

## Special Article – Family Caregivers

# Training Leaders of Neurodegenerative Disease Support Groups: Development of a Support Group Well-Being Measure

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Community support groups provide resources and emotional support to individuals with neurodegenerative illnesses and their caregivers. Support group leaders play a pivotal role in maintaining healthy support groups, but these leaders have their own personal need for support and also typically lack formal training in managing more complex behaviors commonly observed in neurodegenerative disorders. Two neurodegenerative disorder clinics and a local community agency collaborated to provide training for support group leaders of various neurodegenerative diseases support groups. The training consisted of dissemination of educational materials designed to improve support group leaders' knowledge of neurodegenerative disorders and access to important resources. A support group well-being survey, designed to assess functioning of a support group, was also developed and piloted among the participants. An exploratory factor analysis evaluated the psychometric properties and internal consistency of the survey. The analysis identified a single factor five-item solution with good internal reliability, which was titled the Support Group Functioning Scale. Descriptive statistics and comparison of mean differences from pre- to follow up for this scale were evaluated and preliminary interpretation guidelines were proposed. Development of this scale is a first step in identifying areas of need for support group leaders. This tool can help improve the training and ongoing support of support groups leaders as they provide front-line assistance to caregivers and individuals with neurodegenerative illnesses in communities. We encourage support group leaders, community agencies, and clinics to use and further assess the Support Group Functioning Scale to identify areas of need for support group leaders.

**Keywords:** Support group leaders; Volunteer support group facilitators; Caregiving; Leadership; Development; Training needs**Abbreviations**

PD: Parkinson's Disease; MS: Multiple Sclerosis; HD: Huntington's Disease; ET: Essential Tremor; NAMI: National Alliance on Mental Illness; EFA: Exploratory Factor Analysis

**Introduction**

A new focus on multidisciplinary care of individuals with neurodegenerative disorders is increasingly recognized for improved patient care and outcomes [1-3]. Support persons play an important, and all too often unrecognized, role in patient outcomes as well, despite research demonstrating that the presence and well-being of caregivers are associated with reduced rates of institutionalization of individuals with neurodegenerative disorders [4-8]. While national organizations have often facilitated local support groups for patients and/or caregivers, an increase in demand for support from community resources is anticipated due to several factors. The aging of the US population is expected to contribute to an increase in the number of adults with dementia [9]. At the same time, family care of individuals with neurodegenerative disorders is also increasing, given delayed institutionalization of individuals with Parkinson's

Disease (PD) [10] and the high level of mobility assistance needs of individuals with Multiple Sclerosis (MS) across the disease trajectory [11].

In the context of these changes, a critical development is that many local support groups are led by family members of individuals with neurodegenerative disorders. These community leaders have their own personal need for support and also typically lack formal training in managing more complex behaviors commonly observed in neurodegenerative disorders and dementias. Unfortunately, there are few readily available resources for individuals who volunteer to lead support groups, let alone formal support group leadership training programs. An academic search for materials on support group leader training identified one manuscript that described ten steps for training volunteer support group leaders [12]. Greif suggests key concepts to aid in the training of lay group leaders, including examination and understanding of the leaders feelings as well as the feelings of the group members and review of common group stages and the roles of leaders in each of the stages. While consideration of these concepts addresses many useful aspects of leading support groups, we posited that an in-person training opportunity would provide lay support

Table 1:

Time	Topic	Speaker
9:30 am	Check-In	N/A
9:45 am	Welcoming Remarks	Members of Collaborative Partners
10:00 am	Patient Centered Care	Gerontologist at VCU, Department of Gerontology
11:00 am	Break	N/A
11:10 am	Recognizing Overload and Coping Strategies	Clinical Neuropsychologist, VCU, Parkinson's and Movement Disorders Center
12:10 pm	Lunch and Networking Time for Leaders	Participants (seated by disease group)
1:00 pm	Small Group Discussions and Report Out	Participants selected one of the following options (not by disease group): a) facilitating a group, b) sustaining a group, and c) keeping the group interesting
1:45 pm	Report Out from Small Group Discussions	Participants
2:00 pm	Break with snacks	Participants
2:15 pm	Engaging and Motivating Others to Facilitate Delegation	Co-led by Clinical Neuropsychologist, VCU, Parkinson's and Movement Disorders Center and Richmond ET Support Group Leader
3:15 pm	Resources Review	Members of Collaborative Partners
3:45 pm	Evaluation Completion and Adjourn	Participants

leaders critical knowledge about neurodegenerative conditions and support group facilitation. In addition, it was predicted that the training would facilitate networking and could assist local support group leaders in creating a community of support, which would be available to them into the future as they continue to facilitate their group.

This study describes efforts of two neurodegenerative disorder clinics and a local community agency to provide training for support group leaders of PD, Huntington's disease (HD), Essential Tremor (ET), and MS support groups. These diseases were selected for the training given similarities of movement-related issues among the different diseases and frequent experience of these diseases at younger ages and different life stages. While there were networking goals for the program, the content of the training, with a focus on the educational materials and resources provided during the training, and participant responses to a support group well-being survey, will be the focus of this report. Study objectives were to 1) disseminate educational materials designed to improve support group leaders' knowledge of neurodegenerative disorders and access to important resources and 2) develop and pilot a support group well-being measure, designed to assess functioning of a support group.

## Materials and Methods

### Collaborative partners

Educational and clinical staff of the Virginia Commonwealth University's Parkinson's and Movement Disorders Center, a multidisciplinary movement disorder specialty clinic in southeastern Virginia (SKL and Andrea Perseghin), the Parkinson's Disease Research, Education, and Clinical Center at the Hunter Holmes McGuire Veteran's Affairs Medical Center (Lynn Klanchar), and the Central Virginia Chapter of the National Multiple Sclerosis Society (Jessica Ramirez) collaborated to develop a day-long support group leader training program. These clinics and agencies collaborated given collective goals to provide clinical care, education, and support for individuals with movement disorders and their support persons. Funding for resource materials and beverages and snacks for participants was obtained from Teva Neuroscience.

### Training details

Email inquiry was disseminated to support group leaders from PD, HD, ET, and MS support groups across Virginia to determine if there was interest in attending support group leader training. Responses were largely positive and feedback on content, timing, and duration of training was obtained to tailor the training to support group leaders needs. A day-long training on May 15, 2013 from 9:30am – 3:45pm was provided with an agenda designed to optimize delivery of content while limiting fatigue and facilitating return to participants' homes. Twenty-seven support group leaders attended the training program (PD=12, MS=8, HD=4, and ET=3). Table 1 provides detailed descriptions of the support group leader training agenda.

### Education and resources

The collaborative partners conducted literature searches and researched foundation materials to identify resources that facilitated leadership skills, leadership and management of support groups, and disease-specific educational materials. The collaborators also prepared local resource pages for leaders of the various disease-specific support groups. Materials were collected from many sources, including the Parkinson's Disease Foundation, the National Parkinson Foundation, the Huntington's Disease Society of America, the International Essential Tremor Foundation, and the National Multiple Sclerosis Society. Foundation-specific manuals for support group leaders were available from the Huntington's Disease Society of America [13] and the National Multiple Sclerosis Society [14].

### Development of a support group well-being measure

During the literature search on resources for support group leader training, while no formal training programs or support group assessment measures were identified, characteristics of successful support groups were described. The National Alliance on Mental Illness (NAMI) website detailed eight characteristics of a well-functioning support group [15]. The items appeared to capture key aspects of healthy functioning support groups in a succinct manner and so the items were minimally edited into a survey format. The Support Group Functioning Survey was piloted during the training program (Table 2). Participants in the support group training

**Table 2:** Initial items of the Support Group Functioning Survey.

1. The group is effectively structured to limit group resistance and engage participants in the group.
2. The group is able to function on its own so that the facilitator does not dominate the meeting.
3. The group involves as many members as possible in discussions so that no single member monopolizes the meeting.
4. Group members follow shared behavioral guidelines and observe them independently.
5. Group members feel that they have contributed something valuable to others in the group.
6. Strategies to avoid negativity and hopelessness are effectively used.
7. Group members are connected to resources and service organizations in their community, state, and nation.
8. Group members feel they have directly benefited from attending the support group meeting.

described above were given the option to complete the survey prior to the training program.

### Survey participants

An initial sample of support group leaders ( $N=24$ ) undergoing training in leading support groups for a variety of movement disorders were recruited to complete the Support Group Functioning Survey pre-training. Nine participants reported they had not yet begun leading a support group and so had no information to provide about the functioning of their groups, and so these individuals were excluded from analyses. The remaining fifteen participants had prior experience with group leadership and were able to answer questions about their experiences leading support groups. Primary analyses were performed on this sample of support group leaders with prior experience ( $N=15$ ). Of these, 46.7% had led groups supporting individuals with MS, 26.7% supporting individuals with PD, 13.3% supporting individuals with HD, and 13.3% supporting individuals with ET. Follow up data were collected at 6 and 17 months following the training from a small number of support group leaders ( $N=7$ ), with only three of these having completed the survey prior to the training. Because of the small sample size and lack of overlap in those completing the survey at pre- and post-time points, analyses with these data are considered exploratory.

### Survey design and procedure

As noted above, the eight characteristics of well-functioning support groups by NAMI were edited so the items were appropriate for individuals to answer regarding their personal experiences with support groups. The Support Group Functioning Survey (Table 2) was then piloted at the support group leadership training for a variety of movement disorders. Support group leaders were given the opportunity to complete the survey prior to the training. Participation consisted only of paper survey procedures and was voluntary and anonymous and therefore data collected was exempt from institutional review board review. As described above, a small subset of individuals who completed the support group leader training provided follow up survey data by completing an online version of the measure administered to assess support group functioning. Exploratory analyses were performed comparing pre- and post-training responses to the survey to assess the efficacy of the training and evaluate the measure's sensitivity to change.

### Survey

An eight-item survey was developed to assess support group functioning. The survey was modeled on NAMI's list detailing characteristics of a well-functioning support group. This report cites

eight tenets of support group efficacy, including, "Provides strategies that will circumvent negativity and hopelessness," and, "Encourages participants to abide by shared behavioral guidelines and to observe them in a self-enforcing way." Participants answered on a 5-point Likert-style scale, with responses ranging from 1 "Does not describe my group" to 5 "Very much describes my group". Table 2 provides the actual items administered to participants before the training and at follow up.

## Results

Data analysis consisted of descriptive statistics performed on each survey item, exploratory factor analysis (EFA) to determine the psychometric properties of the survey, and evaluation of the internal consistency of the measure.

### Descriptive statistics for pre-training survey items

Responses to the eight items were fairly consistent, with means ranging from 3.47 to 4.53 and standard deviations from 0.640 to 1.457. The ranges of individual participant's responses varied more widely item to item; however, with items 2, 4, 6, and 7 ranging from 1 to 5, item 5 ranging from 2 to 5, and items 1, 3, and 8 ranging from 3 to 5. Items 4 and 6 were slightly above the acceptable range for skewness ( $\pm 1.5$ ) and substantially outside of limits for kurtosis ( $\pm 2$ ). Two types of transformations (i.e., square root and log10 transformations) were applied in an effort to normalize these variables; however, skewness and kurtosis values remained constant. Evaluation of outliers by generating z-scores for each survey item revealed outliers (z-scores greater than or equal to  $\pm 2.5$ ) on items 4, 5, and 6, but there were no multivariate outliers. Because of the small sample size and lack of response to transformation, all data points were retained. Means, standard deviations, and skewness and kurtosis values for each of the eight items are presented in Table 3.

### Exploratory factor analysis

EFA using the maximum likelihood extraction method, with a Varimax rotation, was performed to determine the underlying factor structure of the eight items. Assumptions of factor analysis were tested, and Kaiser's measure of sampling adequacy was .61, indicating mediocre to adequate level of factorability. Bartlett's test of sphericity indicated that there were correlations within this dataset that were suitable for factor analysis, Chi-square=55.80,  $p=.001$ . The proportion of variance accounted for by the factors was adequate for all items, except that items 7 and 8 did not meet our selected cut-off of  $>.30$  [16]. Initial EFA showed three individual factors, with negligible loadings on the second and third factors and items 4, 7, and 8 loading only on these factors with little correlation to each other or

**Table 3:** Means, standard deviations, and normality of Support Group Functioning Scale items.

	Minimum	Maximum	Mean	Standard Deviation	Skewness	Kurtosis
Q1	3	5	4.20	.775	-.383	-1.117
Q2	1	5	3.87	1.457	-1.174	.112
Q3	3	5	4.20	.775	-.383	-1.117
Q4	1	5	4.00	1.134	-1.696	3.011
Q5	2	5	4.27	.884	-1.317	1.821
Q6	1	5	3.93	1.033	-1.647	4.028
Q7	1	5	3.47	1.125	-.772	.206
Q8	3	5	4.53	.640	-1.085	.398

**Table 4:** Rotated factor matrix for Support Group Functioning Scale initial eight items.

	Factor		
	1	2	3
Q1	.854	.282	.218
Q2	.823	.286	.309
Q3	.736	.023	.196
Q4	.056	.944	-.324
Q5	.956	-.006	-.291
Q6	.495	.225	.742
Q7	.108	.431	.064
Q8	-.004	-.147	.481

the survey's other items. Table 4 displays the rotated factor matrix of the initial EFA performed on all eight items. Analysis was performed again after removing these three items, and a single factor was found upon which the remaining five items loaded strongly. This factor was termed Support Group Well-Being. Table 5 shows the component factor matrix of the final EFA performed on the five items composing the single Support Group Well-Being factor.

#### Internal reliability

Cronbach's Alpha was calculated to determine the internal consistency of the measure both before and after removing the three lesser-correlated items. Before removing these items, the Cronbach's Alpha of the initial measure was .775. After removal, the analysis produced an alpha of .882, signifying a "good" level of internal consistency.

#### Support group functioning scale total score

Based on the single factor solution identified in the EFA, the five-items were titled the Support Group Functioning Scale. A total score for the Support Group Functioning Scale was calculated. Descriptive statistics and comparison of mean differences from pre- to follow up for this total score was evaluated. Prior to receiving training, the mean total score for support group leaders ( $N=15$ ) was 20.47 ( $SD=4.19$ ), with scores ranging from 12 to 25. This total score conformed to assumptions of normality, including skewness and kurtosis of less than +/- 1.5. At follow up, the mean total score for support group leaders ( $N=7$ ) was 19.14 ( $SD=4.02$ ), with scores ranging from 16 to 25. Assumptions of normality were met for the total score at follow up as well. A one-way analysis of variance was performed to determine

**Table 5:** Support Group Functioning Scale component factor matrix.

	Component
	1
Q1	.926
Q2	.930
Q3	.825
Q5	.798
Q6	.739

whether the mean total score significantly differed from pre-training to follow up. The total score did not significantly differ from pre- to follow up,  $F(1, 21)=.49, p=.493$ .

## Discussion

In the support group leader training program, educational materials were successfully disseminated to improve support group leaders' knowledge of neurodegenerative disorders and access to important resources. Participant evaluations of the program were overall positive, with average ratings of 4.24 to 4.64 on a 0 to 5 point scale; with 5 reflecting high satisfaction with the program. A support group well-being survey was also piloted. This survey was designed to assess functioning of a support group. The EFA identified a single factor five-item solution, which we titled the Support Group Functioning Scale. The scale achieved a "good" level of internal consistency. We propose that total scores falling between +/- one standard deviation of the mean, or between 16.28 and 24.66 are within a "well-functioning" range for a support group. Total scores below 16.28 may tentatively be considered "in need of improvement", and total scores above 24.66 may be classified as "optimally functioning". Verification of our proposed interpretation guidelines is encouraged as well as additional evaluation of the scale among different populations. We posit that this scale can be used by support group leaders, community agencies, and clinics to identify areas of need for support group leaders and the groups they run.

Healthy functioning of community support groups has the potential to provide individuals with neurodegenerative illnesses and their caregivers with important information and resources as well as emotional support. Identifying areas of need for support group leaders is one critical way to help community support groups thrive. Variability in personal experience with caregiving, other roles and responsibilities, knowledge about medical illnesses, personality traits, and other unknown factors, may all impact the range of needs that support group leaders may have. Pilot testing of the Support Group Functioning Scale provides an initial attempt to facilitate communication between support group leaders and health care professionals in a systematic manner.

Future directions of collaborations among specialty clinics and community support groups include facilitating networking opportunities among caregivers and support group leaders. In our prior work, we suggested that collaborations among specialty clinics and community support groups occur as potential ways to address a diverse range of caregiver needs [17]. Developing ways to provide ongoing support of caregivers and support group leaders is critical, given the length of time individuals are often providing caregiving

and the fact that both patient and caregiver needs can change over time, particularly in the context of neurodegenerative illnesses. Other formats that our clinic has found to foster communication between caregivers, community support group members, and health care professionals include regular community events, such as annual education days, retreats, and fundraising events. Inquiry about caregivers, support group members, and support group leaders' interests in topics for retreats and focused lectures and discussions about caregiving needs and leadership roles are also recommended to address their concerns.

Another potential collaboration among specialty clinics and community support groups includes facilitating the selection process of identifying support group leaders. Pomery and colleagues [18, p. 673] posit that "there is a clear need to establish an evidence-based framework to inform the selection process of group leaders seeking legitimacy, funding or support from external agencies". They conducted a literature review to begin to examine the knowledge, skills and attributes of cancer support group leaders as well as non-cancer support group leaders. They found that qualities of successful support group leaders were subdivided into factors relevant to selection (i.e., awareness, willingness, agreeableness, and openness) and those relevant to knowledge and skills. They asserted that volunteer leaders are unlikely to have strong knowledge and skills prior to taking the leadership role and encouraged agencies to provide support and training to support group leaders.

## Conclusion

Providing support group leader training is one vital way to provide support and improve quality of care available to caregivers and individuals with neurodegenerative illnesses in a community setting. We adapted items to create the Support Group Functioning Scale and then piloted use of the scale and explored the preliminary psychometric properties of it. We encourage support group leaders, community agencies, and clinics to further assess and use this scale to identify areas of need for support group leaders. This tool may help improve the training and ongoing support of support groups leaders as they provide front-line assistance to caregivers and individuals with neurodegenerative illnesses in communities.

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