Use of Alzheimer family support group by community-residing caregivers

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Abstract: This paper describes the author's experience as a new co-facilitator for an Alzheimer's Disease Family Support Group and reviews the preliminary phase of group practice and the dynamics of the beginning phase of co-facilitating the Alzheimer's Family Support Group. The paper reviews the needs that Alzheimer Support Group would meet, purpose of the group, agency and sponsorship support for Alzheimer Support Group, recruitment, group composition, group timing and structure, leadership of group, orientation of group members, content of group meetings, group sessions, and anticipated obstacles, and concludes with the importance of empowerment-oriented social workers who share the message that change is possible with others who are struggling, while working side-by-side with them to achieve changes and provide a new beginning – a new path for caregivers – a path of self discovery. As Alzheimer's disease progresses caregivers and loved ones of people with the disease are often challenged on a daily basis – emotionally, mentally, and physically. Being with other people in similar situations encourages group members to share information, exchange coping skills, give and receive mutual support, vent their frustrations and share their success stories. Caregiving for a person with cognitive impairments can be a very difficult task, but knowing that you are 'all in the same boat' provides the life preserver to the caregiver – giving nourishment to the soul.

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Introduction and history

For this paper, I will examine the development of an Alzheimer's support group I conducted while working for Elder Independence of Maine (EIM) as an Alzheimer Specialist in the Caregiver Companion Program. EIM is part of Senior's Plus (one of the five Area Agencies on Aging) that serves Androscoggin, Franklin and Oxford counties. According to Toseland (2009), an Alzheimer support group would be classified as a treatment group and a reciprocal model of groupwork practice as it is 'ideally suited for support groups designed to help members cope with distressing life events' (p.52). The paper will focus on the planning stage, the first meeting, and the members' behavior in the early stages. The Caregiver Companion Program was an extremely unique (the only one in the country) model program funded by Maine's Alzheimer's Project and the Administration on Aging (Alzheimer's Demonstration Grant to States Program) that focused solely on the needs of the caregiver. As an Alzheimer Specialist, I provided companionship (taking caregiver out to lunch or for coffee and participating in activities with the caregiver such as cooking or gardening), support (in-home visits, telephone calls), education, resources (visits within the community with the caregiver to nursing facilities), and referrals to caregivers of persons with dementia receiving home care provided by Maine's Home-Based Care system.

Needs that Alzheimer support group would meet

After visiting with caregivers in three counties (Androscoggin, Oxford, and Franklin), it was evident to me by listening to their concerns and questions that having them attend a support group would be beneficial. By visiting the caregivers, I witnessed that many of them did not have a support network and that my visit (i.e. taking them out to lunch) was their only human contact outside of the providers who cared for their loved one such as: nurses, personal care attendants, and homemaker services (light housework). The more involved the consumers' needs became the more isolated the caregiver became. Many caregivers did not have extended family members, and often times those that had family, did not wish to be actively involved with their family members. As an Alzheimer Specialist at EIM, I had first hand knowledge and experience

with Alzheimer's disease, and providing support and education for caregivers of dementia consumers and would often attend support groups with the caregivers.

Basically, the Alzheimer support group would be a place where caregivers would meet other caregivers and provide mutual aid. According to Shulman (2009), 'simply bringing people together does not guarantee that this aid will emerge,' and the group leader is an integral part of the group in assisting members to 'create the conditions in which mutual aid can take place' (p.283). Miley, O'Melia & DuBois (2004) agree with Shulman and cite that connections with others alone do not guarantee experiences of social support; however, 'support occurs when relationships are based on reciprocity, mutuality, and shared power in an atmosphere where people can offer what they have to offer and receive the resources they seek' (p. 352).

Purpose of the group

The purpose of the Alzheimer's support group is to offer individuals (spouses, care partners, adult children, and other family members) support and information that is specific to dementia (Support Groups). The support group is a

> place for caregivers and families to learn together, deal with feelings of frustration, sadness or isolation, and 'link arms' with others that have a mutual understanding. (Dwyer, 2009)

or as Shulman (2009) phrased mutual understanding with group members as 'all in the same boat' phenomena (p.288).

Agency and sponsorship support for Alzheimer support group

Reflecting on the mission statements of both Senior's Plus (*Enriching the lives of seniors. Seniors Plus believes in maintaining the independence, dignity and quality of life of older adults. To that end, we work consistently to remove barriers and strive to provide services in a reliable and coordinated manner,*

and EIM (*Serve people First. Respect Choice. Promote Quality of Life*), it is clear that the goals and objectives of the Alzheimer Support group coincide with the mission and goals of the group. Toseland (2009) states the importance of how the group 'should fit within the organization's policies and goals and the purpose of the proposed group' (p. 155).

An Alzheimer support group was already in existence at Senior's Plus during my employment at EIM, therefore I stepped in to co-facilitate in the established group. Shulman (2009) cites the importance of having the service be 'owned' by the agency and not the personal project of a concerned social worker and Toseland (2009) cites how the 'agency sponsorship determines the level of support and resources available to the group,' therefore the support of the agency or organization is essential for group success (p.154).

The group

Recruitment

The Alzheimer Family Support Group was an established entity at the agency, but due to my daily contact with caregivers as part of my job (pre-group contact), I witnessed first hand the stress and isolation that many caregivers were experiencing and could make suggestions on the benefits of a support group. Due to the relationships I had developed with the caregivers, and the trust we had built (although many of them had never attended any type of support group), some caregivers were willing to step out of their comfort zone and attend a group. How the group is announced and explained often directly influences both the way it will be received by potential members and who will join. Both According to Corey & Corey (1997)

> how a group is announced ... influences both the way it will be received by potential members and the kind of people who will join [and] .... that making personal contact with potential members is one of the best methods of recruiting. (p.109).

Another effective method of announcing and recruiting is through your agency colleagues. Potential members were frequently referred to

me by the Care Managers (who managed the care plan of the consumer – the client with Alzheimer's disease) at EIM. The Alzheimer Association was also vital in recruiting members of the community through various methods such as: press releases, association newsletters, and website. The Alzheimer Support Group was additionally advertised in the local newspaper in the 'Calendar of Events' section, as well as flyers and brochures which were hand delivered to local doctors' offices, hospitals, and other elder and community service agencies.

Composition

The Alzheimer support group was made up of spouses, care partners, family members, loved ones, and friends of those with Alzheimer's disease, and was an open and ongoing (drop-in) group. Some Alzheimer Association chapters have specialized support groups such as: early stage groups, male care partners, and adult children caring for a parent etc., but this particular one was a Family Support Group (Support Groups).

The number of participants can vary from meeting to meeting, but the Alzheimer Association states the ideal size for a support group is 6-12 members (Support Groups). According to Miley et al., (2004)

> small groups provide opportunities for enhancing mutual aid among clients, a setting in which clients help themselves by helping each other, (p.346)

Similarly, Corey & Corey (1997) report

> about eight people with one leader may be ideal ... big enough to give ample opportunity for interaction and small enough for everyone to be involved and to feel a sense of 'group'. (p.116)

According to Bigtree Murphy (n.d.) the Family Support Group (drop-in group) tends to be less homogeneous than other Alzheimer specialized support groups (i.e. early stage groups) due to nature of the group (monthly meeting with attendance varying from meeting to meeting). Caregivers and family members attend when they can, when care needs become critical or problems arise, or when 'they can't take it

any longer.' Sometimes 'it can be months before a new attendee bonds with the older more regular attendees'(Bigtree Murphy (n.d.). Caregivers and family members attend when they can, when care needs become critical or problems arise, or when 'they can't take it any longer.' Due to the open-ended style of the group, 'members are entering and leaving the group at different times;' consequently, 'each member is constructing an idiosyncratic and unique history with the group – sharing common experiences with some group members but having very little interaction with others.' (Miley et al., 2004, p. 454).

According to Toseland (2009), the principle of homogeneity implies that members should have a similar purpose and share some personal characteristics. The members in the Family Support Group share in 'caregiving' for their loved ones. Caring for an individual with dementia, (Alzheimer's disease) 'requires different techniques than those needed to care for someone who is not cognitively impaired' (Support Groups). Corey and Corey (1997) report that the 'similarity of the members can lead to a degree of cohesion' (p. 115), thus allowing for an open exploration of their problems. For many family members an Alzheimer support group provides a place to exhale – to take a break from 'caregiving' with others who have been there. Many caregivers hesitate to confide in family and friends for fear they will be criticized about their feelings of guilt, frustration, or anxiety and worry that what is said will have an effect on family dynamics (Spencer, 2009) Members are allowed to express feelings that have been kept confidential (even from other family members) and their life circumstances can provide a link with one another (Corey & Corey, 1997). Many caregivers hesitate to confide in family and friends for fear they will be criticized about their feelings of guilt, frustration, or anxiety and worry that what is said will affect family dynamics. In addition, Miley et al., (2004) reports 'the group is an enterprise in mutual aid, an alliance of individuals who need each other, in varying degrees to work on certain common problems' (p. 346).

Toseland (2009) also states the importance of heterogeneity – 'how differences among members can provide multiple opportunities for support, validation, mutual aid, and learning' (p.164). All the caregivers in the Alzheimer Family Support Group share a common problem, but are diverse in respect to coping skills (i.e. *resilience*), life experiences (*family dynamics – family system theory),* geographic location *(rural*

town vs. urban city), spirituality *(religious backgrounds, personal beliefs),* generational differences *(adult children caregivers, young elderly, elderly elderly),* cultural differences *(Franco-American),* socioeconomic status and level of expertise (i.e. *education, length of caregiving).* Toseland (2009) goes on to state – the existence of differences in members' coping patterns 'opens the eyes of members to options, choices, and alternatives, and makes it possible for them to learn from one another' (p. 164). Members of the Alzheimer Support Group can experiment with new behavior and develop new coping skills with the help of feedback from a broad variety of other caregivers in a safe environment that represents out-of-group reality (Corey & Corey, 1997).

 According to Miley et al (2004), groups provide a forum for the members

> to develop skills in critical thinking, receive information and validation, and organize a power base from which to advocate change in larger social systems [and] ... group work may well be the method of choice for empowerment-oriented social work practice. (p.344)

'Empowerment-oriented practitioners view self-help as integral to clients' experiences of empowerment' (Miley et al., 2004, p. 350). Furthermore, Sullivan and Rapp (1994) describe the empowering nature of peers helping peers as a process in which an individual 'is no longer simply a passive object of services who hopes to recover, survive, or regain health, but an active remember of a synergistic group' (p. 95).

 In working with a group it was important for me to remember the foundation of generalist social work practice; that is, for any particular problem or situation, a generalist practitioner might have to intervene with individual, families, groups, organizations, or communities. Working at the mezzo level with the Family Support Group, it was imperative to bear in mind that

> mezzo skills are based to a great extent on micro–level skills [and] ... practitioners must thoroughly understand the communication and interaction occurring between individuals. (Kirst-Ashman & Hull, 2001, p. 19)

Timing and structure

The Alzheimer Family Support Group (ongoing) meets once a month on the 2nd Monday of the month from 6:00-7:30pm at Seniors Plus in Lewiston. There are other Alzheimer support groups that meet in Androscoggin County on various other days of the week and at different time frames to accommodate the caregiver's demanding schedule. This meeting structure allows caregivers to have dinner with their loved one and attend to bedtime routines prior to attending the meeting. The evening time frame also lends itself for family members, friends, and/or neighbors to sit with the loved one for a few hours. If the caregiver does not have someone to stay with the consumer, prior contact with the agency would permit for a personal care attendant for respite coverage.

The meeting is held in a good size conference room at the agency where members sit in a circle (lets participants see one another easily and allows for freedom of movement and for members with physical disabilities) with tables in front of them – thus providing a comfortable seating arrangement. The meeting is held after normal business hours providing the members privacy. Restrooms are very close in proximity, as well as a kitchen area (right off conference room) where coffee, tea and water are available. Snacks are provided at meetings (I would buy items and the agency would provide reimbursement) such as: fruits, crackers and cheese, mini cupcakes, birthday cakes etc. The Family Support Group had the 'willingness of the sponsor to provide external support [...] such as funding for supplies that might be needed to conduct group' (Toseland, 2009, p.157). Shulman (2009) states the importance of the formation stage related to group structure and setting – which had already been thoughtfully and carefully planned and laid out with attention to details.

Leadership

The Alzheimer Family Support Group was already in existence when I initially started to co-facilitate the group. I had attended and observed the group many times with the caregivers I had been working with (as a support person as a component of my position as an Alzheimer Specialist) prior to co-facilitating and eventually progressing to the facilitator of the group. So even though I was new to co-facilitating the group, I was not the 'newcomer' in the group with established patterns

of relating. According to Toseland (2009, p.192), 'the worker should become familiar with group's structure and its current functions and processes' when working with previously formed groups, and fortunately I was well versed in that area due to my position in the agency. The transition to being a co-facilitator was more easily accomplished, as I had witnessed the relationships among the current group members and had observed the current facilitator (an employee of Senior's Plus) and was also familiar with the formal and informal leadership structure of the group. The meetings I had attended with the caregivers and simply observed the leader's behavior had enabled me to learn vicariously. As Shulman (2009) notes, 'working with a more experienced worker provides learners with an opportunity to test their wings without taking full responsibility for the outcome' (p. 365) and this was comforting to me as a new co-facilitator.

I believe the process of accommodation and assimilation of my presence into the culture of the group was relatively unproblematic, but as a new co-facilitator (and member of the group) I brought a new set of expectations, preferences, and style of relating to the group. Toseland (2009) states

> as people enter into a group and take part in shaping its purpose and goals, the underlying premises that they bring to the encounter and their ways of perceiving, thinking, and interpreting will inexorably determine how the process unfolds. (p. 119)

Orienting members/ content of group meetings/ first group sessions

The Family Support Group had an established format (a ritual) for introductions and they utilized a round robin method. The group also had an established agenda (through group consensus) that consisted of a combination of:

1. candid conversations (sharing stories about their experiences, coping with problematic behaviors);
2. lectures from special guests on common topics of interest (adult day care programs, self-care techniques, nursing facility placements);

3. topic centered discussions (incontinence, combativeness, how to find time for yourself).

One of the caregivers I had been working with (a new member to the group) attended the first meeting I co-facilitated. Due to the luxury of having one-on-one contact during my home visits, I had the opportunity to share in depth with the potential new member regarding the format of a 'typical meeting' and also address her concerns and reservations about attending for the first time (this was truly an advantage as in most group settings this would not be feasible due to the expense). I was able to address issues regarding what would be expected of her, and assure her she would not be asked to self-disclose until she was comfortable in doing so.

On the night of my first meeting as a co-facilitator there were five members and the new member I had been working with. The facilitator went first and set the stage with her personal introduction (and she introduced me and my new role) and I followed with a brief introduction as co-facilitator. The returning members introduced themselves round robin fashion (for the benefit of the new member) and the new member followed their lead (stating her name, where she was from, who in her family had Alzheimer's disease, and the length of time her loved one had been afflicted with the disease, how the group has been helpful to them). By going into a few personal details during the meeting, the members are sharing commonalities – helping in the process of members feeling at ease with one another and providing much needed comfort and support. Toseland (2009) cites that commonalities also '… helps develop group cohesion and demonstrates to members that they are not alone with their problems and concerns' (p. 189). Likewise, Yalom (2005) describes this phenomenon as universality – or 'simply put the phenomenon finds expression in the cliché 'We're all in the same boat' – or perhaps more cynically, 'Misery loves company' (p. 6).

Next, the current facilitator went on to define the purpose of the Alzheimer Family Support Group – to offer family members support and information that is specific to dementia and also explained the importance of confidentiality. According to Toseland (2009), 'trust among members is essential for cohesion and the smooth functioning of the group' (p. 195). She followed with a brief description on the function and services of Senior's Plus and I added the description of

EIM services. The co-facilitator announced that there would be a guest speaker (Leslie, the Administrator for Marshwood Healthcare (24 beds for Alzheimer/dementia patients) in Lewiston) for the second half of the meeting. The meeting was then 'opened for discussion' of any urgent concerns, problematic issues or behaviors, and/or sharing of a 'good event' or positive reactions to experimenting with new coping methods.

One of the members (Mona[1]) shared an event where her husband (Jerry) climbed out of the kitchen window and wandered into the neighborhood while she was taking a shower. She explained how she was 'frantic' when she saw the opened window and realized what he had done. She elaborated on how she thought she had taken all the necessary precautions for safety such as dead bolt locks on all exterior doors, alarm on the bed, an alarm on his favorite chair in the living room, and all the windows were also locked. She immediately contacted the police to alert them of the situation. Mona does not drive, so she also called her daughter for assistance. Luckily, a man (Stan) driving several streets over recognized that Jerry's behavior (sitting on the curb) was unusual and stopped to talk with him. Stan worked in a nursing home as a CNA and was aware of atypical behaviors in the elderly. Stan called the police from his cell phone and they sent a patrol car to assist with the situation stating they had received a call from the man's wife alerting them of her husband's disappearance.

Mona went on to state that she was proceeding to buy security latches for all the windows and was grateful for the outcome … that a stranger had stopped to help – because the result could have been much worse. Jerry told Mona he left because he needed 'to get to work.' Two members interjected with short phrases and empathized with Mona's plight (i.e. 'that must have been a horrible experience for you'; 'you must have been so terrified'). The group members had a much deeper understanding of Mona's feelings of sheer terror than I had as a worker. The expression of empathy by group members facilitated healing for both Mona and the members who responded to Mona. According to Shulman (2009, p.290), 'the idea of acceptance and caring of the group introduces a new concept … the group as a whole – involves more than just the simple sum of the parts (members). I was able to observe what Shulman (2009) refers to regarding a general tone or atmosphere of the group displayed through words (tone of voice, gasps), expressions (facial expression of shared fear (eyes wide open), nodding) and physical posture (open body language)

that conveyed the caring of the group for the individual. Shulman (2009) also reports one of the most central ideas regarding groupwork – 'that the groupworker always has two clients – the individual and the group' (p.256) – how true! The beauty of co-leadership according to Toseland (2009) lends well to attending to both the individual and the group by allowing 'greater coverage of the dynamics of the group' by sitting opposite one another and also 'in focusing on 'process and content issues' (p. 123).

Another group member responded to Mona by informing her about a program through the Alzheimer's Association (AA) called 'Safe Return.' AA has bracelets (much safer as they cannot be removed as easily), necklaces, and iron-on clothing labels imprinted with pertinent personal information, so if someone wanders they have identification on them. I shared next about the AA having monies available to defer the cost of the bracelet if one is not able to afford the cost, or another option would be to have an inexpensive bracelet engraved with name, phone number, and the words 'memory impaired' at one of the local mall stores (that engraves key rings, pens etc.). My job as a co-facilitator was to help connect the group to the member to facilitate mutual aid (Shulman, 2009).

Another member shared next enlightening the group on a method she utilized to prevent wandering. She said her husband would not go outside if he didn't have his shoes on, so she made sure all his shoes were not accessible to him. Also, she added she notified all her neighbors of her husband's disease – reassuring them that he was not 'crazy' or dangerous, but just disoriented due to Alzheimers, thus alerting others to be aware of her situation.

Mona was appreciative for all the input and suggestions – and consequently the group had been given additional ideas, and information to help them with the safety of their loved ones. Shulman (2009) cites 'one of the simplest yet most important ways that group members can help one another is by sharing data'(p. 286). The group took a short break to enjoy some cookies, decaf coffee, and tea, and resumed 10 minutes later for the guest speaker from Marshwood Healthcare, who spoke for the second half of the meeting and incorporated a question and answer period at the end of her presentation. The group was adjourned on time.

Anticipated obstacles

Some of the initial obstacles were:

1. the format of an open–ended group;
2. ambivalence and misconceptions from potential new members;
3. the evening time frame for the support group.

According to Shulman (2009), 'a technical problem associated with open-ended groups is that each session may be a new beginning for some members, an ending for other members, or both' (p. 371). An example of this occurred at the first group that I co-facilitated with the introduction of a new member. Her participation at her first meeting was minimal (consisting of her brief introduction at the beginning of the group – round robin). As the co-facilitator, it will be important to brief a newcomer prior to their attendance if possible, so that the ongoing work of the group can continue in spite of the changes.

I also anticipated some ambivalence of potential new members attending the support group. Many of the caregivers I visited with expressed a number of ambivalent feelings and misconceptions about attending support groups. Some caregivers and family members have had past negative experiences from attending other support groups. One of the caregivers expressed the stigma of being in a group, stating 'only people who cannot cope join groups.' Some caregivers are simply unsure of the 'expectations' of support groups and are fearful that 'they will not be able to contribute in a way they think is expected of them' (Toseland, 2009, p.210). From my experience, I *sometimes* found that caregivers were so overwhelmed and tired that they found excuses for not joining a support group such as: 'I can't drive at night', 'I can't talk to strangers about my loved one's behavior', 'I can't leave my loved one', or I am not a 'group type of person.'

The evening time frame for the support group may pose a hardship on the caregiver's (some of the caregivers I work with at EIM) ability to attend the group. Many people with dementia related illnesses often seem to have more behavior problems (agitation, restlessness, pacing) in the evening (sundowning). Fortunately both agencies, Senior's Plus and EIM, provided respite support to caregivers, allowing them the option of attending a support group provided staffing could be found

and scheduled ahead of time by one of the local home care agencies. The respite care was a key component in helping 'caregiver burnout' and in supporting 'self-care' among caregivers.

Conclusion and recommendations

This paper has reviewed the 'Preliminary Phase in Group Practice', as well as the dynamics of the 'Beginning Phase of the Alzheimer Family Support Group' that I co-facilitated. Corey & Corey (1997) believe that

> groups are the treatment of choice, not a second-rate approach to helping people change ... Groups provide a natural laboratory that demonstrates to people that they are not alone and that there is hope for creating a different life ... Groups have immense power to move people in creative and more life-giving directions. (p. 5)

Despite the numerous advantages to groupwork, 'numerous research findings *underscore* the significance of social support in protecting, moderating, and buffering the effects of crisis and in contributing to peoples' resiliency in the face of ongoing stress' (Miley et al., p. 352). As social workers, sharing the message that change is possible with others who are vulnerable, marginalized, and oppressed while working with them to achieve those changes – allows us to become the 'change agent' (Rothenburg, 2004).

Note

1. Names have been changed throughout this paper to protect confidentiality.

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