

Exploring Caregiving Rewards for Formal Caregivers of Individuals with IDD and Dementia

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Introduction

- Individuals with intellectual disability (IDD) often develop dementia as they age, which compounds their care needs.¹
- Formal caregivers experience caregiving rewards², but little is known about these rewards for formal caregivers for individuals with IDD and dementia.

Research Aim

This study aims to explore rewards of caregiving among formal caregivers of individuals with IDD and dementia.

Methods

Research Design: descriptive qualitative case study

Participant: “Allie,” a 28-year old white female, formal caregiver at a local IDD residential care facility for over 2 years

Recruitment: purposive, convenience sample

Data: one semi-structured interview in the participant’s workplace

Analysis: transcription, close text readings, triangulation, and synthesis

Findings

- ❖ **Central reward: Allie feels meaningful when she has effectively cared for and cared about the residents.**

“It just makes me feel good knowing that my job is meaningful and knowing that I’m genuinely helping these people...I wouldn’t want [Randy] to go to a random place where they don’t know him...and they’re just--you know, ‘caring for him’. Whereas we’re living with him.”

- ❖ **Indicators: Allie measures her effectiveness as a caregiver by absence of conflict and presence of positive interactions with residents.**

- ❖ **Dementia’s interruption: Residents with dementia are less engaged and more agitated as the disease progresses.**

- ❖ **Supportive factors: Allie draws from a complex transaction of intrapersonal, interpersonal, organizational, and systemic factors across time and space to support effective caregiving.**

Discussion

- Alignment with literature: formal caregivers are rewarded by feeling impactful in caregiving roles.³
- Rewards, indicators, and supports are interwoven.
- Characteristics of IDD/dementia (e.g. agitation and withdrawal) can disrupt the experience of caregiving rewards.
- A broad web of supportive factors can mitigate dementia’s disruption by restoring positive interactions and minimizing conflict.

Implications for OS & OT

- Invites opportunity for consultative OT role
- Highlights the importance of examining outcomes like caregiving rewards in context for effective intervention target identification
- More research on this population and their caregiving rewards is needed

References

1. National Task Group on Intellectual Disabilities and Dementia Practice. (2012). ‘My Thinker’s Not Working’: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports.
2. Harris-Kojetin, L., Lipson, D., Fielding, J., Kiefer, K., & Stone, R. I. (2004). Recent findings on frontline long-term care workers: A research synthesis 1999–2003. Washington, DC: Institute for the Future of Aging Services, 1-29.
3. United States Department of Health and Human Services (USDHHS). (2011). Understanding direct care workers: A snapshot of two of America’s most important jobs, certified nursing assistants and home health aides [PDF]. Retrieved from https://www.ahcancal.org/quality_improvement/Documents/UnderstandingDirectCareWorkers.pdf

