

The Positive Impact of Caregiver Support Groups On Adult Children of Aging Parents

Susan Beerman

Follow this and additional works at: <http://scholarship.law.marquette.edu/elders>



Part of the [Elder Law Commons](#)

Repository Citation

Beerman, Susan (2003) "The Positive Impact of Caregiver Support Groups On Adult Children of Aging Parents," *Marquette Elder's Advisor*: Vol. 4: Iss. 3, Article 5.

Available at: <http://scholarship.law.marquette.edu/elders/vol4/iss3/5>

This Featured Article is brought to you for free and open access by the Journals at Marquette Law Scholarly Commons. It has been accepted for inclusion in Marquette Elder's Advisor by an authorized administrator of Marquette Law Scholarly Commons. For more information, please contact megan.obrien@marquette.edu.

The Positive Impact of Caregiver Support Groups on Adult Children of Aging Parents

By Susan Beerman

Adult children of aging parents often suffer from a multitude of problems, which they endure quietly and alone. This article describes how five such caregivers formed a support group and derived invaluable help in coping.

Adult children of aging parents are the unsung heroes of eldercare. What caregivers do “for free” has been estimated to have a value of \$196 billion per year.¹ They devote countless hours, physical stamina, and emotional strength to help care for one or both of their parents. In many instances caregivers neglect their own health and emotional well-being. They often suffer from feelings of depression, isolation, sleeplessness, weight gain or loss, chronic pain, and anxiety. “It is noteworthy that each of the most common caregiver health problems can potentially impair the caregiver’s ability to provide physical and emotional support for a frail elder.”²

Although caregivers may suffer from a multitude of problems, they often endure their pain isolated and alone. Their profound silence often belies the caregivers’ intense need for help, support and validation that they are doing a good job.

According to a national caregiver study con-

ducted by the National Council on Aging and the Robert Wood Johnson Foundation,

[A] recurring theme in most of the (caregiver) interviews was the reluctance of many caregivers to seek help, even when on the verge of physical exhaustion. The reason given most often: the caregivers (and sometimes the care recipients) felt that they would somehow be failing to cope with a basic family responsibility if they acknowledged a need for support. Caregiver respite and service providers often must find tactful ways to convince caregivers that they can work even more effectively when they accept help.³

A support group often provides caregivers with the type of help they need. It is considered a safe venue for many caregivers to discuss their feelings, concerns, anger, and frustration. But a group setting is not for everyone. Some caregivers feel uncomfortable because they feel a loss of anonymity in a group or they may find it difficult to talk about personal issues with several people. Often caregivers express disdain about listening to other people’s problems. They sometimes admit that if they can deny the reality of the future they can live and cope with the present. If caregivers express feeling uncertain about a group experience they may want to try a particular group through a recommendation from a friend, or geriatric professional, such as a social worker or registered nurse. If they decide it is not the type of experience they are looking for then it is their right—and choice—to reach out for another type of intervention.

For the willing caregiver, the group can provide a meaningful array of supports and experiences. A caregiver study conducted by Louisiana State University provided, “[O]ur findings suggest that

Susan Beerman, M.S., M.S.W., A.C.S.W. is founder and president of Barrister Consulting Services, Ltd., a consulting firm specializing in geriatrics and individuals with special needs. Her book *ELDERCARE 911: THE CAREGIVER’S COMPLETE HANDBOOK FOR MAKING DECISIONS* is available in bookstores.

caregivers are likely to experience fewest relational conflicts and unmet expectations when their networks are composed of individuals who have had caregiving experience.”⁴

Historically, in the field of social work, “group work did not begin as a method of helping people in trouble to solve their problems but as a way of organizing individuals into groups for purposes of self-help toward a better life.”⁵ It is a forum that brings people together with similar problems in an atmosphere that can provide the individual with a level of comfort, acceptance, and security. Support groups for the adult children of aging parents may focus on eldercare, caregiver issues, and the complexities of family relationships and dynamics. “A support group can be a vital link in your self-help education network.”⁶ According to a study conducted in Wisconsin and Michigan,

Caregivers stressed three main areas they felt should be incorporated into caregiver support groups:

1. Practical issues such as legality and financial issues, letting the doctor know whether or not the family wishes life support to be used, and learning as much as possible about the dementia and its course from beginning to end;
2. Caregiver needs, both emotional and practical; and
3. Help with nursing home placement.⁷

According to the psychotherapist I.D. Yalom, some of the curative factors in groups include:

1. Instillation of hope;
2. Universality;
3. Imparting of information;
4. Altruism;
5. The corrective recapitulation of the primary family group;
6. Development of socializing techniques;
7. Imitative behavior;
8. Interpersonal learning;
9. Group cohesiveness;
10. Catharsis; and

11. Existential factors.⁸

In general, considering Yalom’s curative factors, one may conclude that providing education, hope, and friendships in a group setting is a positive therapeutic tool for adult children caring for their aging parents.

The following discussion will examine the process through which five people came together to form a specific caregiver support group. Some of the information about this group was excerpted from an actual caregiver support group.

Organizing the Group

A social worker at a local hospital identified and contacted five women in order to form a caregiver support group. The women shared the following characteristics: They were all daughters of an aging parent, they all had jobs outside the home, and at least one of their parents had received a diagnosis of Alzheimer’s disease.

The social worker sent the women a short questionnaire. They were asked to complete a brief biographical section, and then they selected the most convenient days, times, and the number of sessions per month. The women agreed to participate in a group that would meet twice a month, for six months at 7:30 p.m. in the social work conference room of the local hospital. At the end of the six months the group members would have the option to decide whether they wanted to continue or terminate the group.

The Initial Phase

All the group members arrived on time. Initially, they decided that they preferred to use only their first names. The only other knowledge they had of one another was that they shared a common eldercare problem. The social worker that facilitated the group began by talking to the women about the participants’ commonalities. She addressed eldercare problems in general and tried to provide a common ground for the women.

The social worker made it clear that the group had control of what they would do with the time they spent together. After the introductions she talked to them about the structure of the group.

Group structure refers to how the group is organized, how often it meets, where it meets,

who attends, and so on. These arrangements affect how participants will interact with each other in the group by making the relationships more intense and exclusive, as when a group meets frequently and does not admit new members, or more diffuse as in a group which meets monthly and has an open membership.⁹

The group leader then spoke to the women about their expectations. They unanimously agreed that they were looking forward to talking about their feelings and concerns. One member expressed an interest in learning more about Alzheimer's disease and what to expect as the disease progressed. Two members agreed with the woman and two disagreed. The group decided to discuss this issue at a later date. Another member of the group suggested that they invite a guest speaker such as a geriatric physician to join the group.

During this type of session the women would have the opportunity to ask questions about their parent's physical condition as well as to learn about the advances in treatment options. The group appeared to be interested in the idea, but decided to wait for a month or two before they made a final decision. The facilitator mentioned to the women that in an emergency or crisis one of the members might need more of the group's time than at other times. They discussed how they felt about focusing on one group member during a particular session. The group agreed that if a member needed the attention of the group due to a crisis or emergency, then the group would put aside their plans for that particular session for the good of the individual. The women decided that at the next session each member of the group would have an opportunity to talk about the unique situation that brought her to the group. If any members did not want to participate in the next session, the other members would respect and accept their decision.

The participants also decided on the initial overall goals of the support group:

- To vent their feelings and concerns;
- To learn more about Alzheimer's disease;
- To receive educational materials, information and appropriate community referrals for their parent; and
- To learn techniques to help them cope

with their feelings such as frustration, guilt, loneliness, anger, and isolation.

At the end of ninety minutes, five individual caregivers left as one group, with specific goals and certain individual expectations for their group experience.

The Middle Phase

After several weeks the group clearly had its leaders and followers. It miraculously took on a life of its own. Although the members adhered to the original format, they made some adjustments to accommodate the needs of the group's members. For example, two of the members realized that the 7:30 p.m. time slot was too early for them due to certain family obligations. The group agreed to meet at 8:00 p.m. in order to stay together and accommodate the members. They also spent time discussing the prospect of inviting guest speakers. They decided against it, citing the fact that they are willing to share the information that they received through organizations, the Internet, and their parents' physicians.

As the weeks progressed the group facilitator was able to identify some of the small changes group members were making in their lives. For instance, one woman worked as a waitress from 8:00 p.m. to 6:00 a.m. She slept for a few hours during the day, and took care of her father the rest of the time. The physical exhaustion and mental stress left her feeling ill and irritable. The group devoted an entire session to helping this member express her feelings. They surrounded her with the support she needed to begin thinking about how she could change her quality of life, and still remain an effective caregiver for her father. The following week she told the group that she hired a professional caregiver during the day so that she could get more rest, and she talked to her employer about more flexible hours.

Another woman expressed that she felt conflicted about the inordinate amount of time she spent with her father. She said, "My dad needed me every day this week for one thing or another, but my fifteen-year-old son needed me also." The group asked the woman what she did to help her father. She told them that she grocery shopped and cooked dinner for him every night. The group suggested

that she would save time and energy by shopping and cooking once a week and freezing meals in individual containers. Two weeks later the woman reported that she tried both suggestions and she saved several hours each week. Although she had other problems, she felt that these changes provided her with a helpful place to start.

One of the women did not participate in the group discussions very often. Each week she seemed more and more removed from the group. The group leader noted that she appeared increasingly distant and depressed. She spoke to the woman about her behavior and the woman consented to talk about her feelings with the group. When she finally shared her feelings with the group they learned that she had a history of depression and anxiety. The group asked her if she saw her doctor and she said that she did not have time because she was so busy with her mother. The group spent the entire session talking to her, empathizing and encouraging her to get the medical attention she needed. To the amazement of the group the woman returned the following week and admitted that she had not called her physician. They asked her what it would take for her to do what she needed to do. She said, "Someone has to dial the number." To the surprise of the group leader and the other group members, one of the women took out her cell phone and said, "What's the number?" The woman gave her the number and left a message for her doctor. The following week she returned to the group and announced that she had seen the doctor and he had prescribed the appropriate medications.

The members recognized that the group was an important addition to their lives. At the end of the six months the group unanimously voted to stay together for another six months. It became increasingly clear that their new relationships brought them together as friends outside the group setting. The group remained intact for almost two years until it terminated due to an unfortunate cut in the hospital budget.

The Final Phase

The women knew that the last meeting of the caregiver support group was inevitable. Fortunately for these group members, the facilitator was experienced in the "ending" phase of group work and

began the termination process several weeks before the final session. "Whenever termination is being considered, a thorough review and evaluation of what has or has not been accomplished and of the processes by which these gains were made or failed to be made, is imperative."¹⁰ For several weeks the group members talked about their feelings, what they felt they had learned from one another, and their expectations for the future.

At 8:00 p.m. four of the five women arrived for the last session. The fifth woman arrived forty minutes late. "Clients refuse to accept the notion of termination and behave as though it were not going to happen."¹¹ The group facilitator encouraged the group members to talk about how they felt about there last day together. Two of the members expressed the fact that they felt the support of the group and that it carried them from week to week. One woman said, "I felt like people really understood what I was going through. I knew that sometimes I get loud and angry but you accepted me." Another woman added, "I'll miss all of you because you said things that made me think about my life and my parents. Thinking about things in a new way was very important and helpful."

Two of the women expressed a sense of loss and separation due to the unique relationships they formed with the group members and the leader. One woman fled the group during the last session and never said goodbye. She left a note in the facilitator's mailbox that described how much the group meant to her and that she was afraid to see it end. She expressed her deep regret for not saying goodbye. At times group members may demonstrate their grief by "[a] precipitate break in the relationship by the client as though to say that the client will leave the worker before the worker leaves the client."¹² A few days later the group leader tried to reach out to the woman and contacted her by telephone. When the woman answered the telephone she said, "I don't have time to talk to you."

As the group continued to explore their feelings the women began to express some very deep emotions. "I leave all of the problems here; the girls take away the hurt and pain." "I escape and feel safe." "These women are my friends. They understand the agony of taking care of a parent." Another woman said, "I only wanted to learn

about the disease. I didn't talk for weeks and that was okay with the group. When I felt safe I began to open up and nothing will ever be the same for me. I know I can do what I have to do. I don't feel alone anymore."

The group then turned to the facilitator and asked how she felt about ending the group. The facilitator openly and caringly responded that she would miss the group. She expressed her admiration for the five women who grew to help, support, and provide one another with strength and direction. "Nevertheless there comes a time when the worker and the members must face the fact of separation from each other and often, also, the end of the group itself."¹³

Conclusion

A caregiver support group often has a profound, lasting, and positive impact on a caregiver. The research is clear that the group experience is beneficial and "individuals whose networks contain pri-

marily non-caregiving members may stand to gain the most by being placed in contact with other caregivers through support groups."¹⁴

Although a trained facilitator has certain expectations about group dynamics it is difficult to fully predict how the group will evolve, who will lead the members and what will happen from one session to another. Diverse personalities, individual techniques in problem-solving, subject matter, and a variety of coping mechanisms often determine the group's growth and development. It is a forum that allows its members the freedom to speak openly, without the fear of criticism from loved ones and friends. A support group provides acceptance when a member is depressed or enraged, but most of all a cohesive support group provides an accepting cocoon for a weary caregiver.

As a group evolves and meaningful relationships develop, one can only marvel at a process that serves so many caregivers so well.

Endnotes

1. Suzanne Mintz, *The Depressed Caregiver* (2001), at <http://my.webmd.com/content/article/4041.161> (last visited June 17, 2002).
2. Cheryl Dellasega, *Health in The Sandwich Generation*, 10 GERIATRIC NURSING 242 (1989).
3. Constance Todd & William Oriol, *Innovations*, 30 J. OF THE NATIONAL COUNCIL ON AGING 15 (2001).
4. J. Jill Suitor & Karl Pillemer, *Support and Interpersonal Stress in Social Networks of Married Daughters Caring for Parents With Dementia*, 28 J. OF GERONTOLOGY S1-S8 (1993).
5. BEULAH COMPTON & BURT GALAWAY, SOCIAL WORK PROCESSES 478 (3d ed. 1994).
6. David L. Cram, *Helping Yourself with Support*, at <http://my.webmd.com/content/article/1680.53338> (last visited June 17, 2002).
7. University of Wisconsin School of Social Work, *Widows and Widowers of Alzheimer's Victims: Their Survival After Spouses' Death*, 2 J. OF INDEPENDENT SOCIAL WORK, Winter 1987, at 21.
8. STEVEN H. ZARIT, NANCY K. ORR & JUDY M. ZARIT, THE HIDDEN VICTIMS OF ALZHEIMER'S DISEASE: FAMILIES UNDER STRESS 148 (1985).
9. *Id.*
10. COMPTON & GALWAY, *supra* note 5.
11. *Id.*
12. *Id.*
13. *Id.* (citing, HELEN NORTHERN, SOCIAL WORK WITH GROUPS 222 (1969)).
14. *Id.*