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.1-5

Self-management is a set of behaviors to help a person manage their own illness in addition to what medical care provides.6 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.7-12

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:

- Arrange logistics: meeting set-up, publicity, etc. 80
- Discourage information
- Maintain group conversation 51
- Make sure everyone has an opportunity to speak 70
- Prevent group from becoming a pity party 69
- Promote ways for members to have optimal health 56
- Provide a social environment 50
- Schedule guest speakers 70

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.

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.

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.

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.

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.”

References


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