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

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Learner Objectives:

- The main purposes of this study were:
  - Describe elderly parents’ perceptions of burdening the next generation with caring for adult siblings with chronic mental illness.
  - Examine factors that parental caregivers believe contribute to the potential for abuse and stigma by healthy siblings towards mentally ill siblings.
  - Determine elderly parents’ views of caregiver burden for themselves and adult family members who may serve as future caregivers for their adult mentally ill siblings.

Conflict of Interest Statement:
I have no relationships to disclose.

Sponsorship or Commercial Support:
I have no support to disclose.
Parents often provide life-long assistance to their adult children with chronic mental illness. Consequently, a concern for elderly parents is who will meet the needs of their adult children when they are no longer able to provide care. Sibling relationships, stigma, abuse and a viable living situation for the mentally ill family member are issues that distress elderly parents.
Background of the Study

- Often there are little to no services or support groups where the caregivers may verbalize their concerns and frustrations about the problems their adult children with mental illness encounter.

- There is minimal literature which discusses the interrelationships among the concepts of:
  - caregiving for adult children with mental illness
  - their elderly parental caregivers
  - the caregiving roles of adult siblings for their sibling with mental illness
Research Question

- What are the perceptions of elderly parental caregivers about their adult children providing care for adult siblings with chronic mental illness?
Purpose of the Study

The purpose of this study was to describe elderly parental caregivers’ perceptions of their adult children providing care for adult siblings with chronic mental illness.
Qualitative Methodology

- Secondary Analysis of a Retrospective Descriptive Qualitative Study

- Participants attended the presentation of an educational program entitled, Freedom from Stigma for Individuals and their Families, and consented to the videotaping of the educational program, group support and discussion sessions.
Freedom from Stigma Content

- The Stigma of Mental Illness
- Addressing Stigma in the Health Care System
- Education: The Starting Point
- More Strategies to Address Stigma
- Communication That Promotes Understanding
- Reducing Discrimination and Stigma in Daily Life
- How Family Members Can Heal
- Advocating for People with Mental Illness
- Developing a Stigma Free Society
- Where Do We Go from Here?
Data from the First Study Revealed . . .

Parental Perceptions Of STIGMA in the Community AND IN THE FAMILY

Adult Children experienced: Exclusion Isolation ABUSE in the Community AND IN THE FAMILY

Hurts the individual and the parents Impairs the journey to recovery Detrimental to health and well-being Diminishes individuals’ and parents’ quality of life HARMs FAMILY RELATIONSHIPS
Population - Sample - Setting

- **POPULATION**
  Adult mothers and fathers who were caring for an adult child family member with serious mental illness

- **SAMPLE**
  Convenience sample of 18 parent participants

- **SETTING**
  Mid-Atlantic region of the United States
  Group meetings were held and video-recorded in an outpatient community mental health center
Data Analysis

- Descriptive statistics were used to compile the demographic and evaluation data.
- Data from each of the ten sessions were transcribed.
- Elo and Kyngas’ content analysis method was used for data analysis.
- The process consists of coding participant statements, developing code categories and identifying themes.
Demographic Data

- Caregiver Parents: 14 females, 4 males
- Age Range of Parents: 59 – 83 years (average: 71 years)
- Caregiver Couples: 4 (8 participants)
- Years Married: 30 – 42 years (average: 36 years)
- Caregivers Divorced: 5
- Caregivers Widowed: 5
- Race: 12 Caucasian, 6 African American
- Religious Affiliation: 10 Catholic, 5 Baptist, 2 Muslim, 1 Jewish
Demographic Data

- Parental Employment
  - 3 Males Employed Fulltime
  - 2 Males Retired
  - 6 Females Employed Fulltime
  - 5 Females Employed Part-time
  - 2 Females Retired

- Number of Children/Family: 3 - 5
- Adult Children with Mental Illness: 10
- Age Range Adult Children With MI: 32 – 48 years
- Age Range Adult Children Without MI: 32 – 50 years
Demographic Data

- Employment of Adult Children (10 males, 4 females)
  - 7 Employed Part-time
  - 3 Unemployed
- Places of Employment for Adult Children
  - 3 Grocery Store
  - 2 Drug Store
  - 1 Veterinary hospital
  - 1 County Mental Health Office
Demographic Data

Primary Mental Health Diagnoses of Adult Children
- 6 Bipolar Disorder
- 2 Schizophrenia
- 2 Major Depressive Disorder

Health Problems of Adult Children Identified by Parents
- 7 Overweight
- 5 Smokers
- 4 Heart Problems
- 4 Diabetes
- 4 Depression
- 3 Emphysema
- 2 Thyroid Problems
- 2 Substance Use (1 Marijuana Use; 1 Alcohol Use)
Demographic Data

Parents’ Self-Identified Health Problems

- 9 Hypertension
- 8 Heart Problems
- 8 High Cholesterol
- 6 Arthritis
- 6 Back Pain
- 6 Diabetes
- 4 Osteoporosis
- 2 Depression
Findings: Four Themes

- Caregiver burden
- Potential for abuse
- Rewards needed by siblings to undertake the caregiving role
- Experience of stigma from siblings
Findings: Theme One

- **Caregiver burden**

  “I have always been there for him, but now everything that I do just seems too much for anyone to handle.”

  “No one in the family seems to notice, let alone help or even offer to help . . . It is all too much for everyone but me. After all these years I do more and more for her and others do not notice what I do . . . they only see it as a problem. What happens when I’m not here to do it?”
Findings: Theme One

- **Caregiver burden**

“It’s the day-to-day stuff, . . . the worrying . . . and that I have to think for two people . . . that is something that no one is willing to do.”

“He [the healthy son] knows what to do, but I can’t depend on him doing it . . . I’m weary . . . my life is now about convincing him to do the right thing and about how he will be able to care for his brother in the future . . . and help him meet his needs.”
Findings: Theme Two

- **Potential for abuse**

“There are times when they get on each other’s nerves . . . can’t have civil conversations . . . avoid each other . . . and don’t act like family.”

“I am scared about the threats that I hear him say to his brother . . . at times I have said don’t you ever hurt him, he has been hurt enough.”
Findings: Theme Two

- **Potential for abuse**

  “I’ve seen my son grab and shake my daughter . . . I had to do something to stop it . . . when he saw me intervene, he went to hit me . . . but stopped himself and pushed me away.”

  “My son said, ‘Some day you won’t be here to save him . . . and again I heard the anger and resentment in his voice . . .’”
Findings: Theme Three

- **Rewards needed by siblings to undertake the caregiving role**

  “If you want me to take care of him, then give me the house and the money to do it . . . You can’t expect me to ruin my life for him.” “. . . Leave me everything.”

  “I was told to leave my son everything, if you want me to be responsible for him.”
Findings: Theme Three

- **Rewards needed by siblings to undertake the caregiving role**

  Many participants expressed concern about being told, “What will I get out of doing this?” “What is the reward?” “Don’t expect me to . . .,” “I am not like you . . .,” “This is not my problem . . .,” “It was your choice to take care of him . . . not mine.”
Findings: Theme Four

- **Experience of stigma from siblings**

Participants stated comments made by their healthy children, “There are putdowns . . . saying nasty things . . . belittling . . . getting in his face . . . calling him out if he can’t think . . . using him . . . manipulating her . . . taking advantage . . . treating her like his slave . . . saying don’t mess with me or I'll hurt you . . . he always starts trouble . . . he can’t do things . . . he is different and he needs to be treated differently.”
Findings: Theme Four

- **Experience of stigma from siblings**

“All my kids think that something is wrong with him and treat him badly . . . that he’ll never be okay . . . and they are angry about how it has affected them over the years.”

“It was hard to have a brother with a mental illness, who had bizarre behavior, and my other kids often believed that there was something wrong with them too.”
Conclusions

• Parents acknowledged the burden that caring for a person with MI places on the family from their personal perspectives and the perspectives of their children.

• Parents verbalized that their healthy adult children expressed a sense of unfairness and injustice about being asked to take on complex and repetitive requirements of being a caregiver for a sibling with MI.
Conclusions

- Parents perceived the need to persuade or sell their healthy adult siblings on the idea of providing care for a sibling with MI.

- According to parents, siblings expressed that if they choose to participate in providing care for a sibling with MI, they desired or required compensation.
Conclusions

- Healthy adult siblings had an intolerance and impatience for struggles that their siblings with MI manifested; this intolerance had the potential to trigger abusive behaviors from healthy siblings.

- The level of emotional distress and frustration felt by healthy siblings, along with years of experiencing stigma by association, created a negativity in the healthy siblings that produced additional stigma to their siblings with MI.
Implications

- There is a strong need for parental caregivers to become educated about strategies to advocate for continuing care and realistic placement for their mentally ill family members when they become unable to provide the required care.

- Information and education must be directed to all family members, particularly healthy siblings to promote understanding of MI and to eliminate stigma and abuse.

- The stigma associated with mental illness must be identified and addressed in the context of holistic family care. Ongoing efforts to prevent the various types of stigma must be implemented.
Implications

- An inter-professional approach including representatives from health care, financial and legal communities must be developed to promote effective decisions about the future care of adults with MI when they cannot be cared for by family members.

- Education, clinical practice and research are integral to developing guidance and action strategies for providing care and eliminating stigma and abuse of people with chronic mental illness and their family caregivers.