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Training Neurodegenerative Disease Support Group Leaders: A New Support Group Functioning Scale

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Abstract

Support group leaders play pivotal roles in maintaining healthy community support groups; however, these leaders also have personal support needs and typically lack formal training in managing complex behaviors of neurodegenerative disorders. A support group well-being questionnaire, assessing support group functioning, was developed and piloted among participants of an educational training program designed for support group leaders of various neurodegenerative disorder-specific support groups. An exploratory factor analysis evaluated the questionnaire's psychometric properties and identified a reliable single factor five-item solution, which was titled the Support Group Functioning Scale (SGFS). Preliminary interpretation guidelines were proposed. Development of this scale is a first step in identifying support group leaders' needs as they provide frontline assistance to caregivers and individuals with neurodegenerative illnesses. This tool shows promise as an efficient way to identify support groups in need of assistance and to assess the impact of trainings on support group functioning. Further validation of the scale is needed.

Keywords

support group leaders, volunteer support group facilitators, caregiving, leadership, development, neurodegenerative disease

Introduction

A new focus on multidisciplinary care of individuals with neurodegenerative disorders is increasingly recognized for improved patient care and outcomes (Newsome et al., 2017; Sauerbier et al., 2017; Tso, Farinpour, Chui, & Liu, 2016). 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 (Aarsland, Larsen, Tandberg, & Laake, 2000; Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Spitznagel, Tremont, Davis, & Foster, 2006; Terriff, Williams, Patten, Lavorato, & Bulloch, 2012; Yaffe et al., 2002). Although national disease-specific 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. These factors include the aging of the U.S. population, which is expected to contribute to an increase in the number of adults with dementia (Langa et al., 2017). At the same time, family care of individuals with neurodegenerative disorders is also increasing,

given delayed institutionalization of individuals with Parkinson's disease (PD; Hassan et al., 2012) and the high level of mobility assistance needs of individuals with multiple sclerosis (MS) across the disease trajectory (Dunn, 2010).

In the context of these changes, a critical issue 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 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. A rigorous literature search for articles on support group leader

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training identified one manuscript, which described 10 steps for training volunteer support group leaders (Greif, 2010). Greif suggested key concepts to aid in the training of lay group leaders. These included examination and understanding of leaders' and members' feelings, in addition to a review of common group stages and the roles of leaders in each of those stages. However, further research about training volunteer support group leaders is lacking.

Current literature has documented the success of training lay leaders to teach chronic disease self-management. Self-management education in chronic disease includes problem-solving skills that enhance patients' quality of life (Bodenheimer, Lorig, Holman, & Grumbach, 2002). In this field of research, overall evidence has documented how different approaches to education, such as lay-led versus professional-led training, appear comparable in various conditions (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). However, receiving information from peers has been noted to align with the shift of greater patient involvement in day-to-day disease management in chronic illnesses (Barlow et al., 2002; Bodenheimer et al., 2002). The increased individual patient role in long-term management of chronic conditions has successfully been underway for decades based upon evidence documenting how optimal chronic care occurs when an interactive team works with an informed, active patient (Bodenheimer et al., 2002). Barlow et al. (2002) asserted, "self-management may be one means of bridging the gap between patients' needs and the capacity of health and social care services to meet those needs" (p. 178). Similarly, training lay support group leaders may be another means to provide unique supportive care, particularly given lay leaders experience managing everyday issues with individuals with neurodegenerative disorders throughout the course of their diseases, which are not necessarily known by health professionals.

Given the complex behaviors commonly observed in neurodegenerative disorders and dementias, the authors of this research posited an in-person training opportunity would provide lay support leaders critical knowledge about neurodegenerative conditions and support group facilitation, while facilitating networking and creation of an ongoing community of support. Two neurodegenerative disorder clinics and a local community agency collaborated to provide support group facilitation 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 various ages and life stages. Although there were networking and education and resource dissemination goals for the training, development and piloting of a support group well-being questionnaire was the focus of this report. The aims of this study were to develop and pilot a support group well-being questionnaire 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, the Parkinson's Disease Research, Education, and Clinical Center at the Hunter Holmes McGuire Veteran's Affairs Medical Center, and the Central Virginia Chapter of the National Multiple Sclerosis Society 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, Inc., a subsidiary of Teva Pharmaceutical Industries Limited.

Training Details

E-mail 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 a 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 6-hr training 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 (Barton, Edmonson, Paterson, Staveley, & Meyer, 2013) and the National Multiple Sclerosis Society (Koch, 2010).

Table 1. Support Group Leadership Training Agenda.

Time	Topic	Speaker
9:30 a.m.	Check-in	NA
9:45 a.m.	Welcoming remarks	Members of collaborative partners
10:00 a.m.	Patient-centered care	Gerontologist at VCU, Department of Gerontology
11:00 a.m.	Break	NA
11:10 a.m.	Recognizing overload and coping strategies	Clinical neuropsychologist, VCU, Parkinson's and Movement Disorders Center
12:10 p.m.	Lunch and networking time for leaders	Participants (seated by disease group)
1:00 p.m.	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 p.m.	Report out from small group discussions	Participants
2:00 p.m.	Break with snacks	Participants
2:15 p.m.	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 p.m.	Resources review	Members of collaborative partners
3:45 p.m.	Evaluation completion and adjourn	Participants

Note. VCU = Virginia Commonwealth University; ET = essential tremor.

Table 2. NAMI-CARE Characteristics of a Well-Functioning Support Group.

1. Has a facilitator skilled in using various elements of structure to counter group resistance and engage participants in group work.
2. Provides ways for the group to "do its own work" so that the facilitator does not dominate the meeting.
3. Involves as many group members as possible in group discussions so that no one group monopolizes the proceedings.
4. Encourages participants to abide by shared behavioral guidelines and to observe them in a self-enforcing way.
5. Allows group members to feel they have contributed something valuable to others in the group.
6. Provides strategies that will circumvent negativity and hopelessness.
7. Connects participants to resources and service organizations in their community, state, and nation.
8. Makes group members feel they have directly benefited from attending the support group meeting.

Note. NAMI = National Alliance on Mental Illness.

Development of a Support Group Well-Being Questionnaire

Although no formal training programs or support group assessment measures were identified in a literature search, a prior website of The National Alliance on Mental Illness (NAMI) detailed eight characteristics of a well-functioning support group (National Alliance on Mental Illness, n.d.). The items are reproduced in Table 2, as this website is no longer accessible online. As the items appeared to capture key aspects of healthy functioning support groups in a succinct manner, the authors minimally edited the items into a questionnaire format and titled the adapted items as the Support Group Functioning Questionnaire (SGFQ; Table 3). Editing of the items was done independently by the authors, without permission or review by NAMI. Participants answered on a 5-point Likert-type-style scale, with responses ranging from 1, *does not describe my group* to 5, *very much describes my group*.

Questionnaire Participants and Procedures

A description and rationale of pilot testing the SGFQ were given to the participants of the training program, who were then invited to voluntarily and anonymously complete the SGFQ pretraining. Participants were informed their responses would be kept confidential and the decision to complete the questionnaire or not would have no bearing on their ability to participate in the training. Data collected were deemed exempt from institutional review board review, as participation consisted only of paper questionnaire procedures and was voluntary and anonymous. Twenty-four support group leaders were initially recruited to complete the SGFQ pretraining. Nine participants reported they had not yet begun leading a support group and had no information to provide about the functioning of their groups, and so these individuals were excluded from analyses. The remaining 15 participants had prior experience with group leadership and were able to provide responses to the questionnaire. 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 online at 6 and 17 months following the training from a small number of support group leaders ($n = 7$), with only three of these

Table 3. Initial Items of the Support Group Functioning Questionnaire.

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.

Table 4. Means, Standard Deviations, and Normality of Support Group Functioning Questionnaire Initial Eight Items.

	Minimum	Maximum	*M*	SD	Skewness	Kurtosis
Q1	3	5	4.20	0.775	−0.383	−1.117
Q2	1	5	3.87	1.457	−1.174	0.112
Q3	3	5	4.20	0.775	−0.383	−1.117
Q4	1	5	4.00	1.134	−1.696	3.011
Q5	2	5	4.27	0.884	−1.317	1.821
Q6	1	5	3.93	1.033	−1.647	4.028
Q7	1	5	3.47	1.125	−0.772	0.206
Q8	3	5	4.53	0.640	−1.085	0.398

having completed the questionnaire prior to the training. Because of the small sample size and lack of overlap in those completing the questionnaire at pre- and post-time points, analyses with these data were considered exploratory. Exploratory analyses were performed comparing pre- and posttraining responses to the questionnaire to assess the efficacy of the training and evaluate the measure's sensitivity to change.

Results

Dissemination of Educational Materials

In the support group leader training program, educational materials were successfully disseminated in a day-long program designed to improve support group leaders' knowledge of neurodegenerative disorders and their access to important resources. Participants completed individual evaluations of each of the speaker-led topics (i.e., patient-centered care, recognizing overload and coping strategies, small group discussions and report out, engaging and motivating others, and resource review). Participant evaluations of the program were overall positive, with average ratings of these topics ranging from 4.24 to 4.64 on a 1- to 5-point scale, with 5 reflecting high satisfaction with the topics addressed in the program.

Pilot Testing of the SGFQ

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

Descriptive Statistics for Pretraining Questionnaire Items

Means and standard deviations were calculated for each item and for each participant's response to each item. Assumptions of normality were assessed by examining skewness and kurtosis values. Responses to the eight items were fairly consistent; however, individual participants' responses had a larger range across items (Table 4). Items 4 and 6 were slightly above the acceptable range for skewness (±1.5) and substantially outside of limits for kurtosis (±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 questionnaire item revealed outliers (*z* scores greater than or equal to ± 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 4.

EFA

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 0.61, indicating mediocre to adequate level of factorability. Bartlett's test of sphericity indicated there were correlations within this data set that were suitable for factor analysis, chi-square = 55.80, *p* = .001.

Table 5. Rotated Factor Matrix for Support Group Functioning Questionnaire Initial Eight Items.

	Factor		
	1	2	3
Q1	0.854	0.282	0.218
Q2	0.823	0.286	0.309
Q3	0.736	0.023	0.196
Q4	0.056	0.944	−0.324
Q5	0.956	−0.006	−0.291
Q6	0.495	0.225	0.742
Q7	0.108	0.431	0.064
Q8	−0.004	−0.147	0.481

Table 6. Support Group Functioning Questionnaire Five-Item Component Factor Matrix.

	Component
	1
Q1	0.926
Q2	0.930
Q3	0.825
Q5	0.798
Q6	0.739

The proportion of variance accounted for by the factors was adequate for all items, except Items 7 and 8, which did not meet our selected cutoff of >0.30 (Worthington & Whittaker, 2006). 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 the questionnaire's other items. Table 5 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 6 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 (SGFS) Total Score

Based on the single factor solution identified in the EFA, the five items were titled the SGFS (Table 7) and

a total score was calculated. Descriptive statistics and comparison of mean differences from pre- to follow-up for this total score were 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 whether the mean total score significantly differed from pretraining to follow-up. The total score did not significantly differ from pre- to follow-up, $F(1, 21) = 0.49$, $p = .493$.

Discussion

A support group well-being questionnaire, assessing support group functioning, was developed and piloted among participants of an educational training program designed for support group leaders of various neurodegenerative disorder-specific support groups. The EFA identified a single factor five-item solution, which the authors titled the SGFS. The scale achieved a "good" level of internal consistency. The authors proposed total scores falling between ± one standard deviation of the mean, or between 16.28 and 24.66 reflect 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 these proposed interpretation guidelines is encouraged as well as additional evaluation of the scale among different populations. The authors posited 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 and to evaluate the impact of trainings on support group functioning.

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. Corbin and Strauss (1988) have described three tasks critical for people with chronic conditions to manage and these include (a) medical management of the condition, (b) development of new roles, and (c) coping with reactions to having a chronic condition. Support groups have the potential to play key roles in all of these areas. 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 support group leaders' needs. Development and pilot testing of the SGFS provides an initial attempt to facilitate communication

Table 7. The Support Group Functioning Scale.

Instructions: The statements below describe qualities of support groups. Please answer each item honestly based on what is generally true for the support group that you lead/facilitate or co-lead/co-facilitate. If you have not yet started to work with a group, please check here and leave the questionnaire blank. ❏

	Does not describe my group				Very much describes my group
	1	2	3	4	5
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 feel that they have contributed something valuable to others in the group.					
5. Strategies to avoid negativity and hopelessness are effectively used.					

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 support group leaders and caregivers. Lageman, Mickens, and Cash (2015) suggested collaborations among specialty clinics and community support groups occur as potential ways to address a diverse range of caregiver needs. Developing ways to provide ongoing support of support group leaders and caregivers is critical, given the length of time individuals are often providing caregiving and how both patient and caregiver needs can change over time, particularly in the context of neurodegenerative illnesses. Other formats the authors have found to foster communication between community support group members, caregivers, 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 caregiver concerns.

Another potential collaboration among specialty clinics and community support groups includes facilitating the selection process of identifying new support group leaders. Pomery, Schofield, Xhilaga, and Gough (2016) posited "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" (p. 673). 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 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. The authors developed and piloted use of the SGFQ and then explored the preliminary psychometric properties of it and proposed the single factor SGFS for further use. The authors encourage support group leaders, community agencies, and clinics to further assess this scale and its potential use to identify areas of need for support group leaders and to evaluate the impact of trainings on support group functioning. This tool may help improve the training and ongoing support of support groups leaders as they provide frontline assistance to caregivers and individuals with neurodegenerative illnesses in communities. Further validation of the scale is needed and encouraged.

Authors' Note

Therese V. Cash was previously affiliated with the Department of Psychiatry, Virginia Commonwealth University, Richmond, Virginia, United States, and Christopher Kilbourn was previously affiliated with the Department of Psychology, Virginia Commonwealth University, Richmond, Virginia, Unites States. Data presented in this article consisted only of paper survey procedures and were voluntary and anonymous and, therefore, data collected were exempt from institutional review board review. Any questions regarding data presented in this article can be directed to the corresponding author.

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Declaration of Conflicting Interests

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