

Group-Based Psychotherapy for Military Veterans with Multiple Sclerosis

A Systems-level Case Series

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This paper describes the development of a program of group-based psychosocial services offered to patients with multiple sclerosis at a Veteran's Health Administration facility. Four groups are currently offered: "Living Well with MS," "Enhancing Cognitive Skills," "Enhancing Interpersonal Relationships and Managing Mood," and "Caregiver Support." The theoretical and practical evolution of these groups is discussed, along with suggestions to assist mental health professionals in designing similar group programs at their facilities. The principles described are appropriate for persons with a variety of physical and cognitive impairments. Int J MS Care. 2004;6:110–115.

In addition to physical changes, over half of persons with MS also report cognitive, psychological, and social changes.¹⁻⁴ At the Veteran's Administration of Puget Sound Health Care System (VAPSHCS), a coordinated group-based psychosocial program was developed to address these issues. This program is specifically tailored to the needs of veterans with MS, who are more likely to be older, male, unemployed, and disabled, with lower levels of income and education than non-veteran MS patients.⁵

The VAPSHCS provides care to approximately 350 veterans with MS (Table 1).⁶ Of veterans in this region, 22% meet criteria for current major depressive episode and 29% endorse suicidal thoughts.⁷ Most report receiving moderate levels of social support, with veterans who are male, married, living with someone, or with higher incomes reporting significantly higher levels of social support than participants who are female, unmarried, living alone, or living on less than \$22,000 annually.⁸

Efficacy of Group-Based Interventions

Enhanced social support may be one method for facilitating adjustment to MS.⁹⁻¹¹ Social support has been shown to promote well-being and protect persons from the deleterious effects of stressful life events and illnesses such as cancer,¹² depression,¹³ traumatic brain injury,¹⁴ and chronic pain.¹⁵ Support groups are one avenue by which individuals may enhance social support.¹⁶ disease type and geographic location.

There is good theoretical support for group-based interventions.¹⁶ Yalom,¹⁷ an early proponent of group-based psy-

chotherapy, describes several important curative factors that are distinctly different from those present in individual psychotherapy. Table 2 lists those most relevant to persons with a disability or illness.

The research evaluating support groups is mixed, reflecting differences in outcome measures, treatment duration, and design features. Nevertheless, there is generally good support for professionally led, skills-based interventions, particularly those that focus on the development of cognitive and behavioral skills.^{12,18-20}

A review of MS-specific group literature supports the efficacy of structured educational opportunities to treat depression and facilitate adjustment.²¹⁻²⁴ For example, Schwartz found that after controlling statistically for neurological deterioration and gender, a coping skills group intervention was associated with improvement in a variety of areas compared with peer telephone support.²² The participants in the coping skills group reported enhanced psychosocial role performance, coping behavior, family and spiritual satisfaction, personal growth, social relatedness, and self-acceptance, as well as a shift from negative (e.g., blaming others) to a positive (e.g., reframing) coping strategy. In contrast, the peer-support telephone intervention appeared to lead to a "realistic, albeit negative appraisal of one's abilities" and reduced self-efficacy. However, a subgroup of participants with baseline affective problems were more likely to benefit from the peer-support intervention than the coping skills group on measures of depression, anxiety, the use of avoidant coping, and self-acceptance.

In summary, it appears that both individual and group-based structured interventions can enhance outcomes among persons with MS. Relatively unstructured social support interventions have also shown to be beneficial over time, although are perhaps associated with fewer positive changes and may be of particular benefit to only a subset of persons.

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Table 1. Patient Profile at Veterans Administration of Puget Sound Health Care System

n = 350; male: 86%; mean age: 53.9 years

MS type:

- Relapsing remitting 40%
- Secondary progressive 28%
- Primary progressive 17%
- Progressive remitting 14%

Mobility limitations:

- 25% use power wheelchair
- 16% use scooter
- 40% use manual wheelchair
- 33% no longer drive
- 74% report at least occasional falls

Pilot Work and Assessment of Program Needs

A needs assessment survey administered to veterans in the Northwest region of the country in 2000 (coordinated by VAP-SHCS) provided data to quantify and support the clinical observation that many veterans had unmet psychosocial needs. These included low levels of social support, high rates of depressive symptoms and suicidal ideation, high rates of unemployment and lack of opportunity for meaningful work, and activity/participation limitations. Additionally, 50% of veterans in the region received all of their MS-related care from their spouse, suggesting a need for programs to support caregivers.

Focused Interviews

Prior to beginning groups, physicians, nurses, and therapists were consulted to gather information about the types of psychosocial services needed. Interviews with these clinicians highlighted the need for a program: 1) for both caregivers and veterans; 2) with ongoing openings and starting points; 3) able to accommodate participants with a range of cognitive and physical abilities; and 4) able to accommodate a fairly large number of veterans, many of whom did not meet diagnostic criteria for any particular psychological or psychiatric problem.

Concurrently, patients were interviewed to develop group content and format. Veterans and their spouses reported a large unmet need for caregiver (spouse) support and education. Many veterans reported that they had participated in other support groups as well as more formal psychotherapy treatment groups within the hospital and community since their MS diagnosis. Veterans who had participated in formal, psychologist-led treatment groups at the hospital for concurrent disorders—such as posttraumatic stress disorder (PTSD) or substance abuse—generally reported favorable group attitudes, experiences and treatment efficacy. They attributed their success to group cohesion, trust in the leader, and perceived improvement in symptoms and self-efficacy. However, qualitative reports of veterans' expe-

riences in unstructured peer-led groups for MS were highly variable. Many said they stopped attending after a few sessions because the groups felt like “venting sessions,” with little discussion of coping, improvement, or treatment. Moreover, many veterans reported that they felt uncomfortable with a lack of leadership and structure in groups, and reported that the open, “drop in” format made it difficult to develop a sense of cohesion with other members. Veterans commonly requested groups that focused on skill development, symptom management, information, and an opportunity to share their experiences and learn from others.

Group Descriptions

Over the past three years, five different groups have been developed: 1) Adjusting to MS, 2) Caregiver Support, 3) Cognitive Behavioral Therapy for Depression, 4) Enhancing Cognitive Skills and 5) Improving Interpersonal Relationships and Managing Mood (for veterans with cognitive impairment).

Based on the priorities identified by veterans and providers, we began with two groups, one specifically addressing depression and one addressing general adjustment for veterans and caregivers, combined. After the first year, we dropped the depression group and added a separate caregivers' group and a group that focused on enhancing cognitive skills, to reflect the needs that emerged once we began providing the services. We subsequently modified the program again by adding a group that focused on emotional regulation and interpersonal skills enhancement for persons with cognitive impairment. Hence, the current combination of groups offered has evolved, reflecting our learning curve and increasing ability to tailor the program to meet the needs of the veterans served.

Table 2. Curative Factors in Group Psychotherapy

- 1) instillation of hope that quality of life will improve;
- 2) universality of experience;
- 3) learning new information;
- 4) altruism, or improvement through giving to others;
- 5) development of socializing techniques;
- 6) imitative behavior (modeling and rehearsal);
- 7) group cohesiveness and belonging;
- 8) opportunity for catharsis;
- 9) discussion of existential factors.

Source: Yalom, 1985.¹⁷

Groups are offered on a rotating basis, so generally at least one is always available. The specific goals, evolution, strengths, and problems associated with each type of group are described below.

Common Elements

All groups, except the caregiver group, are led by a licensed clinical psychologist with special training in rehabilitation, and frequently are co-led by a pre-doctoral level psychology intern.

A speech-language pathologist helped with the development of the “Enhancing Cognitive Skills” group and occasionally co-leads it. The “Caregiver Support” group was designed and is led by a licensed social worker.

All groups are structured around eight weekly 90-minute sessions. Each group is offered three times per year. Group times, day of the week, and room location are constant, which is critical given the visual and memory problems of many of the participants. All groups are held from 10:30-12:00 AM, which accommodates the VA transportation system, and also generally corresponds with participants’ most energetic time of day. The rooms are accessible, well cooled, and large enough to accommodate up to 10 persons in power wheelchairs. We gather around a table for all groups except the “Adjustment to MS: group, to make note-taking and written exercises possible. For the “Adjustment to MS” group, we sit in a circle without a table. A large white board is used occasionally for teaching purposes in all groups. At the start of each eight-week session, group members are provided with a folder to collect handouts. These are designed with large, dark font so participants with visual impairments can read them. We have also learned to color-code handouts for easy reference and organization. Finally, we provide participants with large name tags.

There are two primary components to all group interventions: discussion with peers and structured didactic education. Ideally, both occur within a caring and accepting social environment. To facilitate this, we screen participants systematically. Persons with personality disorders, psychotic disorders or features, active substance use, poor ability to keep appointments, or a history of poor success in group are not invited to participate, and are instead seen for individual therapy. To further facilitate a safe and comfortable group environment, each eight-week session begins with a review of behavioral expectations of both participants and leaders.

We conclude each session with 15 minutes of “free time” discussion, which serves several purposes. First, it provides participants with an opportunity to socialize in a more natural way, as discussions tend to center around enjoyed activities, hobbies, and current events. Second, it provides leaders with an avenue for managing the group. For example, if discussion moves away from the planned topic, leaders have the option of asking participants to save that discussion for the “free time.” Third, it gives participants an opportunity for “show and tell,” to share current and former hobbies, projects and accomplishments, and collections. This provides a needed opportunity to cultivate meaning; share mastery, interests, and humor; and to focus on life roles and activities beyond that of “MS patient.”

“Adjusting to MS” Group

The first pilot group was offered in 2000. Five veterans and their spouses participated. The group focused on enhancing resilience, interacting effectively with a medical team, and improving relationship quality. Participants reported these topics were appropri-

ate and generated useful discussion. However, it quickly became apparent that veterans and their spouses had different needs that may be better served by separate groups. We observed that spouses did the majority of talking, often openly venting frustration about their disabled partners. Hence, for the second eight-week group we divided into two concurrent groups: a caregiver support group and a veteran group.

Veteran Group: Adjusting to MS

This group’s goals include: 1) encouraging participants to become advocates for themselves and empowered members of their care teams; 2) educating participants about self-management strategies, MS, social skills and support, relationship quality, quality of life; and 3) providing a supportive and cohesive group atmosphere in which members feel safe to share and explore feelings and thoughts.

Each week, group activities generally consist of an initial brief check-in, during which members identify any significant events of the previous week and any needs or hopes for that day. These check-ins often require significant time-management interventions and focused questions from the group leaders. We then generally have a structured discussion about a particular topic.

Topics participants have appreciated include: self-management and self-advocacy; specific symptom management (i.e., fatigue, bladder health); using humor; overview of the medical team; preparing for a clinic visit; improving social relationships; engaging in pleasant activities; finding meaning in day-to-day life; sexuality and intimacy; enhancing resilience; decision making; monitoring mood; relaxation and meditation; complementary and alternative therapies; and grief and loss. Guest leaders are encouraged, and group members have particularly appreciated visits from the clinic attending physiatrist and neurologist, MS nurse specialist, urology nurse specialist, social worker (who answered questions about legal and financial issues), and representatives from national and community agencies. Finally, we have begun to incorporate a “journal club” format occasionally, where the leader or a group member will bring in an article of interest for discussion.

To date, this group has been offered nine times, and a total of 30 persons have participated in at least one 8-week session. Five candidates were screened who were not considered appropriate for the group. All but three participants have been male, mean age 55 (median 56 and only three have been under 40), and all but three have been Caucasian. All participants have had MS for at least 10 years and all use a mobility aid (10% cane; 5% walker; 5% scooter; 40% manual wheelchair; 40% power wheelchair). Average group size is 8 members, with a range from 4-13. Three members have died, two have been asked to leave, and 12 have left the group because of relocation, transportation difficulties, or a desire to take a break.

Recently this group was renamed “Living Well with MS” to

better reflect the philosophy that it provides for ongoing psychosocial needs, rather than facilitating adjustment in a finite fashion. Toward a similar end, we now offer “booster sessions” every three weeks during the months when the group is not offered weekly, to facilitate ongoing cohesion and social contact.

Caregiver Support Group: Living Well with (a family member who has) MS

The Caregiver Support group is offered concurrently with the “Living Well with MS” veteran group, to make attendance more feasible for caregivers. After the second eight-week session, the members had developed such strong friendships both within and outside of the group that they elected to continue to meet informally during the breaks when the group was not formally in session.

This group also includes didactic, structured components, guest lectures, and emotional support. Specific topics covered include enhancing resilience, self-care, negotiating the VHA system, accessing community resources, dealing with guilt and loss, mood management (focusing on anxiety and depression), financial and legal planning, and asking for help. The group has also had guest lectures from specialists in legal and financial planning and decision making.

To date, all participants in this group have been female spouses of male veterans with MS, except for one daughter. Average group size is 5 to 7 participants; mean age is 56 years. Membership has been remarkably stable, with spouses of veterans who are most severely impaired comprising the group. Regular participants have voiced their support for its perceived value, and some evidence suggests that participants are now more likely to use VHA resources (e.g., annual respite care for veterans) and engage in other self-care activities.

Of note, several participants whose spouses were comparatively less impaired dropped out of this group because they found it depressing to learn about those with more severe impairment. In planning for another facility, we might recommend two different caregiver support groups; one for persons whose family members are newly diagnosed or with mild to moderate disability, and a second group for those whose partners have severe impairments.

Cognitive Behavioral Therapy for Depression

This group was based on existing empirically validated approaches to cognitive behavioral therapy for depression. We adapted several existing treatments^{25,26} by simplifying them and by converting suggested activities (e.g., take a walk) to more reasonable options for persons with physical activity limitations. Despite these modifications, after offering this 8-week group three times, it was terminated for several reasons. First, most participants had significant difficulty grasping the concepts cognitively and completing any homework assignments consistently. Second, for most participants depression was one of a constellation of difficulties.

Participants expressed interest in more broad discussion. Third, most participants observed that while their depression was fairly chronic, day to day symptoms were quite variable and situational. Despite education about treatment efficacy, many participants showed variable levels of interest, often correlated with symptom severity. In planning a similar group at other facilities, we would recommend consultation with a psychiatrist in order to address participants’ numerous medication questions, as well as perhaps a broader focus on mood management.

Enhancing Cognitive Skills

This group was originally co-developed and led by a speech-language pathologist. Participants included those with cognitive impairments due to MS, brain injury, or stroke. The initial goals were to assist veterans in developing good compensatory strategies for cognitive difficulties (e.g., organizational and memory systems) and gaining insight into their cognitive strengths and relative weaknesses. Secondly, the goal was to provide validation, support, and an opportunity for discussion. Over the course of two years, the goals have expanded, partly reflecting observations of progress from the veterans who participated. The goals of this group are summarized in a handout for participants during the first session (Table 3).

Throughout the sessions, cognitive rehabilitation strategies are used that reinforce coping strategies, such as repetition, review, practice, homework, using multiple senses to learn, have group members actively engage in activities and teach each other at times, minimize distractions and keep “lectures” very brief, and break down larger topics into manageable, meaningful chunks.^{27,28} Handouts are provided for every topic so that participants do not have to take many notes. We include self-assessment measures to encourage self-monitoring that focuses on strengths, progress, and difficulties.

To date, this group has been offered seven times, and a total of

Table 3. Goals of Enhancing Cognitive Skills Group

- 1) develop an improved awareness and understanding of changes in cognition after brain injury, stroke or MS;
- 2) appreciate the role of pre-illness skills and personality in current cognitive function;
- 3) assess the impact of cognitive abilities in social relationships and everyday life;
- 4) become informed regarding cognitive strengths and weaknesses;
- 5) learn specific ways to maximize cognition and memory abilities and compensate for weaknesses;
- 6) obtain support, encouragement, and feedback from colleagues;
- 7) cultivate a sense of hope;
- 8) create an environment as a group that encourages respect, sensitivity, tolerance and safety.

35 persons have participated in at least one 8-week session. Currently there are 14 participants. All participants but two have been male, and all but three have been of Caucasian descent. On average, 30% of any given group is comprised of persons with MS, and 70% is persons with acquired brain injury. Three individuals have been asked to leave the group due to co-morbid psychiatric problems that have interfered with their ability to participate. Four members have died; a fifth committed suicide. The remaining 13 veterans who stopped coming to the group have done so for various personal reasons, such as transportation difficulties, a sense of completion, or worsening health.

Assessment of the efficacy of the group suggests that participants perceive a general improvement in their memory and organizational skill.²⁷ More informal review of post-group feedback suggests that participants are satisfied with the experience and appreciate the structured nature of the sessions, feel they are learning worthwhile skills, and benefit from the group cohesion.

Improving Interpersonal Relationships and Managing Mood

The most recently developed group focuses on relationship and mood management, and evolved after veterans expressed a need to discuss the impact of cognitive impairment on their relationships and mood in greater depth. The group is offered to veterans with cognitive impairment resulting from MS, stroke, or other acquired brain injury. The group's goals are summarized in Table 4.

To accomplish this broad range of goals, we have developed a number of structured activities that are designed to facilitate awareness, discussion, and practice of the skills within the microcosm of the group. Group expectations are provided in written format and discussed at the outset, which provides an opportunity to concretely define and discuss "good" social behaviors. Many veterans with cognitive impairment appreciate the opportunity to practice social skills in this fashion. Topics are addressed using a range of strategies, including discussion, role-play, structured written exercises, and small-group activities.

We have devoted many sessions to events and within-group processing. For example, when one group member committed suicide, we spent three sessions discussing this in depth, reviewing this event in light of its psychological/mood implications and also considering the possible role of cognitive impairment. We highlight ways that cognitive compensatory strategies might be employed specifically for managing mood or improving interpersonal relationships. For example, members are encouraged to make notes and look for associative cues when remembering the names or relevant details about new group members. This provides an opportunity to practice meeting new people, asking socially appropriate questions to show interest and establish rapport, and using repetition and other strategies to remember new members' names. Members are also challenged to solicit specific

Table 4. Goals for Improving Interpersonal Relationships and Managing Mood

- 1) improve ability to identify and articulate emotions;
- 2) improve ability to notice and incorporate social cues;
- 3) develop improved awareness and understanding of changes in mood and relationships after injury/illness;
- 4) appreciate the role of pre-illness skills and personality in problem adjustment;
- 5) learn specific ways to manage depression, anxiety, irritability, and anger;
- 6) assess the impact of your emotions and injury/illness on family, friends, and peers, and improve interpersonal relationships;
- 7) provide and obtain support, encouragement, and feedback from colleagues;
- 8) to cultivate a sense of hope, and
- 9) create a group environment that encourages respect, sensitivity, tolerance and safety.

ic feedback and input from each other (i.e., state what they would like from the group each week, such as advice, support, information) and provide feedback to each other. Group leaders role model behaviors (e.g., use judicious self-disclosure and emphasize being emotionally present) to help participants understand effective ways of self-expression.

To date, this group has been offered three times. Of the 20 veterans who have participated, four elected to leave the group (two relocated, one stopped to care for an ill relative, one switched to a different group), one died (suicide), and 15 remain with the group. All participants have been male to date, approximately one third have MS; 90% have been of Caucasian descent, the other 10% were African-American. The efficacy of this group has not been formally evaluated, but participants informally have mentioned satisfaction with it and report better mood and feelings of social support.

Discussion

In summary, our clinical experience has been congruent with research suggesting that group-based psychotherapy is a valuable way to provide psychosocial and educational services to veterans with MS. We have developed a combination of group-based interventions that address the cognitive, mood, and general adjustment issues that are prevalent among individuals with MS. Although more systematic evaluation is required to determine program efficacy, clinical observation suggests that participants experience improved mood and sense of self-efficacy, improved relationships with their VA care providers, and new coping skills.

Many also report decreased social isolation, improved awareness and use of resources, and a sense of mastery and satisfaction associated with helping others. Caregivers who have participated

in the support group also mention improved mood, decreased isolation, decreased guilt and anger, and more awareness and use of available resources (e.g., respite care, financial planning).

Veterans with MS can be a challenging population for group leaders because of the complex, unpredictable, and potentially devastating nature of the disease. It is important to acknowledge the psychological and emotional implications for group leaders. Working with persons who have a significant illness or impairment calls for leaders with both specialized training and knowledge to handle these challenges, as well as peer support, self-awareness, and humor.

Some of the specific professional and personal challenges and skill requirements may be best illustrated by way of trainee experiences. Of the nine pre-doctoral psychology interns who have co-lead groups to date, all initially expressed anxiety about this population. Most felt hopeless about working with individuals with a disease that has no known cure, and often a progressive and degenerative course. They felt depression was a natural and understandable response to a disability or chronic illness, and felt ambivalent treating it. They felt uncomfortable “teaching” about hope, resilience or other coping skills they were not sure they personally could muster in the face of similar circumstances. They also felt ashamed of their discomfort at being around people with certain physical impairments (e.g., respiratory problems and secretion management, bladder and bowel management problems), and guilty about voicing distress about their own (seemingly less severe) problems and stressors.

However, after four months, without exception, interns reported that co-leading these groups had been among the most important of their professional and personal development experiences. They were impressed by the resilience, warmth, humor, and wisdom of the participants. They also described a desensitization process by which they became comfortable with impairments and an increased awareness of ways to be more respectful and comfortable around persons with challenges to their ability to participate in a full range of activities. Most also noted that as they learned to be more genuine and informal than they had been in other therapeutic settings, and to use humor more regularly, they felt more comfortable and effective with these groups.

In summary, group-based psychotherapy for persons with MS has the potential to be a powerful, beneficial and rewarding experience for both the participants and the leaders. The organizational and logistical preparations described here can increase the likelihood of ongoing success.

MS

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