



**Support Group Facilitator Survey (2010)**

**13. If a member shares information I think may be incorrect, I follow up with a medical or health expert for accuracy.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**14. When a member expresses a strong sense of self-blame, I try to encourage them to see things differently.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**15. When a member has not attended a meeting for awhile, I make a point of contacting them.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**16. It is not appropriate for members to ask each other for any type of help outside the meeting.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**Support Group Facilitator Survey (2010)**

**17. I often try to help a member evaluate their beliefs or behaviors.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**18. A list of support group members contact information is available to the group.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**19. As a group we often brainstorm possible solutions to a member's problem.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**20. Support group activities are organized to guide the group toward optimal health.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**Support Group Facilitator Survey (2010)**

**21. My role is to help validate members' experience or feelings about having a chronic health condition.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**22. I coach members toward understanding a new way of thinking or doing things.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**23. I have encouraged members to carpool to meetings.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**24. Practical skills such as operating an electronic wheelchair can be learned at this support group meeting.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**Support Group Facilitator Survey (2010)**

**25. I encourage members to form partnerships with their health care providers.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**26. Each year I identify goals for the support group.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**27. My role as the facilitator includes modeling healthy behaviors.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**28. I regularly notify members of health or disability-related events in the community.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**Support Group Facilitator Survey (2010)**

**29. I have organized social events for members outside of the regular meeting time.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**30. I encourage members to make requests at meetings for help with some of the challenges they are dealing with.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**31. Members can learn valuable information from their peers in the group.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**32. I encourage members to applaud others small or big personal successes.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**Support Group Facilitator Survey (2010)**

**33. When I know a member has an important decision to make, I follow up with them at the next meeting.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**34. To help make a topic more meaningful to members, I break down the main points beforehand.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**35. There is nothing to do for a member with low self-esteem issues.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**36. It is difficult to predict how a group meeting will turn out.**

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Does Not Apply

**Support Group Facilitator Survey (2010)**

**37. During our meetings I encourage members to share personal experiences that will provide helpful information to others.**

- Strongly Agree  
 Agree  
 Disagree  
 Strongly Disagree  
 Does Not Apply

**38. I discourage members from meeting outside of the assigned support group meeting time.**

- Strongly Agree  
 Agree  
 Disagree  
 Strongly Disagree  
 Does Not Apply

**39. I practice active listening by focusing on the speaker and suspending judgment.**

- Strongly Agree  
 Agree  
 Disagree  
 Strongly Disagree  
 Does Not Apply

**40. I believe that recently diagnosed members have different needs in the support group.**

- Strongly Agree  
 Agree  
 Disagree  
 Strongly Disagree  
 Does Not Apply

## Support Group Facilitator Survey (2010)

### 41. I wish I had more control of the support group's direction.

- Strongly Agree  
 Agree  
 Disagree  
 Strongly Disagree  
 Does Not Apply

### 42. I have witnessed remarkable changes with members over time.

- Strongly Agree  
 Agree  
 Disagree  
 Strongly Disagree  
 Does Not Apply

## 5. Your Role as a Facilitator

Support group facilitators may play several roles. Please select the two statements that best describe your role as a support group facilitator.

### 43. Which two statements best describe your role as a support group facilitator?

- Arrange logistics -- meeting set-up, publicity, etc.  
 Disseminate information  
 Maintain group conversation  
 Make sure everyone has an opportunity to speak  
 Prevent group from becoming a *pity party*  
 Promote ways for members to have optimal health  
 Provide a social environment  
 Schedule guest speakers  
 Other (please specify)

## 6. Symptom Management

For the next seven questions, identify the different ways your support group handles symptom management for the following symptoms. Select YES or NO for each statement.



**Support Group Facilitator Survey (2010)**

**44. In the support group, how have you handled the management of breathing techniques?**

|                                   | Yes                   | No                    |
|-----------------------------------|-----------------------|-----------------------|
| Demonstration                     | <input type="radio"/> | <input type="radio"/> |
| Distribute informational handouts | <input type="radio"/> | <input type="radio"/> |
| Email with links to websites      | <input type="radio"/> | <input type="radio"/> |
| Group discussion                  | <input type="radio"/> | <input type="radio"/> |
| Guest speaker presentation        | <input type="radio"/> | <input type="radio"/> |
| Participatory activity            | <input type="radio"/> | <input type="radio"/> |
| Other                             | <input type="radio"/> | <input type="radio"/> |
| (please specify)                  |                       |                       |
|                                   |                       |                       |

**45. In the support group, how have you handled exercise?**

|                                   | Yes                   | No                    |
|-----------------------------------|-----------------------|-----------------------|
| Demonstration                     | <input type="radio"/> | <input type="radio"/> |
| Distribute informational handouts | <input type="radio"/> | <input type="radio"/> |
| Email with links to websites      | <input type="radio"/> | <input type="radio"/> |
| Group discussion                  | <input type="radio"/> | <input type="radio"/> |
| Guest speaker presentation        | <input type="radio"/> | <input type="radio"/> |
| Participatory activity            | <input type="radio"/> | <input type="radio"/> |
| Other                             | <input type="radio"/> | <input type="radio"/> |
| (please specify)                  |                       |                       |
|                                   |                       |                       |

**46. In the support group, how have you handled the management of fatigue?**

|                                   | Yes                   | No                    |
|-----------------------------------|-----------------------|-----------------------|
| Demonstration                     | <input type="radio"/> | <input type="radio"/> |
| Distribute informational handouts | <input type="radio"/> | <input type="radio"/> |
| Email with links to websites      | <input type="radio"/> | <input type="radio"/> |
| Group discussion                  | <input type="radio"/> | <input type="radio"/> |
| Guest speaker presentation        | <input type="radio"/> | <input type="radio"/> |
| Participatory activity            | <input type="radio"/> | <input type="radio"/> |
| Other                             | <input type="radio"/> | <input type="radio"/> |
| (please specify)                  |                       |                       |
|                                   |                       |                       |

**Support Group Facilitator Survey (2010)**

**47. In the support group, how have you handled the management of nutrition and diet?**

|                                   | Yes                   | No                    |
|-----------------------------------|-----------------------|-----------------------|
| Demonstration                     | <input type="radio"/> | <input type="radio"/> |
| Distribute informational handouts | <input type="radio"/> | <input type="radio"/> |
| Email with links to websites      | <input type="radio"/> | <input type="radio"/> |
| Group discussion                  | <input type="radio"/> | <input type="radio"/> |
| Guest speaker presentation        | <input type="radio"/> | <input type="radio"/> |
| Participatory activity            | <input type="radio"/> | <input type="radio"/> |
| Other                             | <input type="radio"/> | <input type="radio"/> |

(please specify)

**48. In the support group, how have you handled the management of medications?**

|                                   | Yes                   | No                    |
|-----------------------------------|-----------------------|-----------------------|
| Demonstration                     | <input type="radio"/> | <input type="radio"/> |
| Distribute informational handouts | <input type="radio"/> | <input type="radio"/> |
| Email with links to websites      | <input type="radio"/> | <input type="radio"/> |
| Group discussion                  | <input type="radio"/> | <input type="radio"/> |
| Guest speaker presentation        | <input type="radio"/> | <input type="radio"/> |
| Participatory activity            | <input type="radio"/> | <input type="radio"/> |
| Other                             | <input type="radio"/> | <input type="radio"/> |

(please specify)

**49. In the support group, how have you handled pain management?**

|                                   | Yes                   | No                    |
|-----------------------------------|-----------------------|-----------------------|
| Demonstration                     | <input type="radio"/> | <input type="radio"/> |
| Distribute informational handouts | <input type="radio"/> | <input type="radio"/> |
| Email with links to websites      | <input type="radio"/> | <input type="radio"/> |
| Group discussion                  | <input type="radio"/> | <input type="radio"/> |
| Guest speaker presentation        | <input type="radio"/> | <input type="radio"/> |
| Participatory activity            | <input type="radio"/> | <input type="radio"/> |
| Other                             | <input type="radio"/> | <input type="radio"/> |

(please specify)

## Support Group Facilitator Survey (2010)

### 50. In the support group, how have you handled the management of relaxation and emotions?

|                                   | Yes                   | No                    |
|-----------------------------------|-----------------------|-----------------------|
| Demonstration                     | <input type="radio"/> | <input type="radio"/> |
| Distribute informational handouts | <input type="radio"/> | <input type="radio"/> |
| Email with links to websites      | <input type="radio"/> | <input type="radio"/> |
| Group discussion                  | <input type="radio"/> | <input type="radio"/> |
| Guest speaker presentation        | <input type="radio"/> | <input type="radio"/> |
| Participatory activity            | <input type="radio"/> | <input type="radio"/> |
| Other                             | <input type="radio"/> | <input type="radio"/> |
| (please specify)                  |                       |                       |

## 7. Final Questions

Select only one response for each question.

### 51. What is your main challenge facilitating a support group?

- Encouraging people to be vulnerable
- Finding guest speakers
- Getting people to attend the meetings
- Keeping the group discussion interesting
- Managing difficult personalities
- Dealing with the death of a support group member
- Other (please specify)

### 52. Have you ever been a participant in any support group prior to facilitating this support group?

- Yes
- No

## Support Group Facilitator Survey (2010)

### 53. What is your occupation?

- Medical doctor  
 Nurse  
 Psychologist  
 Social worker  
 Other (please specify)

### 54. How many years of formal education do you have?

- Less than high school education  
 High school diploma or GED  
 Community college or AA degree  
 Some college  
 Bachelor's degree  
 Master's degree  
 Doctoral degree  
 Other (please specify)

### 55. How many different support groups do you now facilitate?

Face-to-face support groups

Online support groups

### 56. Do you share the same chronic neurological health condition as the support group members?

- Yes  
 No  
 If you answered NO, do you have a different chronic health condition?

### 57. What is your gender?

- Female  
 Male

**Support Group Facilitator Survey (2010)****58. What is your age?**

- 20 - 30
- 31 - 40
- 41 - 50
- 51 - 60
- 61 - 70
- Over 70 years old

**59. What is your ethnic background?**

- African American or black
- Asian
- European American or white
- Hispanic
- Native American
- Other (please specify)

**8. Thank You for Your Participation.**

This is the end of the survey. Thank you for your time. To receive the document, *Tips for Support Group Facilitators*, and be entered in the drawing for an Amazon.com gift certificate, please [click here to enter your contact information](#). Your contact information will not be attached to your survey results.

## Appendix D

National Multiple Sclerosis Society Communication to Self-Help Group Leaders



**PROGRAMS & SERVICES**

|  |                                  |
|--|----------------------------------|
| <b>Date: January 15, 2010</b>  | <b>CC:</b><br>Chapter Presidents |
| <input type="checkbox"/> <i>Do Not Post on NMSS.org</i>                      |                                  |
| <b><u>Exciting Research Opportunity for NMSS Self-Help Group Leaders</u></b> |                                  |
| <b>Action Requested/Deadline: February 1, 2010</b>                           |                                  |

National MS Society self-help group leaders are invited to participate in an exciting research opportunity. Leslie Krongold, a doctoral student at the University of San Francisco, is conducting a survey of support group facilitators as part of her dissertation. The purpose of her research study is to describe support group facilitators' role perceptions, goals, and strategies used to achieve social support goals and self-management behaviors in the group setting. The study will look at both professional and volunteer-lead groups. Ms. Krongold contacted the Society and asked that we partner with her on her outreach and recruitment efforts. The survey instrument, study protocol and related materials have been reviewed and approved by Society staff. Copies are available upon request.

Currently there is very little research about support groups for people with chronic health conditions and even less about support group facilitators. By participating in this voluntary research study, self-help group leaders have the opportunity to contribute to a neglected, but very important area of research. Interested leaders can participate in two ways – either through an online survey or by completing the hard copy version. Data collected from both versions of the survey instrument will be anonymous – name, address and phone number of the responders will not be connected with their responses.

The Programs and Services team is coordinating the outreach and recruitment efforts. Chapters are asked to submit an Excel spreadsheet with leaders' names and email addresses, or mailing address if there is no email address, to my attention (contact information below). The survey closes in mid-to-late February, so we are asking that the contact lists be submitted no later than Monday, February 1, 2010. Information on the survey will also be posted to the Society's list-serve for self-help group leaders.

Thank you in advance for your assistance and participation. Ms. Krongold has agreed to share her final report with the Society, and a future news sheet will announce its availability.

For more information please contact [redacted] at 3 [redacted], ext. [redacted] or [redacted]@nmss.org.

Appendix E

Second Communication from National Multiple Sclerosis Society to Self-Help Group

Leaders





Leslie Krongold <lkrongold@dons.usfca.edu>

## FW: An Exciting Opportunity for National MS Society SHGLs

~~XXXXXXXXXX~~ <~~XXXXXXXXXX~~@nmss.org>  
To: Leslie Krongold <lkrongold@dons.usfca.edu>

Tue, Feb 23, 2010 at 9:57 AM

Hi Leslie,

I can get another email out this week. See below for proposed text.

Thank you,

~~XXXXXXXXXX~~

~~XXXXXXXXXX~~

Associate Vice President, Family and Support Programs

National Multiple Sclerosis Society

Broadway Station

900 South Broadway, Suite 200

Denver, CO 80209

~~XXXXXXXXXX~~nmss.org

Tel: ~~XXXXXXXXXX~~

Fax: ~~XXXXXXXXXX~~



National  
Multiple Sclerosis  
Society

JOIN THE MOVEMENT

Students & Alumni DonsApps Mail - FW: An Exciting Opportunity fo...

[nationalMSsociety.org](http://nationalMSsociety.org)

---

**From:** ~~XXXXXXXXXX~~  
**Sent:** Sunday, January 17, 2010 2:31 PM  
**Subject:** An Exciting Opportunity for National MS Society SHGLs

Dear National MS Society Self-help Group Leaders,

Thank you to everyone who has participated in the survey for Leslie Krongold's dissertation research. We all very much appreciate you taking the time to do so. If you have not already completed the survey, and are interested in doing so, the deadline for participation has been extended until Sunday, February 28<sup>th</sup>.

Ms. Krongold is a doctoral student at the University of San Francisco and is conducting a survey of support group facilitators as part of her dissertation. The purpose of her research study is to describe support group facilitators' role perceptions, goals, and strategies used to achieve social support goals and self-management behaviors in the group setting. The survey instrument, study protocol and related materials have been reviewed and approved by Society staff.

You can participate by taking an online survey (<http://www.surveymonkey.com/s/9XXXXXXXXXX>). The survey should take 15-30 minutes to complete. It is important to note that the survey must be completed in one sitting – the system does not allow you to log back in to complete it at a future time. Data collected from the survey instrument will be anonymous – your name, address and phone number will not be connected to your responses.

As a token of her appreciation for your participation Ms. Krongold will send you a copy of *Tips for Support Group Facilitators* based on her research. In addition, you can be entered into a drawing for a \$100 Amazon.com gift certificate.

It is not often we get this type of opportunity and I hope you find it of interest. Thank you in advance to all who participate. Ms. Krongold has agreed to share her final report with the Society and study participants. I know I am excited to see the results of her efforts.

Sincerely,

~~XXXXXXXXXX~~

---

Appendix F

Myotonic Dystrophy Foundation Communication to Support Group Facilitators

Print

From: [REDACTED] ()  
 To: [REDACTED]  
 Date: Fri, February 19, 2010 9:08:01 AM  
 Subject: Support Group Facilitator Survey Request - Deadline February 28th



**MYOTONIC  
 DYSTROPHY  
 FOUNDATION**

February 19, 2010

Re: Myotonic Dystrophy Support Group Facilitators Survey

Dear Leslie:

I wanted pass along a request from Leslie Krongold, the Oakland California myotonic dystrophy support group facilitator and a member of the MDF community. She is working on her dissertation about support group facilitators and would like your input. Her deadline for taking the survey is February 28 so please take a few minutes to help. The survey will only take about 15 minutes. Some of you may have already received a request directly from Leslie so if you have already taken the survey you can ignore this email.

Thank you in advance for your help.

I

Hello,

I am contacting you because of your role as a support group facilitator for adults with Myotonic Muscular Dystrophy. Currently I am a doctoral student at the University of San Francisco; my dissertation is about support group facilitators. By participating in this research study, you can contribute to the currently limited research on support group facilitators. I am also a support group facilitator for adults with Myotonic Muscular Dystrophy.

In early 2010 I will begin conducting my study with support group facilitators throughout the country. You can participate in the study by completing a survey questionnaire. The survey is available on the web (<http://www.surveymonkey.com/s/...>). All of your responses are completely confidential and your name will not be associated with your responses.

As a token of my appreciation for your participation I will send you a copy of *Tips for Support Group Facilitators* based on my research. I anticipate completing this document

Print

~~mailto:leslie.krongold@usfca.edu~~

before the summer of 2010. In addition, you can be entered into a drawing for a \$100 Amazon.com gift certificate.

Please contact me if you have any questions or concerns. I look forward to your participation.

Thank you,  
Leslie Krongold  
lkrongold@usfca.edu  
~~lkrongold~~

---

## Appendix G

### Data Results from Survey Items 1 – 2

Table G-1

Frequencies and Percentages of Responses to Survey Item-1: Are you the only facilitator for this support group?

| Sole facilitator | Co-facilitate with one other person | Co-facilitate with two or more persons |
|------------------|-------------------------------------|--|
| 40.4%<br>(1180)  | 49.7%<br>(145)                      | 9.6%<br>(28)                           |

n = 291.

Table G-2

Frequencies and Percentages of Responses to Survey Item-2: How long have you been facilitating this support group?

| Less than 1 year | 1-2 years     | 2-5 years     | More than 5 years |
|------------------|---------------|---------------|-------------------|
| 9.9%<br>(29)     | 14.4%<br>(42) | 32.3%<br>(94) | 43.3%<br>(126)    |

n = 291.

## Appendix H

### Data Results from Survey Item 3



Table H

Frequencies and Percentages of Responses to Survey Item-3: How often does this support group meet?

| Weekly      | Monthly        | Every other month | Quarterly |
|-------------|----------------|-------------------|-----------|
| 2.1%<br>(6) | 84.6%<br>(247) | 1.7%<br>(5)       | 1%<br>(3) |

n = 292.

Thirty-one respondents (10.6%) chose the *other* response for this survey item. Fifteen support group facilitators reported meeting two times each month, several of them followed a formal meeting with an informal meeting. Eight respondents meet approximately nine months out of the year, either skipping the summer or winter months due to weather conditions. The remaining meet either quarterly or “10-12 weeks .

## Appendix I

### Data Results from Survey Items 4 - 7

Table I-1

Frequencies and Percentages of Responses to Survey Item-4: How would you describe the membership for this group?

| Everyone has the same chronic neurological health condition | Participants have different chronic neurological health conditions |
|---|--|
| 80.1%<br>(234)  | 19.2%<br>(56)  |

n = 290.

Table I-2

Frequencies and Percentages of Responses to Survey Item-5: Is membership open?

| Open membership or drop-in | Closed membership |
|----------------------------|-------------------|
| 95.9%<br>(280)             | 2.7%<br>(8)       |

n = 288.

Table I-3

Frequencies and Percentages of Responses to Survey Item-6: How many people generally attend each support group meeting?

| Fewer than 5 | 5-9           | 10-14         | 15-19       | 20 or more    |
|--------------|---------------|---------------|-------------|---------------|
| 7.9%<br>(23) | 32.2%<br>(94) | 32.5%<br>(95) | 14%<br>(41) | 12.7%<br>(37) |

n = 290.

Table I-4

Frequencies and Percentages of Responses to Survey Item-7: How long is each support group meeting?

| Les than 1 hour | 1 hour       | 1-2 hours      | More than 2 hours |
|-----------------|--------------|----------------|-------------------|
| .7%<br>(2)      | 8.6%<br>(25) | 82.2%<br>(240) | 7.9%<br>(23)      |

n = 290.

Appendix J

Data Results from Survey Item 51

Table J

Frequencies and Percentages of Responses to Survey Item-51: What is your main challenge with facilitating a support group?

---

|  |               |
|--|---------------|
| Encouraging people to be vulnerable              | 4.1%<br>(12)  |
| Finding guest speakers                           | 17.8%<br>(52) |
| Getting people to attend meetings                | 33.2%<br>(97) |
| Keeping the group discussion interesting         | 19.9%<br>(58) |
| Managing difficult personalities                 | 9.6%<br>(28)  |
| Dealing with the death of a support group member | 2.1%<br>(6)   |

n = 286.

Thirty-three respondents (11.3%) chose the *other* response for this survey item. Several people maintained all or most of the listed responses were challenges for them; several others commented they experienced no problems. While some facilitators detailed aspects of the membership presenting challenges such as “keeping people positive” or “encouraging people to be more receptive to this disease,” others focused on logistical issues such as “transportation/parking/time of meeting” and “finding new subject matters to discuss.” Several respondents are challenged with “getting individuals to take ownership of certain tasks” whether it be co-facilitation or “meeting responsibilities.”

## Appendix K

### Data Results from Survey Items 52 & 55

Table K-1

Frequencies and Percentages of Responses to Survey Item-52: Have you ever been a participant in any support group prior to facilitating this support group?

| Yes            | No            |
|----------------|---------------|
| 65.4%<br>(191) | 32.55<br>(95) |

n = 286.

Table K-2

Frequencies and Percentages of Responses to Survey Item-55: How many different support groups do you now facilitate?

| Face-to-face support groups |              |           |            | Online support groups |            |   |            |
|-----------------------------|--------------|-----------|------------|-----------------------|------------|---|------------|
| 1                           | 2            | 3         | 4          | 1                     | 2          | 3 | 4          |
| 81.8%<br>(239)              | 9.2%<br>(27) | 1%<br>(3) | .3%<br>(1) | 6.5%<br>(19)          | .3%<br>(1) | 0 | .3%<br>(1) |

n = 276-277.