



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

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Introduction

Background

Dementia is one of the most difficult age-related irreversible disease that is common in older adults and can affect their cognitive function and engagement in daily occupations (Lauritzen et al., 2011). Caring for people with dementia (PWD) can be extremely overwhelming, causing a high caregiving burden (Amella & Batchelor-Aselage, 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 (Pudelewicz et al., 2019).

Caregivers frequently overlook their own health care needs to assist family members, resulting in caregiver health and well-being deteriorating (Mausbach et al., 2017). Coping mechanics 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 (Pudelewicz et al., 2019). Engagement in leisure activities and social participation is beneficial to the caregivers' mind and body outside of their call of duty (Pudelewicz 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.

Outcome

- Understand directly how caregivers of PWD partake in leisure, social, and self-care activities while being relieved from the burden.
- Recognize the challenges that caregivers of PWD endure when engaging in 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

- 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.

Data Analysis

- Interviews were transcribed verbatim and analyzed following the interpretative phenomenological analysis of methodology and open coding.

Participants

- Four family caregivers of PWD participated: three females (two sisters and one daughter) and one male (brother).
- African Americans with age ranging from 62 to 77 years
- 50% retired and 50% employed part-time

Results

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

- ☐ Engaged in playing tennis, sewing, physical activity, reaching out to relatives and friends, church activities, morning bible reading, shopping, beauty appointments, and dining at restaurants
- ☐ Bringing their relative with dementia with them 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

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' milestone events 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

“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, choir rehearsal, shopping and she 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)

Discussion

Key Findings

Data analysis shows that caregivers of people living 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 (Brodaty & 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 without being distracted. Furthermore, family caregivers will likely implement more of their alone time to engage in enjoyable activities if the practical duties are fulfilled.

Limitations

- With only four study participants, the results obtained from this small sample may not be generalizable to bigger populations
- The study consisted only of Black/African American caregivers, indicating a lack of diversity.

Discussion (cont.)

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 participation.
- 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 capacity to choose such activities (Xu et al., 2022). 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. (Mausbach et al., 2017).

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