

Meeting individual needs in recreational groupwork for people with dementia

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Abstract: *In describing the Respite Care Adult Day Care agency in Brunswick, Maine, this paper sheds light on the challenges, successes, and potential for recreational groupwork to improve quality of life and care for people living with dementia. The paper begins with an overview of relevant theories and highlights a controversy surrounding the use of groupwork in dementia care with respect to individual members' widely diverse levels of needs and functioning. The paper provides an account of Respite Care, its membership, and a particular situation in which a person-centered, empowerment approach transformed one individual's apathy into engagement with the group. The paper concludes with a discussion of how person-centered recreational groupwork, when done effectively as in the case of Brunswick's Respite Care agency, benefits not only those individuals marginalized by society's treatment of dementia, but also our health-care system, communities, and society as a whole.*

Keywords: *dementia; Alzheimer's disease; recreational groupwork; respite care*

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Introduction

People living with dementia, marginalized by their own society, experience multiple losses beyond those of memory and cognitive ability. Some lose the sense of inclusion within their chosen communities. Others lose self-esteem and happiness due to the onset of depression. Losses extend to caregivers, fifty or sixty percent of whom suffer stress-related health problems (Olsen, 2007). A recent study in the *Journal of Immunology* finds that the burden of caring for a person with Alzheimer's disease can shorten a caregiver's life by four to eight years (Olsen, 2007). This paper reports on groupwork theories and the author's experiences at Respite Care Adult Day Service in Brunswick, an agency devoted to improving quality of life for people with dementia and providing peace of mind to caregivers. This author observed and engaged in Respite Care with the purpose of facilitating a particular member's engagement in activities with her peers.

Relevant theories

Toseland and Rivas (2001) aptly note that

As an end, recreation can be a desirable leisure time activity. As a means, recreation can help a particular population become involved in an activity that has therapeutic benefits. (p. 29).

This *end and means* process is certainly true of Respite Care, a recreation group where members enjoy the health benefits of exercises for body and mind, as well as friendship and socialization to counter isolation and depression. With respect to recreational groupwork in general, Toseland and Rivas note that the ideal situation is for every member to be involved and interested in the group activity (p. 111). In pursuit of a high engagement level for all of her program's participants, Respite Care's executive director invited me to join the morning group in the hopes of engaging one woman's involvement in the group.

Perhaps the most important benefit of a group such as Respite Care, affectionately known as 'the club', is the unity shared by members who experience what Toseland and Rivas describe as a 'sense of belonging'

(p. 29). Obviously, in order to achieve a shared sense of belonging, groupwork is the appropriate modality as opposed to one-on-one interaction. Yet, current literature on groupwork for older adults offers differing opinions about the effectiveness of groupwork for people with dementia.

Certainly, social interaction and networking counteract isolation through exploration of participants' self-worth and by normalizing challenges shared by more than one group member (Cummings, 2003; Barbaccia & Yale, 1994). Support groups help older adults coping with Alzheimer's disease to define themselves in new, more hopeful ways, rather than defining themselves by their disease (Yeh et al., 2001). In reminiscence group therapy, older adults share memories and life experiences (Van Puyenbroeck & Maes, 2006) in a supportive setting, thus improving depressive states of mind among nursing home residents (Cummings, 2003; Dean, 1998). Play-centered interactions, such as balloon or tetherball games, are shown to be highly effective at improving social interaction (Pulsford, et al., 2000; Buettner, 2008), and are a mainstay of Brunswick's Respite Care program.

Reality-orientation groups designed to educate and improve the self-awareness of older adults struggling to maintain orientation to time and place exemplify a format commonly used in institutional atmospheres (Capuzzi & Gross, 1990). Scott and Clare (2003) criticize the latter form of group therapy on the basis that it is often a demanding, aggressive style, at times distressing to participants. Scott and Clare (2003) further suggest that older adults with dementia, who commonly experience failing cognitive abilities, also struggle to focus in the midst of multiple conversations and sensory overload common to groups.

Current trends in research suggest that engaging people with dementia in activities improves quality of life and increases physical activity (Vance, 2004). Furthermore, interventions designed to improve quality of life are most effective when the worker takes an empathic approach in tune with the participant's own experiences and point of view, and when the activity minimizes memory or intellectual processing (Zeisel, 2009; Pulsford et al, 2000;) in favor of the individual's remaining abilities (Zeisel, 2009). Assessment of an individual's interests and abilities is critical to choosing an appropriate activity or sensory therapy (Buettner, 2008). Overall, it seems that improving quality of life for people with dementia demands engagement in person-centered activities and a

focus on the individual's present needs and strengths (Zeisel, 2009; Bastings, 2006).

Background to practice

The obvious challenge to facilitating interaction among group members with dementia, based upon the literature as well as this author's work experience, is how to apply an individualized, person-centered approach in settings characterized by a wide spectrum of memory capacities, levels of functioning, needs, and modes of communication. Past work in resident care at an assisted living community shaped my understanding that although some people with dementia thrive during group cognitive activities, others may become discouraged, frustrated, or embarrassed when they draw blanks or experience confusion that leaves them speechless in the face of expectant peers and group facilitators. These observations seem to coincide with the literature's emphasis on person-centered, individualized activities. Yet, my first-hand exposure to Respite Care's morning group showed that, regardless of the activity strategies in place, every member of the group benefits, in the sense that social interaction is so basic to what makes us human, and thanks to a high level of personal attention to each individual in the group provided by dedicated staff and volunteers.

My challenge was to take a person-centered approach with Sue¹ in the context of a busy group environment while simultaneously taking part in the group activities with Sue and the others. Living with dementia in her ninety-fifth year, Sue frequently appears apathetic during group interaction. Almost every morning, she falls asleep in her wheelchair when the group is involved in activities that require intellectual processing or reminiscing. Sue even confesses to keeping her eyes shut in hopes that no one will ask her a question. Yet, every morning, when the time comes for physical exercise, Sue consistently and actively engages—smiling, laughing, and making eye contact with other participants as the group sits in a circle and taps a balloon around from one person to another.

These observations and a need for further assessment led to a home visit arranged with the permission of the Respite Care directors and Sue's family. During the visit, Sue and I engaged in one-on-one

activities such as playing a magnetic bingo game and reading aloud from her favorite book. During this two-hour visit, Sue sustained interest and actively participated with no signs of apathy or frustration. She especially enjoyed reading aloud and seemed to assume the role of teacher—having been a first-grade teacher for many years—while I assumed the role of student.

Further informed by a discussion with the University of Southern Maine's Nancy Richeson, co-author of a 2008 review of evidence on Alzheimer's-related interventions, I concluded that certain recreational activities, that could be fine-tuned for one-on-one or group situations, were a suitable approach to facilitate Sue's engagement with the Respite Care group. A basic, underlying theme common to my home visit, the literature, and my discussion with Richeson was that in order to be effective, interventions must suit each individual's unique emotional and cognitive abilities and needs.

I arrived early the morning after my home visit for a pre-group discussion with the program director to share my discovery that Sue enjoyed reading aloud. I suggested that during the group's morning cognitive exercises – when Sue typically falls asleep in her chair – perhaps she and I could sit together apart from the group and read aloud. The program director agreed but suggested we first experiment with Sue reading aloud to the group.

Practice context: The setting

Respite Care Adult Day Care Service is a private, non-profit corporation providing a breather for caregivers and enhanced well-being in a supportive environment for people with dementia. Groupwork is the core modality. Those who attend are men and women with dementia, mostly of the Alzheimer's type, who come to socialize, exercise, and otherwise engage in group-based activities. Respite Care's social setting promotes sensory stimulation, laughter, preservation of dignity, friendship, a sense of unity within the group, and involvement with a listening, supportive audience. Members are respected as unique and gifted individuals rather than as people lost or disappearing to a cognitive disorder.

Groups gather on weekday mornings and afternoons. The morning

group I joined generally involves three to six members, plus one to three staff. Despite intermittent health problems for some members—and the progressive nature of Alzheimer’s disease sometimes leading to transfers into assisted living or nursing home settings for others—attendance remains high due to the motivation of caregivers for respite and to improve their loved ones’ quality of life. Group members vary in age from seventy-five to ninety-five and all have Alzheimer’s disease in varying stages and severity. The service providers at Respite Care include the program director who plans and leads activities and discussions. One or two volunteers are usually present to assist and participate as needed. The executive director often visits and joins in the activities when possible.

Respite Care meets at the United Methodist Church in Brunswick. The program has its own space within the church in a comfortable, well-lit room housing a couch, desk, tables, chairs, ample amenities, and walls decorated in themes based on changing seasons, holidays, birthdays, and notable events. The room also contains games, art supplies, and basic electronic equipment. A separate, more spacious room is available for exercise during the late morning. Between 9:00 and 9:30 a.m., members arrive at the church to settle in, where they are offered refreshments such as muffins, donuts, tea, and juice provided by the agency. In addition, family members pack lunches for their loved ones.

Once everyone has arrived, the program director initiates discussion to welcome and check in with members. She often shares information or ideas, drawing from recent, or past, newspaper or magazine clippings. She reads aloud to the group and circulates photos or articles of interest, weaving into her discussion questions to individual group members to spark interaction. Discussion usually lasts forty-five minutes to an hour before she introduces a group activity. For instance, on a large marker board she writes a series of letters or a phrase, and then tasks the group with unscrambling the letters into as many words as possible for her to list on the board. On other days, she directs everyone to the table for games such as Scrabble, bingo, cards games, or word searches. After an hour of mental exercise, the group moves to the exercise room to engage in a balloon game for approximately half an hour. Finally, the group returns to the room for lunch at noon. An effort is made to tailor each day’s events to maximize participation, interest, and variety of

activities to enhance the well-being of all members.

Behavior characteristics vary widely among members, lending to interesting and often unpredictable group dynamics. There is Jeanette¹, whose aphasia causes her to express what sounds to others like gibberish. She holds her hands in her lap and refuses direct engagement in activities. Although she speaks in a series of unique and mostly incomprehensible words and sounds, her non-verbal communication is clearly understood. During exercise, when the others keep a balloon in the air by tapping it to one another, Jeanette joins the circle but clasps her hands in her lap. On rare occasions, she will catch and hold the balloon. Over time, Jeanette's involvement in activities has lessened, but she is still very much a member of the group and has an especially close bond with the program director.

There is John, an extremely polite and quiet man who becomes increasingly withdrawn as his language skills deteriorate. During discussion or reminiscence, he speaks only when asked a direct question. Often, he appears to fall asleep. John once coached track at a prestigious university. He loves family, exercise, games, and has a fun-loving, competitive nature, which shines through during exercise and games. On occasions when I challenged him to knock the balloon past me, John always grinned and focused all his efforts on hitting an 'ace'.

There is Garfield, for whom the attendance of other men on a given day influences the degree to which he engages in activities. On days when he finds himself outnumbered by women, Garfield resists taking part in activities for the duration of the day. Much more outgoing than Garfield, Matthew loves to be the center of attention but is also keenly interested and observant of others. On an occasion when I passed a book of poetry to Matthew, he rose from his chair and read poems like a true thespian with impressive stage presence and reluctance to give up the spotlight.

Barbara and Marilyn—two women whose communication skills, unlike Jeanette's, are very much intact—always sit next to one another and have formed a subgroup. The two women appear to find comfort in each other's presence. Barbara has a good sense of humor. However, she is very hard on herself, especially when it comes to her diminishing skills at her favorite word game, Scrabble. Marilyn rarely smiles, even when she is alongside Barbara. She often complains of feeling ill and of being unhappy or hopeless. Although typically resistant to sharing in

activities, she will engage after mild prompting from staff or peers and begins to enjoy herself in spite of herself.

Sue cared for her husband until he died of Alzheimer's disease. Now, Sue is cared for by her devoted daughter and son-in-law at their home. She is quick-witted and loves to observe people around her. However, she disengages frequently from the group dynamic and appears to fall asleep in her wheelchair. Respite Care's executive director appropriately notes that at ninety-five, Sue needs to snooze. However, both the executive and program directors suspect that Sue would remain more alert and upbeat with increased one-on-one attention during group activities. My initial strategy was to learn more about Sue's interests, abilities, and needs.

A poetic voice revealed

One week after my home visit with Sue, I arrived at Respite Care with a stack of books that included a collection of Shel Silverstein's poems. I considered that Sue might not wish to read the poems. The book contained denser words per page compared to what we had read during our home visit. In addition, the illustrations were smaller and lacked the eye-catching colors to which she was she accustomed. Once the other program participants arrived and settled in, I sat next to Sue and began to leaf through the book of poems. Sue appeared interested, so I leaned closer so that together we could flip through the pages. I asked, 'Would you like to read one of these poems?' flipping at first to a short poem, hoping to gauge her comfort level and ability to see the smaller lettering. Discovering Silverstein's amusing illustration, Sue responded with a laugh and an 'oh my golly,' then began to read the following poem slowly and with ease:

SHAKING
Geraldine now, stop shaking that cow
For heaven's sake, for your sake and the cow's sake.
That's the dumbest way I've seen
To make a milk shake. (Silverstein, 1981).

Sue's eyes brightened and she laughed at the conclusion of the poem. The facilitator led the group in laughter and applause. In response,

Sue smiled, then her eyes widened as she looked around the room at everyone. When I asked if she would like to read another poem, Sue immediately agreed. Remarkably to all present, including the executive director, Sue read poem after poem with perfect timing, careful emphasis, and *feeling*. Sue appeared to become increasingly aware and pleased with the fact that she was regaling us. Above all, Sue seemed to enjoy herself fully. After reading aloud to the group and responding to overwhelmingly positive feedback, Sue was tired. She napped briefly, but instead of hanging her head and slouching forward in her chair, she sat upright, leaning her head back with her eyes closed and her hands folded in front of her. After her short nap, she was ready as always to engage in physical exercise.

Discussion and conclusion

Breakthrough moments such as Sue's reading aloud at Respite Care may be explained as follows with respect to activity therapy for individuals with Alzheimer's disease:

They are simply taking part in an agreeable activity that they can comprehend and succeed at. By doing so, they may be experiencing enhanced well-being. (Pulsford et al. 2000, p. 656)

At Respite, we discovered a simple way to support Sue in revisiting her role as a teacher – and as a leader. When Sue's daughter learned that her mother read aloud to the delight of the group, she was surprised and very pleased that her mother's teacher self and special gift were illuminated and shared. Not only did Sue thoroughly enjoy herself when reading aloud, she also contributed to the enjoyment of the entire group, with the exception, perhaps, of one member.

An unexpected dynamic between Sue and Jeanette emerged from Sue's newfound role in the group. Prior to Sue's first poetry reading to the group, there was already tension between Sue and Jeanette. Sue occasionally became frustrated with Jeanette's aphasia. I often noticed Sue staring disdainfully at Jeanette. On the second day that Sue read Shel Silverstein poems to the group, Jeanette became louder and more expressive the longer that Sue read aloud. This culminated

with Sue abruptly stopping her reading in the midst of a poem and chastising Jeanette. Schulman (1999) in his chapter about working with individuals in groups writes about the concept of quasi-stationary social equilibrium in which a balance has been established between 'the individual personality in relation to its environment' (p. 514). Semi-contained tension between these two members suddenly erupted with the change in dynamics. To defuse the tension, we immediately shifted to a new activity as soon as Sue finished the final sentences of her poem. From a systems theory approach, it seemed that the system was suddenly thrown out of balance and required another adjustment from facilitators to limit the duration of Sue's reading according to Jeanette's responses, all in an attempt to establish and maintain equilibrium, appropriate communication, as well as dignity and respect for all members.

The months I spent with the Respite Care group provided many insights into groupwork generally as well as specifically for people with dementia. It was challenging to create optimal group communication, cohesion, and social integration, while also paying special attention to individual needs within the group. The home visit proved helpful, as did creativity and flexibility among all facilitators. As noted by Politis and colleagues (2004) with respect to activity therapy in residential settings, 'an activity therapist who is creative and well versed in the resident's interests can have a greater impact on the patient than the use of a standardized activities kit' (p. 1092). Respite Care continues to evolve with both a reality orientation and activity-based approach for its members. It does this successfully thanks to the care and devotion of the agency's staff and volunteers, who can provide the needed individual attention oftentimes not available at understaffed assisted living communities or nursing homes. Groupwork appears to be a delicate, sometimes tricky balance between meeting the needs of the group as a whole while concurrently tailoring to individuals across widely diverse levels of functioning, needs, and preferences.

Recreational groups promote social and economic justice by breaking down society's fearful and hopeless view of Alzheimer's disease. Groups such as Respite Care promote and demonstrate ways to improve quality of life for people with dementia simply by engaging in pleasurable activities, at a time in our culture when Alzheimer's is commonly viewed as a disease stripping people of hope for quality of life. Economically, therapeutic recreation as a non-pharmacological intervention may

lead to cost savings. As Buettner (1999) notes with respect to Simple Pleasures, multilevel sensorimotor interventions for nursing home residents with dementia,

The cost of making the Simple Pleasures items is very low. ... A community group could make all the projects in the training manual for about \$150.00! These same items can be purchased in specialty catalogs for \$1,500.00, but the benefits go beyond saving money. Community volunteers learn about a disease for which there is no cure, but realize there is something they can do to help. ... Families benefit from this project because they also feel there is something they can do to help. ... Children become re-involved with grandparents or great grandparents through these simple activities (p.51-52).

Furthermore, recreational groups such as Respite Care may empower community members of all ages and roles to engage in positive interactions with people who have dementia. It is an approach focusing on the remaining strengths and abilities of persons with dementia, rather than becoming bogged down in emphasis on loss. Recreational groups may help communities and families empower themselves to be able to care for their loved ones with Alzheimer's within the home or community, if they wish, rather than sending their loved ones away to an isolating institutional setting, one that may very well be sensory-depriving. Through recreational groupwork, volunteers of all ages can build relationships and socially engage in an on-going basis with people with dementia. The implications for improved quality of life for people with dementia extend to possible alleviation of caregiver stress, decreased dementia-related behaviors, and cost savings for the health-care system. In his 2009 work *I'm Still Here*, John Zeisel notes the following:

Everyone has his own unique capabilities. These may include reading the newspaper aloud to others, singing, gardening, or dancing. Whatever they are, they are there and it is our job to uncover, celebrate, and embrace them so that everyone living with Alzheimer's, no matter where in the progress of the illness they are, maintains their dignity, independence, and self-respect. (p.17)

Zeisel's words summarize just one of the reasons why the staff and volunteers at Respite Care Adult Day Care Service do what they do on a daily basis, in addition to providing respite to caregivers, and simply because they love what they do. The agency exemplifies how—with adequate personal attention to address the needs of each member—groupwork proves highly effective at increasing social interaction and promoting a sense of belonging for people with dementia. Respite Care continues to develop its diverse community of people, all of whom embody wonderfully complex personalities, roles, and identities worthy of sharing and celebrating within a supportive, recreational group setting.

Note

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

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