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Social and Leisure Participation by People with Dementia: A Caregiver Resource Guide

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Social and Leisure Participation by People with Dementia: A Caregiver Resource Guide

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BACKGROUND

Approximately 55 million people worldwide are living with diagnosed dementia (WHO, n.d.). This has resulted in an increase in the demand for formal and informal caregivers (Pleasant et al., 2020). Occupational therapists assist family and caregivers of individuals with dementia to increase the quality and safety of care provided at home, decrease the risk of avoidable symptoms worsening due to a lack of medical management, and reduce caregiver burden through advocacy for the caregiver (Marchese, 2023; Raj et al., 2021; Yuill & Hollis, 2011; Yong et al., 2020).

PROBLEM

There are limited caregiver resources for assisting clients and family members with Alzheimer's-related dementia in engaging in social and leisure participation.

PURPOSE

The purpose of this project is to develop a resource guide to better train caregivers to assist their loved ones diagnosed with Alzheimer's-related dementia to participate in social and leisure occupations

Acknowledgement: Special thanks to Sharon Cantrell

METHODS

This project consisted of 4 phases:

1. Predevelopment Phase:

- Interviews with caregivers & observations demonstrate the need for:
- Information about Dementia stages and symptoms
- Strategies for assisting with challenging behaviors
- Activity ideas to engage their loved ones

2. Development Phase:

- Organized findings,
- Developed caregiver resource
- Sent to stakeholders for feedback

3. Implementation Phase:

- Organized immersion event for caregivers
- Disseminated resource guide to a sample of caregivers
- Interviewed family caregivers about usefulness of the guide
- Stakeholders provided feedback on format, navigation, content, and satisfaction.

4. Revision Phase:

- Sought feedback from site supervisor
- Analyzed and revised
- Finalized caregiver resource guide
- Published caregiver resource guide on website

Caregiver Resource Guide Content

Chapter 1: Introduction to Dementia

- Prevalence of Alzheimer's disease and other dementia conditions
- Definition of Dementia
- Stages of Dementia and common barriers to occupational participation

Chapter 2: Caregiver Safety

- Proper body mechanics
- Transfer and mobility instructions
- Common conditions associated with Dementia

Chapter 3: Social & Leisure participation

- Quick Fixes for increased participation
- Social Participation
 - Handling disruptive social behaviors
- Leisure Participation
 - Activities to try at home

Chapter 4: Caregiver Resources

- Caregiver Burden and Grief
- Additional Handouts
 - VA benefits, Bathing Strategies, Guns and Dementia, and Holidays
- Local and Online Resources

MOHO Theoretical Framework:



Discussion

Caregivers need resources and support to feel prepared to provide safe social and leisure participation for their loved ones diagnosed with Alzheimer's-related dementia.

Implications for Population and Practice:

- Promotes occupational participation in social and leisure for the caregiver and their loved one with dementia
- Increases knowledge about dementia, decreasing stigma associated with memory loss conditions
- Increases awareness of the role of OT in caregiver populations
- Increases caregiver's ability to self-advocate

References



Resource Guide



This project did not involve human subjects and does not require IRB approval.