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Experiences of Caregivers in a Dementia Simulation Program

Areum Han^a  and Diane Brown^b

^aDepartment of Occupational Therapy, Yonsei University, Republic of Korea; ^bDepartment of Health and Kinesiology, University of Texas at Tyler, Texas, USA

ABSTRACT

Objectives: Simulation-based training has been used in health care to increase clinical knowledge and skills and understanding the experience of others. There is a lack of research in exploring experiences of caregivers of people with dementia in a dementia simulation program and its potential benefits on caregivers. The purpose of this qualitative study was to explore experiences of caregivers of people with dementia who participated in a dementia simulation program, called Dementia Live™.

Methods: Fourteen caregivers were interviewed after participation in DL, and thematic analysis using NVivo 11 software was used.

Results: Three themes emerged, including: (i) the Dementia Live™ as an eye-opening experience; (ii) the perceived benefits of the Dementia Live™ on themselves; and (iii) recommendation of the Dementia Live™ to other caregivers.

Conclusions: Dementia simulation programs such as the Dementia Live™ may help caregivers to have more empathy, understand better about the behaviors and feelings of people with dementia, and to use strategies that can help when working with people with dementia. Further experimental research is needed to examine effectiveness of the dementia simulation program on caregivers and people with dementia.

KEYWORDS

Alzheimer's disease; caregivers; dementia; empathy; simulation training

Introduction

Simulation-based training has been widely used in health care to increase clinical knowledge and skills and understanding of experiences of others (Mawson, 2014; Merryman, 2010). Simulation is defined as a “a technique to replace or amplify real experiences with guided experiences, often immersive in nature, that evoke or replicate substantial aspects of the real world in a fully interactive fashion” (Gaba, 2007, p. 126). With the increasing number of people with dementia, the need for better educating care partners of people with dementia, including informal and formal caregivers, has increased (Alzheimer's Association, 2017). Because care partners have not personally experienced dementia-related challenges, they may not understand and empathize with persons with dementia. Care partners of people with dementia may gain a better understanding of living with dementia by experiencing dementia-related challenges in a dementia simulation program.

Understanding the world from the perspective of people with dementia, or empathy, is important for person-centered dementia care (Brooker, 2006; Dementia Initiative, 2013). The level of empathy of caregivers of people with dementia is related to the quality of care and has the greatest influence on caring behaviors (Yun & Ryu, 2015). Empathy can strengthen the motivation of caregivers to comfort and help people with dementia, and can be improved by training (Samra, Griffiths, Cox, Conroy, & Knight, 2013). Lecture-based education on empathy, however, has a limited effect, and it can also cause an inexperienced mechanical sympathetic reaction and break the relationship with people with dementia (Maddry et al., 2014). Simulation-based education can be useful in developing empathy and empathetic behaviors (Bearman, Palermo, Allen, & Williams, 2015).

The Dementia Live™ (DL) program, developed by the AGE-u-cate Training Institute, USA,

aims to give a realistic simulation of living with dementia to help people understand symptoms, feelings, emotions, and behaviors of people with dementia. The entire DL program takes about 30–40 min and has three sessions, including the preparation session (10 min), the experience room session (7 min), and the empowerment session (15–20 min).

During the preparation session, a small group of participants (up to four) don specially designed and tested headphones with MP3 players, eyewear, and gloves imitating sensory, perceptual, or cognitive changes associated with dementia, and thus possibly resulting in emotional, cognitive, and behavioral changes. Headphones with MP3 players playing noises and sounds from televisions and radios are used to confuse participants by affecting their attention level and hearing. The eyewear is used to restrict participants' peripheral vision and gloves are used to diminish their sense of touch and fine motor skills.

Right before entering the experience room, each of the participants is told different five daily tasks to complete in the experience room. When reading the list of tasks, a trained person stands side to side with the participant and gently places his or her hand on the participant's shoulder, not looking directly at the participant. This challenges the participant by not allowing the participant to see lips moving and comprehend more of what the trained person is saying and emphasizes the importance of eye contact and clear speech. Four different versions of five tasks are used, so none of the participants is given the same task. Examples of the daily tasks include: taking the checkbook from the purse and putting it on the table; taking Tuesday noon pill; and sorting the silverware into the tray. The experience room is set up with needed items and unneeded items for task completion. Participants' behaviors are being observed by a trained observer who takes notes on the observation form of the manual with the list of tasks and behaviors. The list of behaviors includes: asking for help; following (following someone else and doing what he or she does); gathering (holding onto or collecting things); giving up/shutting down; an expression of negative self-image, frustration, anger, and

confusion; rummaging; talking to self; and wandering. These behaviors may be exhibited by people with dementia as expressions of their needs to understand and make sense of their environment and find purpose in the moment. After approximately 7 min, participants are told by the observer the experience is over and they will be led to the empowerment area for post experience discussion.

In the empowerment session, a trained coach from the DL program starts the small group discussion about how they felt and experienced during the experience room session and expands on their reactions by using prompts, including "why did you feel that way? what happened? what part of the experience contributed to that feeling?" The group discusses their performance, reactions, and behaviors in the experience room and why people with dementia might be exhibiting some of the behaviors (e.g., wandering and giving up). The last part of the empowerment session is to discuss why and what changes in care strategies for people with dementia are needed by relating participants' experiences in the experience room into participants' daily interactions with people with dementia. Related strategies discussed in the empowerment session include communications with people with dementia, understanding, and identifying unmet needs of people with dementia expressed by behaviors, and making changes in environment and tasks to reduce challenges due to dementia and encourage participation in daily activities.

The DL program is based on person-centered dementia care, need-driven, dementia-compromised behavior model, and experiential learning model. Participants enter the world of the person with dementia by experiencing similar feelings and behaviors of people with dementia in the experience room and reflecting on their experiences from the perspectives of people with dementia in the empowerment session. The need-driven, dementia-compromised behavior model views challenging behaviors of people with dementia as expressions of unmet needs in part and empathizes influences of physical and social environment (i.e., noise, lighting, crowding, and staff stability) on behaviors of people with dementia and their participation in daily activities

(Algase et al., 1996; Kolanowski, Litaker, & Buettner, 2005). Equipment, settings of the experience room, and the way the tasks are given interrupt participants with information processing and task performance, and thus possibly resulting in emotional, cognitive, and behavioral changes. Experiencing learning is learning through experience and reflection on experience, involving a process of taking and interpreting the experiences with personal thoughts and emotions, and planning new actions based on their experiences and interpretations (Kolb, 1984; Yardley, Teunissen, & Dornan, 2012). The empowerment session facilitates a participant's reflection on what he or she experienced and felt from the experience room session and discussion on changes in care strategies for people with dementia based on their DL experience.

There is a lack of research in exploring experiences of care partners of people with dementia in a dementia simulation program and its potential benefits on care partners. One survey study examined changes in perspective of health professionals who participated in a similar dementia simulation program (Beville, 2002). No research, however, has been done to explore caregivers' experiences in a dementia simulation program. A qualitative study using interviews is needed to have in-depth understanding of experiences of caregivers of people with dementia in a dementia simulation program. Thus, the purpose of this qualitative study was to explore the experiences of caregivers of people with dementia who participated in the DL program by using individual interviews.

Methods

Participants

A total of 14 caregivers participated in the present study, including ten formal caregivers who worked in an assisted living and memory care setting in Denton, Texas, USA, and four informal caregivers of people with dementia who attended a support group in Denton, Texas, USA. Table 1 describes characteristics of all 14 caregivers who participated in the present study. Formal caregivers included nine females and one male with a

Table 1. Characteristics of participants.

Categorical variable	<i>n</i>	%
Gender		
Male	2	14.3
Female	12	85.7
Ethnicity/race		
Non-Hispanic White	7	50.0
Hispanic or Latino	6	42.9
Black or African American	1	7.1
Marital status		
Married/living with a partner	7	50.0
Single/never married	5	35.8
Divorced/separated	1	7.1
Widowed	1	7.1
Caregiving relationship		
Paid caregiver	10	71.5
Spouse/partner	2	14.3
Daughter	1	7.1
Friend	1	7.1
Caregiving hours per week		
≥40 h	10	71.5
21–39 h	0	0.0
9–20 h	1	7.1
≤8 h	3	21.4
Employment status		
Employed full time	12	85.7
Retired	2	14.3
Numerical variable	Mean (SD); range	
Age	43.4 (17.3); 20–70	
Years of education	14.6 (2.6); 10–18	

mean age of 35.5 years old (range: 20–57 years old). Formal caregivers described themselves as Hispanic or Latino (five caregivers), non-Hispanic White (four caregivers), and African American (one caregiver). Informal caregivers included three females and one male with a mean age of 63 years old (range: 60–70 years old). The majority of the informal caregivers described themselves as non-Hispanic White (three caregivers) and the remaining caregiver as Hispanic or Latino. The informal caregivers were either spouses of people with dementia (two caregivers), a daughter (one caregiver), or a friend of people with dementia (one caregiver).

Procedure

The study was conducted with Institutional Review Board (IRB) approval from Denton campus of Texas Woman's University, USA (protocol no. 19088). Participants were recruited using convenience sampling. Invited participants included formal caregivers who worked in an assisted living and memory care setting in Denton, Texas, USA and informal caregivers of people with dementia who attended a support group in Denton, Texas, USA. Each of the

participants gave informed consent, including consent for audio-recording of interviews, and completed demographic information forms. Face-to-face individual interviews with each of the participants took place about three weeks after they participated in the DL program to explore their experiences in the program and perceived impact of participation in the program on their daily lives and day-to-day interactions with people with dementia. Individual interviews with the formal caregivers took place in a quiet meeting room of the setting where the formal caregivers worked and individual interviews with the informal caregivers took place in a quiet room of the place where the support group met weekly. The informal caregivers participated in the DL program in mid-February, 2017, and were interviewed in early March, 2017. The formal caregivers participated in the DL program in early March, 2017, and were interviewed in late March, 2017.

Interviews

A semi-structured interview guide was developed to use as a flexible general guide during the interview. Each interview began with a general question asking about the experience of participating in the DL program: “Could you tell me about your experience of participating in the program?” Further open-ended questions were used to explore the perceived impact of participating in the DL program on their daily lives, understanding of dementia and people with dementia, and strategies in caring for people with dementia. These questions included: “How do you think participating in the program has affected you?”; “How do you think participating in the program has affected your understanding in dementia and people with dementia?”; and “How do you think participating in the program has affected your strategy in caring for people with dementia?” 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?” The interviews lasted from seven to 26 min (mean: 14 min).

Data analysis

Audio recorded interviews were transcribed verbatim and thematic analysis using NVivo 11 software (QSR International Pty Ltd.) was used to analyze each interview transcript. The data analysis process involved using auto coding function to start coding under each of the interview questions, creating and coding at thematic nodes, and reviewing and reorganizing thematic nodes for final themes. To increase the trustworthiness of the data analysis including credibility and transferability, member checking was used during interviews through the process of reflecting and probing and meetings among researchers were held to check whether emerging themes were well-grounded and represented in the transcripts. In addition, Interpretations and derived meanings against the transcript text were constantly checked to verify that the themes remained reflective of the transcript text, in an effort to increase analytical rigor.

Results

Three themes emerged, including: (i) the DL experience as an eye-opening experience; (ii) the perceived benefits of the DL experience on themselves; and (iii) recommendation of the DL experience to other caregivers.

Theme 1. The DL Experience as an Eye-Opening Experience

Participants described the DL experience as an “eye-opening experience”. It was eye-opening because participants experienced what people with dementia might experience and feel by having similar feelings themselves during the DL experience (subtheme 1a) and being in their shoes which was regarded as the best part of the DL experience (subtheme 1b). Also, the DL experience was eye-opening because the DL experience was harder than they thought (subtheme 1c) and better than they thought (subtheme 1d).

Subtheme 1a. Feelings during the DL Experience. Participants related what they felt during the DL experience to what people with dementia would feel in their daily lives.

Participants reported that they felt “confused”, “frustrated”, “scared”, “embarrassed”, and “overwhelmed” during the DL experience as they faced barriers and realized they could not compete simple daily tasks that they used to do easily. Examples of participants’ statements include: “I was confused and I didn’t know what to do. My first reaction was to just stand there and do nothing, which I think that’s what happens to him” (an informal caregiver, #14); “It really lets you see how people with dementia feel all the time. It was frustrating. It made you feel sad. I had a lot of emotions with it. It’s frustrating sometimes if you don’t really understand” (a paid caregiver, #8); and “I really felt lost and so confused. I felt alone and scared. I can understand how people with dementia feel. I know that probably makes them feel the same way that I feel and it wasn’t a good feeling” (a paid caregiver, #9).

Subtheme 1b. Being in their Shoes as the Best Part of the DL Experience. Participants described “being in their shoes” as the best part of the DL experience because participants could understand what people with dementia might experience in their daily lives through the hands-on experience of the DL program. The DL experience provided participants with understanding of living with dementia and how challenging it is to live with dementia by experiencing difficulties in completing simple daily tasks. Examples of participants’ statements include: “I think the best part is just being in their shoes and know what they’re going through” (a paid caregiver, #1); “Learning what they went through was the best part because now I can see things differently as I have more understanding for them” (a paid caregiver, #2); “The best part was just seeing how their life is every day and how that changes their life. I never knew what they were going through until I went through” (a paid caregiver, #9); and “The best part was understanding that helpless feeling and gaining more understanding of why loved ones want to stay so close to us so that they can ask questions and get reinforcement as to what they need to do” (an informal caregiver, #12).

Subtheme 1c. It was Harder than I Thought. The DL experience helped participants understand how hard it is to live with dementia by experiencing difficulties in completing tasks in

the DL experience room. The extent of difficulty was more than they anticipated. For example, an informal caregiver (#11) expressed why the DL experience was eye-opening relating her perceived difficulty during the experience room session to her anticipated difficulty prior to her participation: “It was eye opening. I didn’t realize how disoriented I would be having all the stuff on and how difficult some of the tasks were. I thought it was much more difficult than I thought it was gonna be” (an informal caregiver, #11). Similarly, paid caregiver participants also reported that it was harder than they thought by relating their performance in completing daily tasks in the DL experience room to their usual performance: “I didn’t think it would be that hard. I thought I was gonna be able to go in there and complete something. I couldn’t complete anything” (a paid caregiver, #3); and “I thought I would’ve been more successful. Definitely. I mean normally if you gave me five tasks, I thought I would do better. It was a huge experience” (a paid caregiver, #5).

Subtheme 1d. It was Better than I Thought. Some paid caregiver participants reported that the DL experience was better than their expectations. That was because they did not expect to learn so much from that experience and for it to have such a big impact on themselves: “It was much better than my expectations because I didn’t expect to learn so much. So, it really did teach me a lot more” (a paid caregiver, #2); and “I had no idea, but it was a lot more than just helping my job. It’s helped me become a better person and a better son because my father has dementia” (a paid caregiver, #10).

Theme 2. The Perceived Benefits of the DL Experience on Themselves

Participants reported several benefits of the DL experience on themselves. These benefits include more empathy and sympathy toward people with dementia (subtheme 2a), better understanding about behaviors and emotions of people with dementia (subtheme 2b), and promoting the use of helpful strategies when working with people with dementia (subtheme 2c).

Subtheme 2a. Having more Empathy and Sympathy. Participants stated that the DL experience helped them have more empathy and sympathy toward people with dementia. Being in their shoes through the DL experience helped them understand better about what people with dementia would experience and feel with challenges due to dementia, and thus leading to having more empathy and sympathy toward people with dementia. Examples of participants' statements include: "Experiencing it and putting on like the eyewear and all of that made me realize what they go through. I could understand them more and actually feel for them a little bit more because I was in their situation" (a paid caregiver, #1); "It really made me sympathize with them and look at them differently because I was in their shoes" (a paid caregiver, #8); "It was really hard to be in their shoes. I've really had a major sense of even more empathy than I already had for the clients here" (a paid caregiver, #10); "It has made me more empathetic. I didn't understand why she got frustrated and couldn't do that with more than one direction. But now I understand that when you've got all of this going on, you're not processing" (an informal caregiver, #11); "I think I definitely have more empathy. It helped me understand why sometimes weird things happened around the house and I realized that he was just trying to help and do something but got it wrong" (an informal caregiver, #13); and "Living in the world like that made me understand them and be more sympathetic and have more empathy towards people with dementia" (an informal caregiver, #14).

Subtheme 2b. Better Understanding about Behaviors and Emotions of People with Dementia. Participants stated that they gained a better understanding about behaviors and emotions of people with dementia. For instance, an informal caregiver (#11) could understand why her mother had isolated herself and did not say anything when they had monthly parties in which about 20 people came over to their house to have a lunch together. The informal caregiver realized how overwhelming it would be for her mother: "That experience helped me understand that the parties were so overwhelming to her. There's just so much going on and she couldn't focus on

anything. It was an ah-ha moment that I could understand why that was happening". Other participants also said that the DL experience helped them have a better understanding about behaviors and emotions of people with dementia, including trying to be close to caregivers and not to do something alone, repetition, giving up, outbursts, anger, fear, frustration, and sadness. Examples of these participants' statements include: "I think it has affected my understanding of the behavior of those with dementia. The confusion and the fear. I understand better why he wants to be close to me and why he does not go some places and do some things" (an informal caregiver, #12); and I think getting closer to their level makes you understand their frustrations and outbursts. Because if I had to do that every day, I would get angry, irritated, frustrated, and sad, so it makes their behaviors make more sense" (a paid caregiver, #3).

Subtheme 2c. Promoting the Use of Helpful Strategies When Working with People with Dementia. Participants stated that the DL experience promoted the use of helpful strategies in caring for people with dementia as they personally experienced how difficult it was to complete simple tasks with challenges which people with dementia might experience. The DL experience helped participants understand why certain strategies are important and needed for people with dementia. Strategies that participants started to use as a result of their DL experience included: minimizing the amount of directions or giving one direction at a time, organizing and decluttering the house, planning ahead, talking slow, giving one task at a time or simpler tasks, taking more time and keeping the outside noise down when communicating with people with dementia, redirecting people with dementia, and being with the person to give help as needed. For instance, an informal caregiver (#11) believed that the DL experience encouraged her to change her strategies in giving directions to her mother: "It has helped me be more patient and try to find different ways of explaining things and minimize the amount of directions I give. It has definitely opened my eyes to things that I probably need to change now". The informal caregiver (#11) talked about her mother's decreased frustration as the

caregiver started to give one direction at a time compared to when she gave four directions at a time before: “I think that it [her changed strategy] is better for her because she’s not as frustrated. I just give her one thing at a time, so I think that has helped her feel better”. A paid caregiver (#1) reflected on the way she talked to her residents with dementia prior to the DL experience. The caregiver realized that she needed to change her way of working with the residents as she related how she felt during the DL experience to how residents with dementia would feel when she talked too fast and did not spend more time with the residents to give them help as needed.

A paid caregiver (#1): “I felt really bad because sometimes we’re in a rush and we kind of talk really fast. When we went through it [the DL experience], instead of just giving me directions like that really fast, I would have rather someone just took their time and just told me one by one or be there with me, helping me. So, it made me realize with our residents we have to be side by side making sure they understand clearly, not just throw stuff at them and just do little by little so they don’t get confused”.

Theme 3. Recommendation of the DL Experience to Other Caregivers

Participants expressed their wish that other caregivers could go through the DL experience as they believed that caregivers need the DL experience (subtheme 3a) and it is better than other training methods (subtheme 3b).

Subtheme 3a. Caregivers Need this Experience. Participants hoped other caregivers have the DL experience because participants believed that others would have similar benefits as they had through the DL experience: “This really helped me get a better understanding of what she’s going through. I have another sister that I’d really like to have do this because she doesn’t have a clue. I think this would really benefit her” (an informal caregiver, #11); and “I just wish every caregiver could do this, and I wish I could’ve done it two years ago” (an informal caregiver, #13). Paid caregiver participants stated that other paid caregivers need the DL experience to understand their residents with dementia better and thus

improve the quality of care for residents with dementia: “The experience was really good. I really liked it. I thought it’s something that a lot of the caregivers did need over here to be in their shoes and improve our work” (a paid caregiver, #1); and “It’s really needed. I hope you provide this just not here, but in more places because t’s eye opening and it’s gonna open up a lot of people’s eyes. It’d be great if it was something national” (a paid caregiver, #10).

Subtheme 3b. It is a Better Training than Other Training Methods. Some paid caregiver participants compared the DL experience to other training methods they had experienced before, and believed that the DL experience was different from other training methods. These participants reported that they liked the DL experience better than listening to a lecture or watching a video because of the hands-on experience of the DL experience. Examples of these participants’ statements include: “I feel it was much better because I actually went through it myself instead of just hearing it. Doing it was way better than just sitting down and listening or looking at a video” (a paid caregiver, #1); “We watch a video but it’s so good to experience it firsthand because it’s eye-opening. Through a video, you don’t know what they go through. It’s different. I would prefer this one over the videos. It was much better” (a paid caregiver, #2).

Discussion

The present study demonstrated the potential of a dementia simulation program as a beneficial dementia education program, through which caregivers experienced what people with dementia would experience and feel in their daily lives. Such experiences helped the caregivers to have more empathy and sympathy, to understand better about the behaviors and feelings of people with dementia, and to use strategies that can help when working with people with dementia.

Empathy toward people with dementia and their daily challenges may only be gained fully by experiences which evoke naturally occurring feelings due to challenges. Similar findings, such as increased empathy and understanding, were found in the literature that measured the impact

of simulation-based programs on health profession students toward older adults and people with mental illness (Chen, Kiersma, Yehle, & Plake, 2015; Merryman, 2010). A recent pilot study using a virtual reality tool with a dementia simulation movie found that informal caregivers improved in empathy, confidence in caring, and positive interactions with people with dementia (Wijma, Veerbeek, Prins, Pot, & Willemse, 2018). The present study adds to a lack of research in simulation programs for caregivers of people with dementia.

Empathy toward people with dementia is a personal quality necessary for caregivers to deliver person-centered care and that influences the quality of care and quality of life and health of people with dementia (Pulsford, Duxbury, & Carter, 2016). For example, residents with dementia in long-term care facilities are more likely to have better mood, delayed functional dependence, and increased food intake when staff treat and interact with residents in an empathetic way (Anderson, Bird, MacPherson, & Blair, 2016). Also, greater levels of empathy in family caregivers were related to higher quality of informal care and lower perceived stress in caregivers (Panyavin et al., 2015; Sutter et al., 2014). Empathy-building interventions through understanding feelings of people with dementia may reduce caregiving burden and help caregivers have positive caregiving experiences (Hayajneh & Shehadeh, 2014; Shim, Barroso, & Davis, 2012).

Caregivers may better understand the behaviors of people with dementia and the need of using certain strategies for people with dementia by being in their shoes in a dementia simulation program. Behavioral problems of people with dementia are significant determinants of caregivers' burden, depression, and mental health, even more so than cognitive impairments or lack of self-care (van der Lee, Bakker, Duivenvoorden, & Dröes, 2014). Better understanding about why people with dementia behave in a certain way may encourage caregivers to use appropriate strategies that can reduce behavior problems of people with dementia and to avoid situations which may contribute to behavioral problems (Roche, MacCann, & Croot, 2016).

Based on the findings of the present study, a dementia simulation program like the DL program may give caregivers maximized benefits if the program is included as part of the education of caregivers of people with dementia. Continuing education experiences may consist of passive listening to a lecture, or viewing a video on the topic of dementia. These experiences, while well-meaning, do not offer the caregiver a first-hand, personal experience of dementia. The role of emotions and active learning in adult and continuing education has been emphasized as a better way of learning than passive ones (Dirkx, 2008; Knowles, 1980). Dementia Live™ offers just such an active, engaged experience involving emotions for those caregivers who are offered the opportunity to participate, then reflect upon their experiences.

Since the present article is a qualitative study focusing on experiences of caregivers in the program using convenience sampling, it cannot verify effectiveness of the program and it weakens generalizability of the findings to all caregivers of people with dementia. Further studies with a high-level quantitative research design and validated outcome measures are needed to measure the effectiveness of dementia simulated learning experiences on caregivers of people with dementia, using insights gained from the present qualitative study. Since Wijma et al. (2018) also had not enough sample size to show effectiveness of the dementia simulation program, further studies should be powered to show effectiveness of such programs using power analysis.

Conclusion

The present study found caregivers' positive experiences in and potential benefits of a dementia simulation program on caregivers of people with dementia. Potential gains include having more empathy and sympathy toward people with dementia and better understanding about behaviors and emotions of people with dementia and promoting the use of helpful strategies when working with people with dementia. Further studies with a high-level quantitative research design such as randomized controlled trials with enough sample size and validated outcome

measures are needed to measure the effectiveness of dementia simulated learning experiences on caregivers of people with dementia.

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ORCID

Areum Han  <http://orcid.org/0000-0003-1369-9052>

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