

## Sigma's 30th International Nursing Research Congress

### Parental Perceptions of Their Adult Children Caring for Siblings With Chronic Mental Illness

**Linda Carman Copel, PhD, MSN, MSMFT, BSN, RN, PMHCNS, BC, CNE, ANEF, NCC, FAPA**  
*College of Nursing, Villanova University, Villanova, PA, USA*

**Background:** Parents often provide long-term or life-long assistance to their adult children with chronic mental illness. Consequently, a concern for these elderly parents is who will meet the future care needs of their children when the parents are no longer able to provide care for them. Sibling relationships, stigma, potential for abuse and a viable living situation for the mentally ill family member are a few of the issues that cause distress for elderly parents. Family conflict can arise related to care giving roles and responsibilities.

**Purpose:** The purpose of this study was to describe elderly parental caregivers' perceptions of their healthy children providing care for siblings with chronic mental illness. An additional purpose was to identify the presence of stigma perpetuated by the siblings towards family members with chronic mental illness.

**Methods:** A secondary data analysis was conducted on data from a qualitative study which explored parental caregivers' perception of stigma as experienced by family members with chronic mental illness. The participants attended an educational program focused on the stigma of mental illness. Data were obtained from a convenience sample of 18 caregivers. Institutional Review Board approval and informed consent were obtained for the study. The data for the secondary analysis were from the original transcripts and were analyzed using Elo and Kyngas' content analysis procedure.

**Results:** Descriptive statistics were compiled from the demographic data. The findings revealed that 16 elderly caregivers addressed their concerns related to the burden they were placing on their healthy adult children to provide care for the siblings with mental illness. Ten participants discussed their concerns of potential abuse occurring when a sibling assumed a caregiver role.

Findings revealed the participants' concerns about the dynamics of the new care giver-care receiver relationship, as well as perpetuation of stigma experienced by the family member with mental illness. Four themes emerged from the data: caregiver burden, potential for abuse, rewards needed by siblings to undertake the care giving role, and the experience of social stigma from siblings.

#### Implications and **Conclusions:**

The parental caregivers expressed strong concerns about arranging care for their adult child with mental illness after they could no longer be the caregivers. Issues related to the reluctance of siblings assuming the care giving role presented a harsh reality to the parents. There was fear of verbal and physical abuse by the sibling caregivers towards the mentally ill family members. There was acknowledgement of the possibility of caregivers not intervening to prevent the day-to-day reality of social stigma occurring for the adult siblings with serious mental illness. The perceived consequences of relying on institutions and state-funded facilities for care were viewed by parents as undesirable places where discrimination and violation of human rights could occur. Additional research is needed to further understand what happens to adults with chronic mental illness after they no longer have parental caregivers and cannot live in their familiar communities.

---

#### **Title:**

Parental Perceptions of Their Adult Children Caring for Siblings With Chronic Mental Illness

**Keywords:**

Adult children with mental illness, Care-giving for mentally ill siblings and Elderly parent caregivers

**References:**

Banerjee, B. (2017). Explanatory models and psychiatric pluralism among family members of mentally ill persons: a narrative inquiry. *International Journal of Culture & Mental Health*, 10(3), 320-337.

Coker, F., Williams, A., Hayes, L., Hamann, J., & Harvey, C. (2016). Exploring the needs of diverse consumers experiencing mental illness and their families through family psychoeducation. *Journal of Mental Health*, 25(3), 197-203.

Hyun, M., Chung, H. C., & Kim, H. (2017) Experiences of family stigma among mothers of adult children with mental illness in South Korea. *Issues in Mental Health Nursing*, 38(10), 845-851.

Park, K., & Seo, M. (2016). Care burden of parents of adult children with mental illness: The role of associative stigma. *Comprehensive Psychiatry*, 70, 159-164.

Ye, J., Chen, T F., Paul, D., McCahon, R., Shankar, S., Rosen, A., & O'Reilly, C. L. (2016). Stigma and discrimination experienced by people living with severe and persistent mental illness in assertive community treatment settings. *International Journal of Social Psychiatry*, 62, 532-541.

**Abstract Summary:**

This qualitative study addresses elderly parents' perceptions of the burdens and responsibilities of their adult children who may provide care for their siblings with chronic mental illness.

**Content Outline:**

1. Introduction
  1. Elderly parents provide life-long assistance to their adult children with chronic mental illness
  2. Issues related to siblings providing care when parents are unable to provide the care
1. Body
  1. Main Point #1 Description of elderly parents' caregiver concerns
    1. Supporting point #1 Problematic sibling relationships
      1. a) Occurrence of stigma towards the care recipient
      2. b) Potential for sibling-to-sibling violence
  1. Main Point #2 Caregiver burdens
    1. Supporting point #1 Responsibilities of sibling as a care provider
      1. a) Arrange care for the family member with mental illness
      2. b) Reluctance to manage and sustain care
  1. Main Point #3 Caregivers' requirements

1. Supporting point #1 Rewards and decision making power desired by potential caregivers
1. a) Financial compensation
2. b) Introduction to use of institutions and state-funded facilities

### III. Conclusion

1. Fear of inadequate care and potential for abuse
2. Possibility of caregivers not intervening on a day-to-day basis

First Primary Presenting Author

***Primary Presenting Author***

Linda Carman Copel, PhD, MSN, MSMFT, BSN, RN, PMHCNS, BC, CNE, ANEF, NCC, FAPA  
Villanova University  
College of Nursing  
Professor  
Villanova PA  
USA

**Author Summary:** Dr. Copel teaches in the undergraduate, graduate, and doctoral programs at Villanova University, College of Nursing. Her research interests include women's health, partner abuse, and community mental health. As a practicing clinician, she provides psychotherapy to individuals, couples and families. She is nationally certified as a clinical nurse specialist in adult psychiatric nursing, a group psychotherapist, a family life educator, and a bereavement counselor. She is a Fellow in Psychotherapy from the American Psychotherapy Association.