THE LIVED EXPERIENCE OF BEING A CAREGIVER OF A PERSON WITH DEMENTIA

Background and significance: The prevalence of dementia is on the rise; 4.4 million people are presently afflicted with Alzheimer's disease or another form of dementia. 80% of the care provided for older adults with dementia is provided by unpaid caregivers. There is ample evidence that caring for persons with dementia can be very costly to caregivers' physical and mental health. However, some positive experiences have been reported by caregivers including finding meaning and joy in the experience. The experience of caring for a loved one is broad and dynamic; thus it is not entirely negative or entirely positive. Purpose: This qualitative study explored the lived experience of being a caregiver of a person with dementia in the light of resilience theory. Conceptual Framework: The current study used resilience theory as a guiding framework. This theory proposes that resilience reflects the interplay between risk factors and protective factors in the face of adversity. Sample Description: The qualitative data for this analysis were collected as a part of a larger study of 80 caregivers of persons with dementia. In the parent study, both men and women, who were able to understand and communicate in English were recruited. No subjects were excluded on the basis of gender, race, or socio-economic status. Setting: In the parent study, subjects were recruited through the Alzheimer's Association early stage programs in Southeastern Wisconsin. Method/Design & Procedure: Qualitative design was used to explore what it like to be a caregiver of a person with dementia. In the parent study, the researcher contacted the administrators at the Alzheimer’s Association early stage programs in Southeastern Wisconsin to explain the purpose of the study and the data collection procedures. IRB approval was obtained and the administrators at the Alzheimer’s Association early stage programs in Southeastern Wisconsin helped to distribute recruitment flyers. Caregivers who were interested contacted the research assistant and caregivers completed the consent form and the questionnaires at an agreed upon date and time. Data obtained from caregivers were transcribed and coded using the phenomenological approach. Each transcript was examined repeatedly to get a sense of the whole, analyzed line by line, and themes were identified from each transcript, and then the common themes were grouped. Results/Outcomes: The themes that emerged were in three distinct categories consistent with resilience theory: risk factors, protective factors and overlapping factors. Risk factors included stressful, difficult, demanding, frustration, draining/exhaustion, lack of social support, and negative feelings (sadness, anger). Protective factors included “rewarding and serving a purpose”. Overlapping factors reflected caregivers’ descriptions of both risk and protective factors that influenced their resilience. Conclusions/Implications: These findings can help to inform the development of tailored interventions to address caregivers' needs and concerns.