Caregivers’ perspectives of care problems: an exploratory study in Taiwan

Background: Caregiver burden is known as a multidimensional phenomenon and strongly influenced by sociocultural contexts. Literature reported cultural differences in the appraisals of dementia that affect caregivers’ perceived burden. This study explores the caregiver’s perspectives of the care problems in daily routine.

Methods: This study adopted a qualitative approach. 30 consecutive consultation sessions from a Dementia Consultation Clinic in Taiwan were videotaped and the content transcribed. The transcripts were coded to identify the most frequent care problems identified by the caregivers. Five follow-up in-depth interviews were conducted with the caregivers who reported most care problems. The participants included one husband, one wife, two sons, and one daughter. They all lived and provided care for their relatives with dementia at home. The transcripts were analyzed with Grounded theory.

Results: Four themes associated with the care problems reported by the caregivers: (1) Most of the caregiving difficulties were associated with behavioral problems associated with dementia. (2) These behavioral problems usually became a source of caregiver distress when they significantly affected the safety of care recipients or caregivers, and/or disrupted the daily lives of the whole family. (3) The behaviors were mostly attributed to the personality or lifelong habits of care recipient rather than the symptoms of dementia. Thus, the behaviors were often not considered modifiable. (4) The caregivers considered the management of disruptive problems as their moral responsibilities and were reluctant to seek help.

Conclusions: The results agreed with the literature that the behavioral problems of dementia were a frequent caregiving stressor. It also supports that Asian caregivers may consider caring for the elderly in the family as their destiny and responsibility that cannot be shared with others. Not discussed in previous literature was that how Taiwanese caregivers’ attribution of behavioral problems influenced their coping strategies. As the caregivers in Taiwan tend to regard the behavioral problems un-modifiable or associate the ability to manage behavioral problems with one’s morale, these considerations influences the caregiver’s decision to seek help. More caregiver educations may help them be well aware of dementia symptoms and develop more useful coping strategies.