

University of Texas at Tyler

Scholar Works at UT Tyler

Health and Kinesiology Faculty Publications
and Presentations

Department of Health and Kinesiology

Spring 11-14-2018

Perspectives of caregivers and volunteers on Stepping Stones for people with dementia

Areum Han

Diane Brown

University of Texas at Tyler, dbrown@uttyler.edu

Follow this and additional works at: https://scholarworks.uttyler.edu/hkdept_fac



Part of the [Kinesiology Commons](#)

Recommended Citation

Han, Areum and Brown, Diane, "Perspectives of caregivers and volunteers on Stepping Stones for people with dementia" (2018). *Health and Kinesiology Faculty Publications and Presentations*. Paper 31. <http://hdl.handle.net/10950/4327>

This Article is brought to you for free and open access by the Department of Health and Kinesiology at Scholar Works at UT Tyler. It has been accepted for inclusion in Health and Kinesiology Faculty Publications and Presentations by an authorized administrator of Scholar Works at UT Tyler. For more information, please contact tgullings@uttyler.edu.

Perspectives of caregivers and volunteers on *Stepping Stones* for people with dementia

Areum Han¹ and Diane Brown²

Abstract

Rationale: Current knowledge in experiences and potential benefits of group-based activity programmes on people with dementia and their caregivers is inconsistent, depending on the quality of interventions. Lacking standardisation in the programme's content and structure, therefore, requires research in a structured group-based activity programme with more details.

Objectives: This study explored perspectives of spouses of people with dementia and older volunteers about *Stepping Stones*, involving a theme-based activity group and a support group.

Methodology: Interpretative phenomenological analysis was used to analyse individual interview data with 12 people.

Results: Findings suggest that (1) *Stepping Stones* promotes participation of people with dementia in a happy, comfortable and accepting environment; (2) *Stepping Stones* fulfils a deep need of family caregivers; (3) *Stepping Stones* is well organised with a purpose and expertise and (4) The partnership between the community and the university makes the programme unique.

Conclusion: Programmes like *Stepping Stones* can be beneficial by promoting participation of people with dementia and fulfilling a need of caregivers. These findings contribute to evidence of group-based activity programmes, in which activities were well planned by a faculty and students in occupational therapy.

Keywords

Caregivers, community participation, dementia, qualitative research, social participation

Received 28 June 2018; accepted 15 October 2018

Introduction

The majority of people with dementia (PwD) live at home and family and friends provide unpaid assistance such as practical and emotional support to PwD (Alzheimer's Association, 2017). Family members are often the primary caregivers of community-dwelling PwD, and especially spouses who live together with PwD provide more hours of care and are likely to have poorer quality of life than other informal caregivers (Bruvik, Ulstein, Ranhoff, & Engedal, 2012). Caring for PwD has been found to have negative impacts on caregivers' health and well-being, but caregivers of PwD also reported positive experiences such as caregiver satisfaction and caregiving personal gains (Ask et al., 2014; Grover, Nehra, Malhotra, & Kate, 2017). Supporting informal caregivers and helping them have good caring experiences are important in order to maintain or improve their own health and well-being and reduce caregiver burden, possibly

delaying institutionalisation of their relatives with dementia, and thus promoting aging in place (Afram et al., 2014).

It is important to help PwD maintain a good quality of life as they go through challenges and changes due to the progression of dementia. Older adults with dementia are less likely to participate in activities including leisure and social activities compared to older adults

¹Department of Occupational Therapy, Yonsei University, Gangwon-do, Republic of Korea

²Department of Health and Kinesiology, Master of Occupational Therapy Program, University of Texas at Tyler, TX, USA

Corresponding author:

Areum Han, Department of Occupational Therapy, Yonsei University, 109 Baekwoon Hall, 1 Yonseidae-gil, Wonju, Gangwon-do 26493, Republic of Korea.

Email: ahan@yonsei.ac.kr



without cognitive impairment, and less activity is related to a lower quality of life in older adults with dementia (Johnson, Whitlatch, & Menne, 2014; Parisi, Roberts, Szanton, Hodgson, & Gitlin, 2015). The lack of daytime activities and social company of community-dwelling PwD are the most frequent unmet needs with psychological distress reported by people with dementia and their family caregivers (Miranda-Castillo, Woods, & Orrell, 2013).

Group-based activity programmes are available in the community for PwD as well as support groups for informal caregivers. Individually tailored activities matched to each person's abilities, interests and self-identity have been found to be beneficial for PwD, but group-based activity programmes are more common for people living with earlier stages of dementia in the community (Han, Radel, McDowd, & Sabata, 2016). Group-based activity programmes are harder to tailor activities to each individual's abilities and interests than one-on-one activity programmes. However, group activity programmes can give additional social benefits through participation in different leisure, social, and cognitive activities with a group of people who also have dementia (Cohen-Mansfield, Hai, & Comishen, 2017). Also, one-on-one social interactions during the group activities can occur. Activities of the group programmes should be planned well by considering overall membership of the group, along with a good understanding of activity modifications to promote engagement in activities while giving social connectivity with other PwD in the community. However, current knowledge in experiences and potential benefits of group-based activity programmes on PwD and their caregivers is inconsistent, depending on the quality of interventions (Tretteteig, Vatne, & Rokstad, 2016). Lacking standardisation in the programme's content and structure, therefore, warrant research in a structured group-based activity programme with more details.

Stepping Stones in Denton, Texas, USA started in 2005 for community-dwelling people with early to middle stages of dementia and their caregivers. The programme meets for 1.5 h on Wednesdays at a local church and the activity group and support group meet at the same time in separate rooms of the church. The activity group for PwD aims to provide opportunities for participation in activities and social interaction, and the support group for caregivers aims to provide support and education. Each meeting of the activity group is based on a theme that is familiar to members with dementia and usually calendar-based and seasonal, such as a New Year's theme in January and a 'Sweetheart' theme near Valentine's Day. Around each theme, activities are planned using music, sensory experiences, physical activity, conversation and props

to encourage participation of members with dementia in activities. Activities are graded by experts in occupational therapy (OT) (a retired occupational therapist and an occupational therapist/faculty) and students in OT to encourage members to participate in activities at various levels depending on each member's abilities and preferences.

Community volunteers who are older adults and graduate OT students assist in provision of services for the activity group. Older volunteers assist the group by facilitating participation of PwD during the group activities. OT students at Texas Woman's University (Denton campus) assist in planning and leading the programme activities with the guidance of a faculty member in School of OT at Texas Woman's University and a retired occupational therapist. Potential members with dementia are evaluated by an occupational therapist to understand cognitive and functional abilities of PwD and ensure a good match with assigned volunteers. Annual assessments with PwD are also conducted for follow-up. The family group is led by a local geriatric care manager who is also a licensed social worker.

The purpose of this qualitative study was to explore experiences and perspectives of family caregivers of PwD and older volunteers about *Stepping Stones*. The research question of the present study, thus, was 'how family caregivers of PwD and older volunteers experienced and thought about *Stepping Stones*?' Family caregivers have perspectives on both the activity group in which their family members with dementia participate, and the support group in which they join. Although family caregivers are not the 'insiders' of the activity group as they participate in the support group at that time, they are the 'insiders' of their own personal lives with the PwD. Family caregivers are able to express how *Stepping Stones* is experienced by family members with dementia in their day-to-day lives and what potential benefits the couples have from participation in the *Stepping Stones* programme overall. Older volunteers, as the 'insiders' of the activity group, have insights on the programme while they are working with PwD during the group activities. It was interesting and important to understand how *Stepping Stones* was experienced by family caregivers of PwD and older volunteers in the programme which was designed and run by experts and students in OT who graded activities to each of the members with dementia as much as possible with a structure in running the programme.

Methods

The present study was a qualitative study in which interviews with family caregivers and older volunteers were analysed using interpretative phenomenological

analysis (IPA; Smith, Flowers, & Larkin, 2009). IPA, as the methodology, guided the present study. IPA focuses on not only shared themes among cases but also the uniqueness of an individual's experience within that shared theme. Such in-depth analysis of single cases allows preserving the uniqueness of each individual's experience in their contexts while searching for patterns across cases. Also, IPA goes through a dual interpretation process, in which a researcher tries to make sense of what a participant meant.

Participants

Participants of the present study were 12 people including, four spousal caregivers (three women and one man) of people with dementia who participated in the *Stepping Stones* programme and eight older adults (six women and two men) who volunteered in the programme (pseudonyms used in Table 1). Spousal caregivers' ages ranged from 70 to 79 (mean: 72.8 years old) and older volunteers' ages ranged from 67 to 83 (mean: 73.2 years old) at the time of the interviews. Three spousal caregivers reported averaging more than 40 caregiving hours per week, and the remaining caregiver reported 8 caregiving hours per week or less. Older volunteers' years of volunteering in the *Stepping Stones* programme varied from 6 months to 10 years at the time of the interviews.

Procedures

The study was conducted with IRB approval from Texas Woman's University, USA (protocol #18962). We recruited participants by using purposive sampling. Each of the participants gave informed consent,

including consent for audio-recording of interviews. Face-to-face individual interviews with spousal caregivers took place in a quiet meeting room on the day of support group meetings for caregivers' convenience and individual interviews with older volunteers took place in the homes of older volunteers. All participants completed demographic information forms prior to beginning the interviews. All interviews with older volunteers were conducted in February and March 2016, and interviews with spousal caregivers were conducted in February 2017.

Interviews

We developed a semi-structured interview guide following recommendations of IPA methodology to use as a flexible general guide during the interview (Smith et al., 2009). Each interview began with a general question asking about the experience of participating (for spousal caregivers) or volunteering (for older volunteers) in the *Stepping Stones* programme and included open-ended questions with general, non-directive remarks used to encourage further explanation or elaboration on the initial statements about the experience. Minimal open-ended probes were used such as 'Can you tell me more about that?', 'What do you mean by that?' and 'How did you feel about that?' Further open-ended questions were used to seek information about the perceived impact of participating or volunteering in the *Stepping Stones* programme on themselves and people with dementia. The interviews with older volunteers lasted from 27 to 74 min (mean: 37 min) and interviews with spousal caregivers lasted from 15 to 21 min (mean: 17.5 min). Partial data of older volunteers were used in the present paper to focus on perspectives of volunteers

Table 1. Descriptions of spousal caregivers and older volunteers.

Caregiver	Age	Gender	Ethnicity	Years of education	Current employment	Caregiving hours per week
Mary	70	F	W	16	Retired	40+
James	79	M	W	22	Retired	40+
Linda	72	F	W	16	Retired	40+
Betty	70	F	A	16	Retired	8 h or less
Volunteer	Age	Gender	Ethnicity	Years of education	Current employment	Years of volunteering in the programme
Susan	80	F	W	14	Retired	5.5
Donna	68	F	W	16	Retired	5
Carol	71	F	W	18	Retired	5
Amy	67	F	W	16	Retired	10
Robert	83	M	W	18	Retired	5
Debra	75	F	W	14	Part time	.5
Joyce	71	F	W	12	Retired	1.3
David	70	M	W	15	Retired	7

A: Asian or Asian American; F: Female; M: Male; W: Non-Hispanic White.

with family caregivers on *Stepping Stones* programme, and other data of volunteers focusing on volunteering experiences were used in another paper (Han, Brown, & Richardson, 2018).

Data analysis

Audio-recorded interviews were transcribed verbatim and analysed following steps of IPA methodology (Smith et al., 2009). We read and reread each interview transcript closely and took notes for key points regarding content, language use, context, observations during interviews and initial interpretations. We then transformed notes into emerging themes and examined emergent themes to search for connections. After creating a list of themes for each interview transcript with all relevant quotes, we searched for repeating patterns and newly emerging issues across participants to identify shared themes (similarities) and individual differences within the shared themes. For example, keywords related to friendship, an accepting environment, programme activities and promoted participation (theme 1) were repeatedly noted on each interview transcript. All relevant quotes and keywords from transcripts were gathered together and searched for repeating patterns and newly emerging issues as we kept reading and reorganising. Keywords that were repeatedly found and that best described relevant concepts became emerging themes (i.e. friendship). Emergent themes were examined for connections, and closely relevant emerging themes were reorganised as subthemes under a major theme.

To increase the trustworthiness of the data analysis, we used several strategies suggested in IPA methodology (Smith et al., 2009). We used member checking during interviews through the process of reflecting and probing to verify that the interviewer understood what participants said and meant as interviews went deeper, documented the process showing how a participant's accounts were transformed to the themes and had meetings among researchers to check whether emerging themes were well grounded and represented in the transcripts. In addition, we constantly checked the interpretations and derived meanings against the transcript text to verify that the themes remained reflective of the transcript text, in an effort to increase analytical rigor.

Results

Table 1 describes characteristics of 12 participants of the present study (pseudonyms). Spousal caregivers' ages ranged from 70 to 79 (mean: 72.8 years old) and older volunteers' ages ranged from 67 to 83

(mean: 73.2 years old) at the time of the interviews. Four themes emerged (Figure 1).

Theme 1. *Stepping Stones* promotes participation of PwD

Family caregivers and older volunteers stated that *Stepping Stones* promoted participation of PwD and provided a happy, comfortable and accepting environment. In particular, the programme promoted friendship among PwD in a happy place where PwD felt accepted, comfortable and encouraged. Also, programme activities promoted feelings of achievement, enjoyment and use of remaining abilities and pleasant memories of PwD and encouraged participation of PwD in activities during and outside the programme.

Stepping Stones promotes friendship among PwD. Family caregivers and older volunteers reported that PwD developed new friendship and talked about how much they care about and encourage each other. New friendships formed in *Stepping Stones* replaced lost connections with former friends. For example, Mary and Linda talked about their husbands' 'lost connection with their former friends' because they became unable to participate in activities they used to do with their friends. As their 'abilities have decreased and people do not know how to react and respond to them', Mary and Linda reported that their 'husbands' friends now are other members with dementia' in *Stepping Stones* with whom their husbands 'feel equal'. Mary talked how much her husband cares about his friends in the programme, giving Mary a sense of joy and satisfaction in her husband's newly developed friendship: 'He talks about his friends all week long. He gets really concerned if they're not there. He wants to make sure they're okay, so it's been a wonderful help for him. I am grateful for it' (Mary).

Having similar abilities might help PwD in *Stepping Stones* develop closer friendships with specific members with dementia: 'My wife loves being with [the name of one male member with dementia]. She says [his name] and I are at the same stage, so she loves being with him. She found a friendship there, somebody she can connect with.' (James) and 'He has one good buddy in the group. They really are friends and they enjoy each other's company a lot. They're about at the same level and people can't separate them in the group. It's good to have a friend' (Mary). Having friendship with other members with dementia motivated Linda's husband to take a bath to go to the programme. Linda talked about her difficulty in getting him to take a bath. After she told him that he could not go to *Stepping Stones* without taking a bath, the couple's 'major

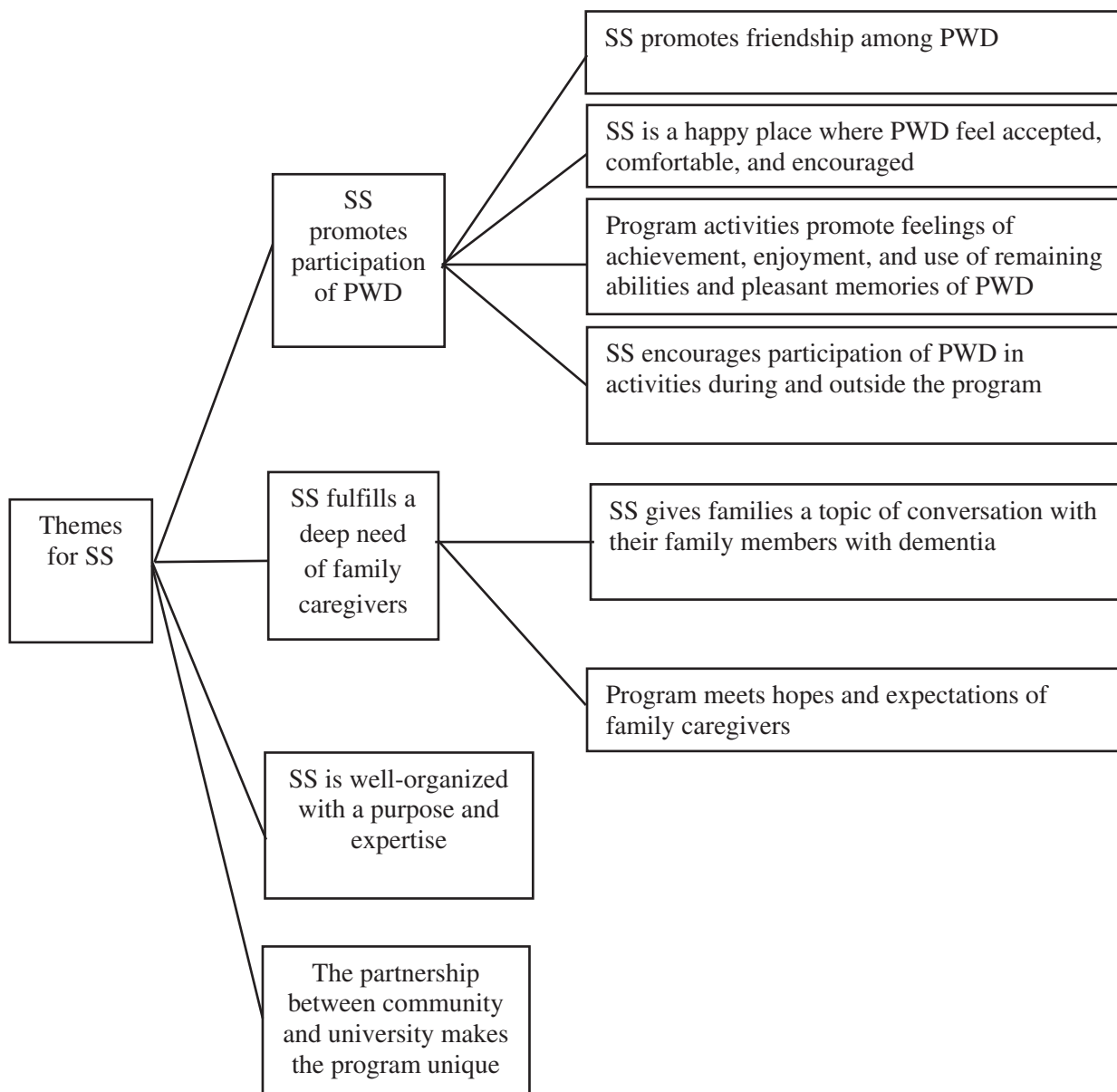


Figure 1. Themes for *Stepping Stones* (SS). This figure illustrates four themes and six subthemes that emerged from the perspectives of family caregivers of people with dementia (PWD) and older volunteers.

battle' in getting him to take a bath became resolved: 'He started taking a bath willingly and was anxious to go and pick out his shirt to wear because he really enjoys the people there. That's a biggie for him. He has what he calls really good friends there' (Linda).

Stepping Stones is a happy place where PwD feel accepted, comfortable and encouraged. Family caregivers stated that PwD feel 'accepted, comfortable, and motivated' in *Stepping Stones*. For instance, Mary said that 'getting together with people who have similar challenges and feelings' made Mary's husband 'feel accepted'. Also, Mary believed that 'people in the program did not expect her husband to know

facts and information that he was not capable of knowing' by understanding PwD, so 'he could feel accepted and valued' in *Stepping Stones*. Similarly, Linda mentioned that her husband feels comfortable in *Stepping Stones* because people in the programme encourage him to participate in activities that are matched with his abilities, so he is not overwhelmed: 'He's very proud of all the little projects that they make, and he feels very comfortable there because of their praising and encouragement. I think it makes him feel comfortable and function at his level, so, he's not overwhelmed' (Linda). Such comfortable and encouraging environment might contribute to Linda's better emotional

health: 'He's happier and he's more outgoing and he's just satisfied. He's not antsy and pacing and he's at peace, I think. I know emotionally he's better off than he was before' (Linda).

Similarly, older volunteers said that *Stepping Stones* provides PwD with a happy place where PwD feel comfortable and understood and function at their best. Expressions by these volunteers include: 'They are in a group that is comfortable for them not to be scared and to be able to react and talk freely without feeling different because they're with a group just like them and they can feel comfortable' (Donna); and 'They're in a world that understands them, so they function as best they can which sometimes is just stellar' (Amy). Volunteers' strategy in giving the right challenge might also contribute to making *Stepping Stones* a happy place where PwD feel comfortable, satisfied, valuable and motivated by encouraging independence as much as each person is able, and giving help when needed, before the person feels overwhelmed.

Programme activities promote feelings of achievement, enjoyment and use of remaining abilities and pleasant memories of PwD. Family caregivers and older volunteers reported that PwD could feel achievement/self-worth and enjoyment by participating in programme activities. Expressions related to activities giving PwD feelings of achievement and self-worth include: 'Activities requiring different skills make him feel as if he has some worth. He's very proud of the little crafts that he does in *Stepping Stones* and brings home' (Mary); and 'She's very proud of the little things that they make in the crafts, and she will put them on the front of the refrigerator where she can admire it and this is her handiwork' (James). How much PwD enjoy the activities also has been emphasised: 'They enjoy activities in the program. I would not be able to do that for him. Even if I tried, he would not participate at home' (Betty).

Family caregivers and older volunteers also talked about programme activities that promote use of remaining abilities and pleasant memories of PwD, possibly leading to delaying the disease progression. Expressions include: 'I'm sure that all activities in the program are designed to stimulate memories and get the patients to pull up those memories. I simply assume that she's not declining as rapidly as she otherwise would have with the activities' (James); 'I think it's very important to have the variety of activities they have. It has made a huge difference in his ability to continue to function. I think *Stepping Stones* is very responsible for slowing down progress and improving him' (Linda) and 'Activities in the program can bring up some memories, so the activities helped them have some pleasant memories' (Donna).

Stepping Stones encourages participation of PwD in activities during and outside the programme. Family caregivers said that *Stepping Stones* became something for their family members with dementia to look forward to: 'The best part of the program is that he can be involved in it. It gives him someplace to go, something to do, something to look forward to. He's eager to go and looks forward to Wednesday' (Mary); 'She looks forward to going to the program' (James); and 'He really looks forward to it' (Linda). Going to *Stepping Stones* might afford a rare opportunity for their family members with dementia to willingly go out and participate in different activities in a comfortable place: 'It's an outing for him. He can get out and he can feel good about his activity' (Mary). Some family caregivers compared typical routine of their family members to the day of *Stepping Stones*. For instance, Linda talked about her husband's typical day sitting and watching TV at home without hobbies. Wednesday was the only day of the week when he actively participates in different activities outside home.

Some family caregivers talked about difficulties in encouraging their family members to do self-care, but PwD were highly motivated to do self-care on Wednesdays when they come to *Stepping Stones*. For example, Mary said that 'Showers are not always easy to get him to take, but he takes a shower that morning and put on a clean shirt. He has two markers in the week. Wednesday is *Stepping Stones* and Sunday is church'. Similarly, Betty said that her husband stays in bed until the afternoon, but his routine starts in the morning on *Stepping Stones* days.

Family caregivers reported that they feel better when they see their family members participate in *Stepping Stones* and enjoy their time. For example, Betty worried that her husband did not want to do anything because of depression, it was depressing for her to watch him have nothing to do, stay home, and watch TV. However, her husband's participation in the programme and enjoyment made her feel relieved: 'I feel better when I see him participating instead of watching TV. He loves puzzle, games, and word-searches in the program. Before he did nothing and wouldn't even talk to me. I mean it's depression. That really worried me' (Betty). Betty believed that not being able to do what he used to do might reduce his confidence and motivation in participating in activities. However, people in *Stepping Stones* motivated him to participate in activities by giving direct guidance in what he needs to do to participate in activities in a comfortable place where he does not have to compete with other people without dementia.

Theme 2. *Stepping Stones* fulfils a deep need of family caregivers

Family caregivers reported that *Stepping Stones* fulfilled their deepest needs. The programme gave families a topic of conversation with their family member with dementia and family caregivers received ongoing support through the support group while their family members with dementia enjoyed their time in the activity group. Also, family caregivers stated that the programme met their hopes and expectations.

Stepping Stones gives families a topic of conversation with their family members with dementia. Some family caregivers stated that their family members' participation in *Stepping Stones* gave their family something to talk about and share. As an example, Mary's husband talked with her about the activities he did in the programme. Mary said that *Stepping Stones* gave her something to talk about with her husband and having a topic of conversation has been meaningful to her: 'We've been married over 51 years and there were many things we could discuss. As time goes on, things we can talk about have really diminished. *Stepping Stones* is something we can talk about, giving me another talking point' (Mary). Sharing what he did in the programme occurred not only with Mary but also with their children when they visit on weekends. Their children asked what he did in *Stepping Stones*, and Mary helped him talk about it by triggering his memories. Mary's husband left the crafts he made on the cabinet for a week, so their children could see the crafts and ask him to talk about the crafts.

Support is ongoing for family caregivers. Family caregivers expressed how helpful it was for them to get support through the support group, while their family members were enjoying their time in the activity group. Varied benefits of attending the support group were reported by family caregivers. These perceived benefits include the following: emotional support by being with and expressing emotions with other caregivers; a better understanding about dementia by sharing information; being more patient and calm through understanding better about dementia and coping with living with PwD and having a little rest to get some relief from all that stress as caregivers and enjoying socialisation. Examples of reported benefits by family caregivers include: 'I desperately need the support group. That is so valuable of being with people who are facing the same problems, so we're not alone. I get support. We feel free to express emotions. It's family. It really is' (James); 'Oh, well, I have much more peace and calm in dealing with my husband, much more accepting of what he can and can't do and what he's responsible for and not responsible for. And, I'm

happier and he's happier' (Linda); 'It's a lot of information sharing. That is the most important thing' (Betty); and 'I've gained all that information and I've learned to be more patient' (James).

Programme meets hopes and expectations of family caregivers. Family caregivers said that their hopes that *Stepping Stones* would be beneficial to their family members and themselves have been met. Family caregivers joined the programme because their psychiatrists recommended it or they heard good things about it from other caregivers. At the beginning, they did not have particular expectations other than the programme might help their family members and themselves: 'I really had no expectations because I didn't quite know. I was hoping that it would be something beneficial to my husband' (Mary); and 'The psychiatrist told me about *Stepping Stones* and I thought it would be really good for him. I was hoping to get some of old [his name] back or just not get worse. I needed to help myself too' (Linda). Family caregivers stated that their hopes have been fully met or exceeded by discovering benefits to their family members or themselves: 'My expectations have more than been met. Just way beyond' (Betty).

Theme 3. *Stepping Stones* is well organised with a purpose and expertise

Older volunteers regarded *Stepping Stones* as a well organised, structured programme with purpose and expertise behind the planned activities. For example, Susan and Amy talked about having experts in dementia, and planning programme activities matched to abilities and interests of PwD make a big difference in *Stepping Stones* from other programmes: 'There are other programs without expertise, but we have experts in occupational therapy. It can make a big difference because we have somebody familiar with the disease to make activities understandable to PwD and enjoyable rather than dread' (Susan); and 'There's behind the scenes work to prepare for the activities that are not too challenging but can give some sense of completion' (Amy). Carol, Amy and Joyce reported that the programme is very well organised with well-planned activities and a well-organised structure that helps PwD know what to expect, become familiar with that structure and motivate PwD. Amy and Susan also believed that the activities have the purposes of promoting socialisation, accomplishment, hand mobility and feelings of being useful and helpful by making and giving something to the community such as a hospice organisation.

Theme 4. Partnership between the community and the university makes the programme unique

Older volunteers and family caregivers stated that involving students who will be future occupational therapists made *Stepping Stones* unique. Older volunteers emphasised that *Stepping Stones* is a wonderful learning experience for students because students directly work with older adults with dementia and get feedback from the professor who is the director of the programme, right after each week's programme activities: 'The best part of the program is student community interaction. That's what makes it unique. Students learn and get feedback about how it went. That is so important. It's a wonderful learning experience for students' (Joyce).

Volunteers talked about how well the students were doing in making and organising programme activities and working with PwD, and how much PwD in the program enjoyed working with students: 'The students do a good job of facilitating and organizing. Most of the time they do, and they're very friendly to PwD' (Carol); 'The students that have come up with the activities are amazing' (Debra); 'He [one member with dementia] enjoyed working with the students a lot getting their encouragement' (Amy); 'The student coordinator [a graduate assistant] is very vital and incredible with good personality. Both volunteers and students are needed to make such a good solid program' (Joyce). Some volunteers observed students' growth in working with PwD by realising how individuals with dementia are different, how fun it is to work with PwD, and knowing PwD as people: 'Students might feel a little scary at the beginning but became ease and see individual differences in PwD. They realized that how fun and nice it is to work with PwD. Student just get to know PwD as people' (Amy).

Family caregivers also talked about their family members' close relationship with and affection toward the students: 'There was one student who was in charge over there, and she loved him [the student coordinator]. He was such a nice fellow. I think it was good for her to feel the affection for him' (James); and 'He enjoys the students that help and the adults who volunteer. All of them are very kind and very involved with him personally. That's really important. It just seems to be their heart in action' (Linda).

Discussion

The present paper found some potential benefits of *Stepping Stones* on PwD including encouraging participation in activities and newly developed friendships of

PwD in a happy place where they felt comfortable and accepted while participating in activities promoting feelings of achievement, enjoyment and use of remaining abilities and pleasant memories. Similar findings from a social recreation group for community-dwelling PwD included established friendships among PwD, having fun and feeling at comfortable and safe within the group (Phinney & Moody, 2011). Literature supports the association between more activity and a higher quality of life in older adults with dementia (Johnson et al., 2014), and older adults with dementia tend to have less activities and lose connections with friends whom they formerly joined for leisure and social activities, as their cognitive abilities decreased due to dementia, similar to PwD in *Stepping Stones*, as reported by family caregivers (Stokes, Combes, & Stokes, 2014). Programmes promoting participation in activities and positive socialisation of community-dwelling people are needed to help them live at home with a good quality of life as long as possible.

The present study found some possibility that programmes like *Stepping Stones* can provide a topic of conversation with their family members with dementia and emotional and practical support to families. Spousal caregivers may experience a lack of common shared experiences with their spouses with dementia due to their decreased cognitive abilities, possibly leading to a loss of emotional closeness and reciprocal interactions (Boylstein & Hayes, 2012). Programmes involving a variety of activities tailored for PwD, like *Stepping Stones*, may help the family be connected and interact more by sharing experiences of PwD in the activity programme. Also, spouses of PwD may need emotional support more than other family caregivers such as daughters and sons (Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010). Support groups for caregivers have been found to provide positive emotional support and strategies in how to cope with everyday challenges in caring for PwD and help them release negative feelings (Lauritzen, Pedersen, Sørensen, & Bjerrum, 2015).

An integrated review found that day care centres for PwD, functioning as a respite and support service, can benefit family caregivers by reducing their burden, increasing motivation for care and giving them feelings of relief and safety (Tretteteig et al., 2016). The review, however, concluded that current knowledge is inconsistent and tentative, needing more research in this area. Since *Stepping Stones* is run for 1.5 h per week, findings of *Stepping Stones* may not be generalised to the findings of day care centres that run for more hours per day and more frequently per week. However, the present study's findings are important because programmes, such as *Stepping Stones*, which do not last as long as day care centres can still have potential positive

benefits. Some findings in the present study support similar benefits of day care centres for PwD on family caregivers such as promoting participation of PwD in activities, giving the family something to talk about and reducing care burden in self-care by motivating PwD on the day they attend the programme (Tretteteig, Vatne, & Rokstad, 2017).

Family caregivers and older volunteers reported that some features of *Stepping Stones* made the programme unique and possibly different from other programmes. *Stepping Stones* was regarded as a well organised, structured programme that has some purpose and expertise behind the planned activities. Making modifications to activities becomes necessary for PwD as their cognitive abilities decrease. Changes made to demands of activities by breaking down activities into steps, using specific verbal and non-verbal prompts and praise, and introducing activities matched to the interests of PwD can increase engagement (Trahan, Kuo, Carlson, & Gitlin, 2014). In particular, positive human social interactions especially tailored to the abilities and interests of PwD are important to increase engagement, mood and behaviour of PwD (Cohen-Mansfield, Thein, Dakheel-Ali, Regier, & Marx, 2010). Family caregivers tend to regard the quality programme for PwD as the one with activities considering abilities of PwD and giving social interaction and pleasure, and with professionals' expertise in PwD and tend to use services when they believe the programme is helpful for their relatives with dementia (de Jong & Boersma, 2009; Donath, Winkler, Graessel, & Luttenberger, 2011). Evaluating the cognitive and functional abilities of members with dementia, before the PwD joins *Stepping Stones* and annually thereafter, has a positive effect on programme activity development. Also, older volunteers have demonstrated flexibility in working with individual members one-on-one, especially for those members with lower abilities who may need more assistance.

Older volunteers and family caregivers believed that involving students made the *Stepping Stones* programme unique. Some studies found that university students can benefit from participating in programmes working with PwD, and these benefits include improved attitudes toward PwD and community involvement, better understanding about dementia and reduced stigma (Corwin, Owen, & Perry, 2008; Harris & Caporella, 2014; Kaf, Barboa, Fisher, & Snavely, 2011). As the older volunteers said, *Stepping Stones* can be a wonderful learning experience for OT students. Establishing collaborations with a university may facilitate development of a sustainable community-based programme for PwD in which students also benefit from involvement as a part of course or a service learning programme. Research is needed to

understand benefits of *Stepping Stones* on involved students. Family caregivers also talked about their family members' close relationship with and affection toward the students. Involving students in activity programmes might make the experiences of PwD in programmes more fun and enjoyable by having intergenerational interaction with young adults (Harris & Caporella, 2014).

Since *Stepping Stones* is a group-based activity programme, challenges in matching the abilities and interests of all PwD have been reported from some volunteers. For example, volunteers stated that some activities were too hard for some PwD with more progressed dementia and suggested getting feedback from PwD and their spouses/caregivers on programme activities to identify the interests of PwD better. Ongoing efforts should be made to tailor group-based activity programmes to match the abilities and interests of PwD as much as possible. Further experimental research with the optimal sample size to detect statistical significance, such as a randomised controlled trial, is needed to measure effectiveness of *Stepping Stones* on people with dementia, family caregivers and volunteers.

Our findings may be generalisable to other cultural and geographical areas by modelling *Stepping Stones* and making modifications in the activity group's themes based on their own cultures as needed. Collaboration may be welcomed by universities and older volunteers in other cultural and geographical areas as higher education has emphasised service learning and social participation of older adults are encouraged for quality of life and psychosocial well-being.

Conclusion

Community-based programmes are needed to enable community-dwelling PwD and their caregivers to achieve full participation in meaningful activities and positive social relationships with others. Findings of the present study support that a community-based programme like *Stepping Stones* can be beneficial to PwD and their family caregivers by promoting participation of PwD in a happy and comfortable place and fulfilling a need of family caregivers. Programme characteristics which seem to contribute to maximising such benefits include having activities that are well organised, planned with a purpose and expertise, and involving OT students in the programme. Programmes for community-dwelling PwD and family caregivers like *Stepping Stones* may help both PwD and family caregivers have increased quality of life and promote aging in place as long as possible.

The present study's positive findings contribute to evidence base of group-based activity programmes for

PwD in which programme activities were well planned by a faculty and students in OT. More research is needed to give a better understanding of the most beneficial programme characteristics for community-dwelling PwD and their informal caregivers, how best to tailor group-based activity programmes to match the abilities and interests of PwD as much as possible and how to create various types of sustainable and beneficial community programmes to meet the unique needs of PwD and caregivers.

Acknowledgments

We appreciate the support of the board members of the *Stepping Stones* programme for the research process and all the study participants. We thank Amber Richardson for interviewing family caregivers.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The research project of this paper was supported by Texas Woman's University Small Grant Program (the grant number: N/A, the name of the principal investigator: Areum Han).

References

- Afram, B., Stephan, A., Verbeek, H., Bleijlevens, M. C., Suhonen, R., Sutcliffe, C., & Hamers, J. H. (2014). Reasons for institutionalization of people with dementia: Informal caregiver reports from 8 European countries. *Journal of the American Medical Directors Association, 15*(2), 108–116. doi:10.1016/j.jamda.2013.09.012
- Alzheimer's Association. (2017). 2017 Alzheimer's disease facts and figures. Retrieved from http://www.alz.org/documents_custom/2017-facts-and-figures.pdf
- Ask, H., Langballe, E. M., Holmen, J., Selbæk, G., Saltvedt, I., & Tambs, K. (2014). Mental health and wellbeing in spouses of persons with dementia: The Nord-Trøndelag Health Study. *BMC Public Health, 14*, 413. doi:10.1186/1471-2458-14-413
- Boylstein, C., & Hayes, J. (2012). Reconstructing marital closeness while caring for a spouse with Alzheimer's. *Journal of Family Issues, 33*(5), 584–612. doi:10.1177/0192513X11416449
- Bruvik, F. K., Ulstein, I. D., Ranhoff, A. H., & Engedal, K. (2012). The quality of life of people with dementia and their family carers. *Dementia and Geriatric Cognitive Disorders, 34*(1), 7–14. doi:10.1159/000341584
- Cohen-Mansfield, J., Hai, T., & Comishen, M. (2017). Group engagement in persons with dementia: The concept and its measurement. *Psychiatry Research, 251*, 237–243. doi:10.1016/j.psychres.2017.02.013
- Cohen-Mansfield, J., Thein, K., Dakheel-Ali, M., Regier, N. G., & Marx, M. S. (2010). The value of social attributes of stimuli for promoting engagement in persons with dementia. *Journal of Nervous and Mental Disease, 198*(8), 586–592. doi:10.1097/NMD.0b013e3181e9dc76
- Corwin, M., Owen, D., & Perry, C. (2008). Student service learning and dementia: Bridging classroom and clinical experiences. *Journal of Allied Health, 37*(4), e278–e295.
- de Jong, J. D., & Boersma, F. (2009). Dutch psychogeriatric day-care centers: A qualitative study of the needs and wishes of carers. *International Psychogeriatrics, 21*(2), 268–277. doi:10.1017/MARY041610208008247
- Donath, C., Winkler, A., Graessel, E., & Luttenberger, K. (2011). Day care for dementia patients from a family caregiver's point of view: A questionnaire study on expected quality and predictors of utilisation – Part II. *BMC Health Services Research, 11*, 76. doi:10.1186/1472-6963-11-76
- Grover, S., Nehra, R., Malhotra, R., & Kate, N. (2017). Positive aspects of caregiving experience among caregivers of patients with dementia. *East Asian Archives of Psychiatry, 27*(2), 71–78. Retrieved from <http://www.easap.asia/>
- Han, A., Brown, D., & Richardson, A. (2018). Older adults' perspectives on volunteering in an activity-based social program for people with dementia. *Activities, Adaptation & Aging*. Epub ahead of print 18 July 2018. doi:10.1080/01924788.2018.1500055
- Han, A., Radel, J., McDowd, J., & Sabata, D. (2016). The benefits of individualized leisure and social activity interventions for people with dementia: A systematic review. *Activities, Adaptation, and Aging, 40*(3), 219–265. doi:10.1080/01924788.2016.1199516
- Harris, P. B., & Caporella, C. A. (2014). An intergenerational choir formed to lessen Alzheimer's disease stigma in college students and decrease the social isolation of people with Alzheimer's disease and their family members: A pilot study. *American Journal of Alzheimer's Disease and Other Dementias, 29*(3), 270–281. doi:10.1177/1533317513517044
- Johnson, J. D., Whitlatch, C. J., & Menne, H. L. (2014). Activity and well-being of older adults: Does cognitive impairment play a role? *Research on Aging, 36*(2), 147–160. doi:10.1177/0164027512470703
- Kaf, W. A., Barboa, L. S., Fisher, B. J., & Snavely, L. A. (2011). Effect of interdisciplinary service learning experience for audiology and speech-language pathology students working with adults with dementia. *American Journal of Audiology, 20*(2), S241–S249. doi:10.1044/1059-0889(2011/10-0025)
- Lauritzen, J., Pedersen, P. U., Sørensen, E. E., & Bjerrum, M. B. (2015). The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: A systematic review. *JBIC Database of Systematic Reviews and Implementation Reports, 13*(6), 373–433. doi:10.11124/jbisrir-2015-2121
- Miranda-Castillo, C., Woods, B., & Orrell, M. (2013). The needs of people with dementia living at home from user, caregiver and professional perspectives: A cross-sectional

- survey. *BMC Health Services Research*, 13, 43–53. doi:10.1186/1472-6963-13-43
- Parisi, J. M., Roberts, L., Szanton, S. L., Hodgson, N. A., & Gitlin, L. N. (2015). Valued activities among individuals with and without cognitive impairments: Findings from the National Health and Aging Trends Study. *The Gerontologist*, 57(2), 309–318. doi: 10.1093/geront/gnSusan44
- Peeters, J., Van Beek, A., Meerveld, J., Spreeuwenberg, P., & Francke, A. (2010). Informal caregivers of persons with dementia, their use of and needs for specific professional support: A survey of the National Dementia Programme. *BMC Nursing*, 9, 9. doi:10.1186/1472-6955-9-9
- Phinney, A., & Moody, E. M. (2011). Leisure connections: Benefits and challenges of participating in a social recreation group for people with early dementia. *Activities, Adaptation and Aging*, 35(2), 111–130. doi:10.1080/01924788.2011.572272
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method, and research*. London, England: Sage Publications.
- Stokes, L. A., Combes, H., & Stokes, G. (2014). Understanding the dementia diagnosis: The impact on the caregiving experience. *Dementia*, 13(1), 59–78. doi:10.1177/1471301212447157
- Trahan, M. A., Kuo, J., Carlson, M. C., & Gitlin, L. N. (2014). A systematic review of strategies to foster activity engagement in persons with dementia. *Health Education and Behavior*, 41(1), 70S–83S. doi:10.1177/1090198114531782
- Tretteteig, S., Vatne, S., & Rokstad, A. M. (2016). The influence of day care centres for people with dementia on family caregivers: An integrative review of the literature. *Aging and Mental Health*, 20(5), 450–462. doi:10.1080/13607863.2015.1023765
- Tretteteig, S., Vatne, S., & Rokstad, A. M. (2017). The influence of day care centres designed for people with dementia on family caregivers – A qualitative study. *BMC Geriatrics*, 17(1), 5. doi:10.1186/Mary2877-016-0403-2