Lived Experience of Informal Caregivers of Persons Living with Dementia in Engagement in Leisure, Social, and Self-Care Activities

Brittany Bell, OTS; Areum Han, PhD, OTR/L

Department of Occupational Therapy | University of Alabama at Birmingham
Vivian Story, MSW | McCoy Adult Daycare

Introduction

Background
Dementia is one of the most difficult age-related irreversible diseases that is common in older adults and can affect their cognitive function and engagement in daily occupations (Laurentz et al., 2011). Caring for people with dementia (PwD) can be extremely overwhelming, causing a high caregiving burden (Amella & Batchelor-Asugye, 2013). Informal caregivers of PwD may have fewer engagements in leisure, social, and self-care activities, which may lead to isolation, depression, loneliness, anxiety, and exhaustion (Padulevicius et al., 2019).

Caregivers frequently overlook their own health care needs to assist family members, resulting in caregiver health and well-being deteriorating (Maushack et al., 2017). Coping mechanisms such as participation in recreational activities, social connections, community organizations, or any preferred enjoyment play an essential part in balancing and limiting the impact on caregivers experience (Padulevicius et al., 2019). Engagement in leisure activities and social participation is beneficial to the caregivers’ mind and body outside of their call of duty (Padulevicius et al., 2019).

Purpose
To explore the lived experience of informal caregivers of people living with dementia regarding their engagement in leisure, social, and self-care activities.

Methods

Qualitative data was gathered through participants, survey, and interviews at McCoy Adult Daycare in Birmingham, AL.

Recruitment
Participants were recruited through a flyer on display at McCoy and word of mouth from the site director.

Interview and Survey
Recruitment
Qualitative data was gathered through participant, survey, and interviews at McCoy Adult Daycare in Birmingham, AL.

Data Analysis
Data were collected through an individual 20–45 min semi-structured interview via Zoom and in-person. Interview questions included seven open-ended questions focusing on experience in engagement in leisure, social, and self-care activities.

A demographic background intake form (survey) was utilized to collect participants’ background information, including age, gender, marital status, ethnicity, education level, years of caregiving, and relationship to PwD.

Results

Theme 1: Strategies and Support Allowing for Engagement in Leisure, Social, and Self-Care Activities

- Engaged in playing tennis, sewer, physical activity, reaching out to relatives and friends, church activities, morning bible reading, shopping, beauty appointments, dining at restaurants
- Bringer their relate with dementia as they engage in activities
- Adult day care services provided participants with a break and an opportunity to engage
- Having another person at home (spouse) who is willing to support and help during times of need

“Sometimes I just go walking. I go to the library and read some books and do some arts and crafts. I do yard work and put flowers in my garden. I cut my own grass at 77 years old.” (Participant 3)

“I don’t do things by myself; unfortunately, I go to church, bible study, other rehearsal, shopping and do is right there with me. It’s hard, but I have to do it.” (Participant 2)

“I have a friend that wants to marry me and my plan was to stop keeping house here and go where he is. I had to change my whole plans with him.” (Participant 3)

Theme 2. Changes and Challenges in Engaging in Leisure, Social, and Self-Care Activities

- Having little to no time for visiting relatives and friends
- Placing life aspirations on hold
- Missing out on others’ milestones and gatherings, e.g., birthday celebrations, weddings, holiday events
- Feeling tired with no energy left for activity participation after assisting with domestic responsibilities for PwD

Discussion

Key Findings
Data analysis shows that caregivers of people with dementia do engage in satisfactory activities, but they also undergo life-adjusting alterations after beginning the caregiving role.

- Findings indicate that family caregivers of PwD are often compelled to decrease or discontinue their hobbies and interests in order to devote more time and energy to their loved one.
- Dunn and Strain (2001) showed that caregivers who restrict their engagement in leisure activities encounter significant caregiving demands and are unlikely to have additional family friends to share caregiving obligations with. Additional research points out that, the more severe the dementia, the greater the burden on caregivers, and this pressure can disrupt lifestyles and be an impediment to their leisure, social, or self-care involvement (Brody & Donkin, 2009).

Another idea that is supported by results is that having extra help/support at home and/or enrolling a PwD in an adult day care can provide relief and support for informal caregivers while strengthening their willingness to participate in activities. According to Tretteteig et al. (2017), attendance at an adult day care makes everyday obligations less stressful for caregivers due to the fact they can do the essential practical activities of everyday obligations with.

Future Implications

- Occupational therapists (OTs) have the opportunity to consult with caregivers and assist them in enhancing the skills they need for performing everyday tasks and establishing balance for participating.
- OTs are well-positioned to establish customized treatments that are patient-centered and to understand caregivers’ difficulties.
- OTs may inform other medical professionals concerning the value of caregivers getting involved in activities and promote utilization of services.
- Caregiver support organizations should focus on the obstacles caregivers have with activity participation and provide caregivers with an avenue to interact, acquire knowledge, and grow.

Conclusion

Leisure, social, and self-care for informal caregivers are characterized as time spent on pursuits other than caregiving, as well as having the ability to choose such activities (Xu et al., 2020). This study confirms that informal caregivers of PwD do engage in leisure, social, and self-care activities but experience less involvement in activities, decreased leisure enjoyment, and limited burden reduction with participation. Furthermore, the challenges and changes they endure can even potentially cause them to stop their participation in activities. Caregivers of PwD may benefit from psychosocial and behavioral interventions that help them find suitable ways to balance caregiving tasks with their leisure, social, and self-care interests (Maushack et al., 2017).

Discussion (cont.)

References


Acknowledgement & Contact information

I would like to especially thank Dr. Areum Han, Dr. Megan Carpenter, the UAB Department of Occupational Therapy, and the employees and caregivers of McCoy Adult Daycare.

Brittany S. Bell, OTS Email: bbell18@uab.edu

The University of Alabama at Birmingham