

Ten Steps in Training Volunteer Support Group Facilitators

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Abstract

Caregiver support groups are often led by volunteer lay leaders who might have personal experiences with Alzheimer's disease. This article offers 10 steps in what to consider and how to conduct training for these lay leaders so that the success of the support groups can be maximized. Steps include helping trainees understand their own feelings and the feelings of their group members as well as teaching about the stages that groups typically experience from beginning to termination and the role of the leader at each stage.

Keywords

support group training, Alzheimer's disease, lay leader training, loss

Many state organizations serving people with Alzheimer's Disease and their caregivers turn to lay (as well as professional) leaders to run their support groups for caregivers. For example, one chapter's website calls for volunteer support group leaders who have either a personal or professional experience with dementia. The purpose of these groups is to "educate people about dementia and care options, offer helpful advice about safety, legal, and financial matters, and provide mutual support in an accepting and supportive atmosphere" www.alz.org/maryland. Those non-professionals who respond to this call for volunteers need specific training in how to lead support groups.

What are some of the steps taken in training these support group leaders to run groups? This article, written by a consultant with 20 years experience in training these support group leaders, most of whom have no professional training, discusses, in cookbook fashion, 10 steps in the 2-hour portion of the all-day trainings that focus on group leadership. Other portions of the trainings focus on the disease process, the structure of the organization, appropriate referral sources, as well as related caregiver issues. It is hoped that these 10 steps will be useful to other trainers of support group leaders as well as the leaders themselves.

The stated philosophy underpinning the group leader training is that (a) all groups (like relationships) go through phases (beginning, conflict, middle, and termination) and (b) the way the leader uses her/himself during each phase varies.

Setting the Context for Support Groups

To train support group leaders, consultants (such as myself) must not only be knowledgeable about the stages of group development, they must be knowledgeable about Alzheimer's disease, dementia, and their sequelae to understand what group

leaders will be facing when they lead groups. It is well established, for example, that caregivers experience a great deal of grief and stress that can include depression.¹ Ambiguous loss, a term coined by Pauline Boss to describe loss that is unresolved,² is a wider frame within which to consider what caregivers experience during their loved ones' decline. Group consultants also must be aware that their trainees are similar to the target members in the caregivers' support group. They, too, may be experiencing depression, grief, and loss. Some lay volunteers have a family member living with Alzheimer's and others have loved ones that have died from the disease.

For these reasons, every communication to the trainees about their future support group members is also education and support to them. As these are voluntary support groups for caregivers experiencing stress and loss, trainees are encouraged to treat all group members in a supportive manner and one that is consistent with ethical practice.

Is This a Therapy Group or a Support Group?

Trainees often have a glamorized conception of group work gleaned from movies, their own readings, or their personal experiences with groups. At times, these conceptions can be a caricature of the wise psychoanalytically oriented leader who offers insightful nuggets that capture the quintessential "aha" moment for the group, resulting in group members bowing in

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obedience to the wisdom handed down from on high. In this conception, group members make significant connections between their current feelings and their early upbringing. At other times, the conceptions may be of the leader as a confrontational figure who, at a critical juncture in the group, forcefully compels a member to face reality by slicing and dicing the member's words and holding a "mirror" up so the member's totality can finally be understood by him or her. Here again, past is seen as prelude to the pain and behavior that underpins the caregiver's stress.

Both of these conceptions can be derived from models of psychotherapy but neither model is appropriate for these support groups. Instead, leaders should be trained to provide support in a kindly, nonconfrontational, and transparent manner. The support should be present-oriented, not inner-directed or past-oriented. Feelings should be elicited carefully by the leader and handled empathetically. The leader should also ask about thoughts (cognition) and behaviors. The leader can state to the group that its primary purpose is support, not therapy, and that if coming to the group raises other issues (eg, about a marriage, dysfunctional sibling relations, or early upbringing), referral to a professional therapist would be possible. The emphasis should be on normalizing the experiences and feelings of group members, including those of sadness or rage, and asking group members for suggestions for dealing with those feelings and experiences. The group leader can offer an occasional suggestion when other members have spoken.

What is the Trainee Feeling Before the Group?

Once the context has been set for these groups, trainees can be asked during the workshop what they might feel before they lead their first group. The trainer can briefly offer his or her own experience, perhaps saying that he or she was nervous before today's training. As the trainees offer their feelings about starting their first group, the feelings are written on a large pad in front of the trainees. Typically, trainees say they might feel nervous, anxious, excited, or intimidated. Some fear they will not be able to control the group. Others worry about specific members with whom they fear they may not be able to connect either because of race, gender, or age differences. The attempt here is to normalize the experiences of these new leaders so that they will see their own anxiety, for example, as a normal part of group leadership.

What Kinds of Members do the Trainees Want in the Group?

Once the door of self-exploration has been opened in the training, the trainees are asked to write anonymously, on a 3 × 5 card, 3 qualities they think they would like in their group members and 3 qualities they would dislike or do not want to see. They are told these will be read aloud to the group and written on the pad at the front of the room. The preferred qualities usually center on members being appreciative, cooperative,

responsive, warm, funny, respectful of others, and supportive. The disliked qualities usually include members' complaining, talking too much, displaying anger or aggression, monopolizing or not speaking, challenging the leader, acting like a "know-it-all," and refusing help. Once these qualities are written in 2 lists, the trainees became aware that they have similar likes and dislikes and that, given the course of the disease, it would be normal for members who are upset to display many of the disliked qualities. These terms are examined again in the next step.

What Are Group Members Feeling Before the Group?

The trainees are next asked what they believe the group members may be feeling before they start their first support group. To do this, trainees are asked what they might be feeling or thinking if they were a new member seeking support. This usually elicits a list ranging from fear about what will happen in the group in terms of how much personal information to reveal, to anger about being in the group, to relief that help may come from group attendance. Trainees also suggest that members might wonder whether they will fit into the group and whether the group will help them or be a waste of time. A link is then drawn between what qualities (the likes vs. dislikes) they are looking for in members and what members are feeling. Discussion centers in the training on how, with the group members feeling fear, sadness, or anger, it would be natural for them to compensate by being angry, too talkative, or too quiet.

At this point, the work of Larry Shulman³ and Irvin Yalom⁴ is then introduced. Both Shulman and Yalom describe the benefits of being in a group. These benefits include, for Shulman, "all in the same boat phenomenon," (ie, the sense that one is not alone with one's concerns), discussion of taboo subjects, and sharing data (ie, keeping each other up-to-date on recent medical advances in the treatment of the disease). For Yalom, the benefits, or curative factors, include catharsis, altruism (ie, the benefit of helping another group member deal with an issue), and the instillation of hope. These usually echo, though with different terms, what the trainees believe the support group members may receive from a support group and provide terms that the trainees can use when discussing the benefits of group to potential new group members. This also allows for an intellectualization of feelings for those who feel more comfortable approaching group leadership in this way.

The Beginning Phase

To help trainees with the beginning phase of group, a wheel with spokes is drawn and the group leader is placed in the middle. It is the leader's job to help people enter the group; to do this, the leader has to be in a central position. Leader position is important because if members arrive and do not have a sense of the group and its purpose, their anxiety may rise and the group may drift. The leader should introduce the purpose of the group, discuss the rules about confidentiality, attendance,

requirements to report to adult protective services if needed, and any other issues relevant to the group. New leaders are encouraged to write down what they want to say and practice it in advance if that will add to their comfort. The notion of entering the group with a checklist of points the leader wishes to tell the members helps to demystify leadership. The leader should not be expected to be superman or superwoman as a leader but rather someone who wants to work with the group and help them support each other. A too competent and too active leader can sometimes take away the members' desire to help each other as they will rely too much on the leader.

The trainees are then taught that after the leader introduces her or himself, group members are asked to tell a little about their situations and what they hope to get from the group. Listening and offering brief support are best at this point to avoid spending too much time on one person's situation. Once all members have introduced themselves, the group leader has 2 options—he or she can pick up on a common thread that the members are offering (dealing with doctors, squabbling with family members, money issues, etc) or can go with a predetermined topic of discussion. Some groups are a combination of education about Alzheimer's and support. Those groups could turn to a pre-determined educational topic and then return to issues related to support later in the group.

At the end of the first session, the leader should check in with everyone to see if the first group fit their expectations and, if not, what they were hoping to get from the group that they did not. This gives the leader the chance to show that he or she wants the group to be beneficial for everyone and that he will take steps to customize the group for the members at the next session.

The Conflict Stage

As group members transition from the beginning stage of the group to the work phase, some may decide to not fully commit to working in the group to address issues that can benefit them. They may take a "pseudo involved" or peripheral position. Members are afraid to commit to opening up in the group and so attend the group but only talk around their issues without directly addressing them and making a commitment to the group as a vehicle of change. This reluctance can manifest itself in questioning the leader's skills or in expressing fear about opening up too much. The leader at this point is trying to move from the hub to the periphery of the group so the members can interact with each other more but may have to return to the "center" of the group to guide discussion. Explaining that reluctance to get involved in the group is a natural stage of group development can help members talk about their reluctance.

The Middle Phase

This stage is where the work of the group occurs. Members are interacting with each other more and group roles start to solidify. The leader, when the group is functioning well, needs to

do little more than open and close the group, introduce new members, and take care of housekeeping. Members look to the leader as a consultant and for occasional assistance with issues that come up but, with a high-functioning group, much of the support comes from the members. Members experience altruism as they derive satisfaction from helping others. The more the leader helps the members when the members are capable of helping each other, the less satisfaction the members will derive.

Role Playing Common Roles

At this point, trainees are taught about commonly appearing group roles: the quiet member, the boring member, the monopolist, the deviant member, the clown, and the internal leader. Trainees often have questions about how to handle the monopolizer though the internal leader, in some cases, can be the biggest threat to the leader (though an unconscious one). The internal leader may be the person that group members turn to for assistance rather than the leader and thus can threaten the leader's sense of competence.

Trainees are then asked to volunteer for a role play of a group where they are given a card with a role on it and asked to act out the role without showing their card to anyone else. Trainees are asked to guess what role was being portrayed by each of the participants. This usually leads to further discussion about how to handle difficult group members.

The Termination Phase

Trainees are taught that the manner in which they handle termination issues in their own life may foreshadow how comfortable they are leading a discussion about termination with the group. If they are unresolved about loss-related issues, they may not spend sufficient time allowing members to process their feelings about terminating with the group. For termination, the leader needs to assume a central position in the group and guide discussion. This stage of the group is particularly salient given the issues of loss and death that group members face outside of the group. Rushing through this stage or allowing members to divert from paying this stage adequate attention may result in missed opportunities for interpersonal growth for the members.

Termination for individuals in the group generally happens in 1 of 3 ways: members leave after their loved one dies; members leave because they have received sufficient support from the group and are ready to move on; members leave because the group has not been helpful and they still need support. Ideally, when members leave the group, they should attend their final session and allow the group to say goodbye to them. Groups can ask the departing member to talk about what she or he gained from the group. If the departure is not on a positive note, the leader should ask, in a nondefensive manner, what the member would have liked to have received from the group and encourage the member to continue to seek ways to get that particular need met. Members can also give the departing member feedback, but it should be restricted to positively tinged feedback, given the

purpose of a support group. If evaluation procedures are not formally in place, this is also an opportunity for the leader to get feedback, either formal or informal, from the remaining members as to how well the group is working for them.

Care should be taken to protect the privacy of the departing member if he or she is not attending the last group. The leader may need permission from that member to share with the group the member's reasons for leaving.

Conclusion

It is hoped that these 10 steps will be helpful to other professionals who train lay group leaders to run Alzheimer caregiver support groups. Such training should not end with 1 workshop. Once the support group is underway, the lay group leader should be supervised by the professional staff at the local level on an ongoing and on an as-needed basis. For these groups to provide the optimum service to those in need, they must be a place of respite, support, and kindness.

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