Indicators of Burden in Conversations Between Family Caregivers

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Background: The Baby Boomers are numbered at approximately 76 million, and ultimately reaching the age of 65 or older. Chronic illness is more prevalent with age and requires greater levels of care. Family caregivers will be required to provide the majority of care, leading to increased stress and burden. The Multidimensional Caregiver Burden Inventory proposed by Mark Novak and Carol Guest identifies and measures time dependency, development, physical, social, and emotional burden. While this phenomenon is well-recognized in research literature, and many quantitative attempts have been made to understand the effects of caregiving on burden, they often lack in-depth and person-centered responses. The purpose of this analysis is to examine the ways in which quantitative indicators of well-being are represented in open-ended conversations amongst caregivers.

Methods: A secondary data analysis was conducted using data from a mixed method study examining the experience of informal family caregivers of older adults age 65 and older. Data was gathered from interviews between experienced caregivers (five or more years) and those new to caregiving (less than five years). Interviews occurred over a four month period, with participants expanding on semi-structured questions and adding to the conversations based on their knowledge and needs. For this project, a total of twenty audio interview recordings were transcribed into text and analyzed using *a priori* and pattern coding.

Results: The results indicated that emotional health was found to be the most discussed out of the five indicators, accounting for 43% of the total codes, and identified five main themes within the topic, including reminiscence, guilt dignity, anger, conflicts, and cherishment. Those that pertained to development were the least discussed, out of the five main indicators, and mentioned in 6% of the total codes. Time dependence from care recipients is a significant factor in the caregiver's ability to commit to the personal growth and development required in different stages of life. Subthemes falling under developmental burden showed close association with those of time-dependency burden. Associations were also found between the caregivers' relationship quality with their care recipient, other family members, the health care provider team and their subjective perception of caregiver burden.

Conclusion: The perception of burden for informal caregivers of older adults in this study supported the role of the quality of relationship between those involved in the caregiving and care-receiving experience. The limited sample size and lack of consideration in distinct diagnoses and caregiver characteristics in this study calls for further research. In future studies, researchers should focus on how such variables would support the identified sub-themes in order to develop appropriate interventions for specific caregiver groups.

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Abstract Summary:
This presentation reports outcomes from a secondary analysis to examine the ways in which quantitative indicators of well-being are represented in open-ended conversations between informal family caregivers.

Content Outline:
I. Introduction

- As baby boomers retire, our population will continue to age.
- Family caregivers will be required to provide the majority of care, leading to increased stress and burden.

II. Literature Review

- The multidimensional caregiver burden inventory measures time dependency, development, physical, social, and emotional burden.
- Quantitative data often lack in-depth and person-centered responses.

III. Methods

- Twenty three caregivers participated in small group discussions over the course of four months.
- Two phases of coding: A priori & pattern coding.

IV. Results

- Most discussed topic is emotional burden, five sub-themes include reminiscence, guilt dignity, anger, conflicts, and cherishment.
- Family, friends, and support group are main contributors to social well-being and burden.
- Problems that lead to physical burden include hygiene, fatigue, violence, and safety hazards.
- Least discussed topic is developmental burden, sub-themes are very similar to those of time-dependency burden.

V. Discussion/Conclusion

- Caregivers' relationship quality with their care recipient are associated with their subjective perception of caregiver burden.
- The limited sample size and lack of consideration in distinct diagnoses and caregiver characteristics in this study calls for further research.

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