

Abstract

Developing a Comprehensive Model for Improving Quality of Life in Individuals with Alzheimer Disease and Related Dementia and Their Informal Caregivers: Qualitative Study of AZL Forum Data

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Abstract

Background: It is estimated that more than five million Americans are living with Alzheimer disease and related dementia (ADRD), and the population of people living with the disease is expected to triple by 2060. Most care for persons living with ADRD is provided by informal caregivers. However, current strategies to improve the quality of life for both people living with ADRD and their informal caregivers are not optimal, especially from a comprehensive approach. Social media and online forums have become increasingly popular tools for ADRD caregivers to manage the burden of caregiving.

Objective: This study was to 1) explore informal caregivers' discussion topics by analyzing the caregiver online forum data, and 2) develop a comprehensive model based on their discussion topics, with the aim to improve quality of life for both persons living with ADRD and their informal caregivers.

Methods: Publicly available peer interactions of 4102 registered users, with 96% self-claimed as informal caregivers (67% as a child of a person with dementia, 13% as a partner/spouse, and 7% as a relative) on the Alzheimer's Association ALZ Connected Caregivers Forum were extracted in January 2019 using computer programming. A total of 40,798 postings were collected. All authors agreed to use a triangular model to serve as the predetermined three major themes to categorize all codes. The three major themes were factors of caregivers, factors of individuals with ADRD, and factors of care context. Inductive coding was used to derive in vivo codes from the data, and the codes were further refined throughout the coding process. Two researchers independently coded postings until saturation was reached. Discrepancies were discussed among the two researchers to reach consensus. A third senior researcher's opinion was referred to whenever necessary.

Results: For factors of caregivers, the most frequent subthemes were perceived caregiver burden, caregiver's life balance, caregiving strategies, communication, expectations, personal health issues, poor relationship, and ineffective coping. Subthemes of factors of individuals with ADRD included changes in abilities and capacities, commodities, behaviors, health conditions, daily living function, disengagement, and ineffective coping. Lastly, for factors of care context, the most frequent themes were family support, financial support, informational support, professional support, length of care provided, living arrangement, activities and stimulation, patient health care coordination, unexpected situations, communication, and physical environment. One theme under one of the triangular factors may influence another theme under another triangular factor and vice versa.

Conclusions: By analyzing the discussions of informal caregivers on ALZ online forum, we found that taking care of a loved one with ADRD is challenging for informal caregivers. The challenges may affect the quality of life for both caregivers and the caregiver recipients; factors of care recipients, caregivers, and the care context interactively affect perceived challenges of caregivers. This study has identified a comprehensive model which may be used to help improve quality of life for both informal caregivers and people living with ADRD. Our next step is to use these manually determined codes to analyze all extracted postings via machine learning to improve this model.

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KEYWORDS

qualitative study; quality of life; model; Alzheimer disease and related dementias; informal caregivers; forum

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