

# The Perceptions of Stigma by Parental Caregivers with Mentally Ill Family Members

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# Disclosure

- Presenter: Linda Carman Copel
- Learner Objectives:
  - The main purposes of this study were to describe the parental perceptions of stigma experienced by their adult children with mental illness, and to determine the educational and advocacy strategies that caregivers perceived as useful.
- Conflict of Interest Statement:

I have no relationships to disclose.
- Employer: Villanova University
- Sponsorship or Commercial Support:

I have no support to disclose.

# Background of the Study

- The concept of stigma is recognized as a universal experience which is a major cause of suffering and a deterrent to obtaining health care.
- Vulnerable populations, such as people with mental illness or psychiatric disabilities, are at risk for various forms of stigma.
- Caregivers can frequently identify the types of stigma experienced by their family members.
- Stigma has a negative influence on people's lives by causing high levels of stress and social disadvantages.

# 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 stigma of mental illness.
- There is minimal literature which addresses the concept and forms of stigma.
- There is a strong need for caregivers to become educated about strategies to advocate for their mentally ill family members, and to reduce or eliminate the stigma associated with mental illness.

# Objectives of the Study

- The main purposes of this study were to describe the parental perceptions of stigma experienced by their adult children with mental illness, and to determine the educational and advocacy strategies that caregivers perceived as useful.
- An additional secondary purpose was to evaluate a community mental health, educational and support program for parent caregivers.

# Qualitative Methodology

- 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.

# Population – Sample - Setting

- POPULATION

Adult mothers and fathers who are 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 Collection

- Eighteen participants were recruited to the program through one of the county family service programs or the outpatient community mental health centers.
- After program registration was completed and informed consent was obtained . . .

A demographic data sheet was completed

Every session was video-recorded

A program evaluation form was completed



# Program 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 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 2 - 4 in each family
- Adult Children with Mental Illness 10
- Age Range of Adult Children 32 - 48 years

# Demographic Data

- Employment of Adult Children (10 females, 4 males)
  - 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 Diabetes
  - 4 Depression
  - 4 Heart Problems
  - 3 Emphysema
  - 2 Thyroid Problems
  - 2 Marijuana & Alcohol

# Demographic Data

- Parents' Self-Identified Health Problems
  - 9 Hypertension
  - 8 Heart Problems
  - 8 High Cholesterol
  - 6 Arthritis
  - 6 Back Pain
  - 4 Diabetes
  - 4 Osteoporosis
  - 2 Depression

# Findings: Six Themes

- Caregiver feelings of frustration, anger and discrimination when their family members experience stigma
- Experience of stigma by association
- Stigma contributing to health problems of people with mental illness
- Concerns about advocacy actions being successful
- Desire to establish mental health advocacy groups for education, employment and vocational training
- Need for consumer centers



# Findings: Coping Strategies

- Learn to handle depression and social stressors
- Seek out needed information
- Use caution when disclosing personal information, needs and problematic situations
- Develop effective communication skills and make choices
- Focus on what is important and have goals
- Educate self and others
- Participate in support groups
- Use humor
- Avoid certain people and situations

# Findings: Program Evaluation

- All evaluations indicated positive rating of program

Excellent            14

Very good            4

- Summary of Comments:

Pleased that they attended the program

Learned some new coping strategies

Encouraged to verbalize concerns and express feelings

Felt they were heard and understood

Did not feel rushed to explain things

Recognized that their concerns were not minimized

Receptive to returning to the community mental health center

# Findings: Reasons for Attending

- Caregiver participants believed that outcomes of stigma experiences included:
  - Increase in conflict and disagreement between caregiver and family member
  - Issues of caregiver being overprotective
  - Decrease in family communication and connection
  - Increase in physical health and mental problems
  - Increase in anger and agitation creating isolation
  - Increase of depression experiences
  - Potential for increase of alcohol and drug use

# Conclusions

- The experience of stigma was not discussed in health care settings, and family caregivers did not know how to address it in their communities.
- Powerful emotions were triggered when stigma occurred.
- Several forms of stigma were frequently experienced: stigma by association, double stigma and health care provider stigma.
- Caregivers were aware of what happens to family members who experience stigma. They believed that they do not know what to do to address it.

# Conclusions

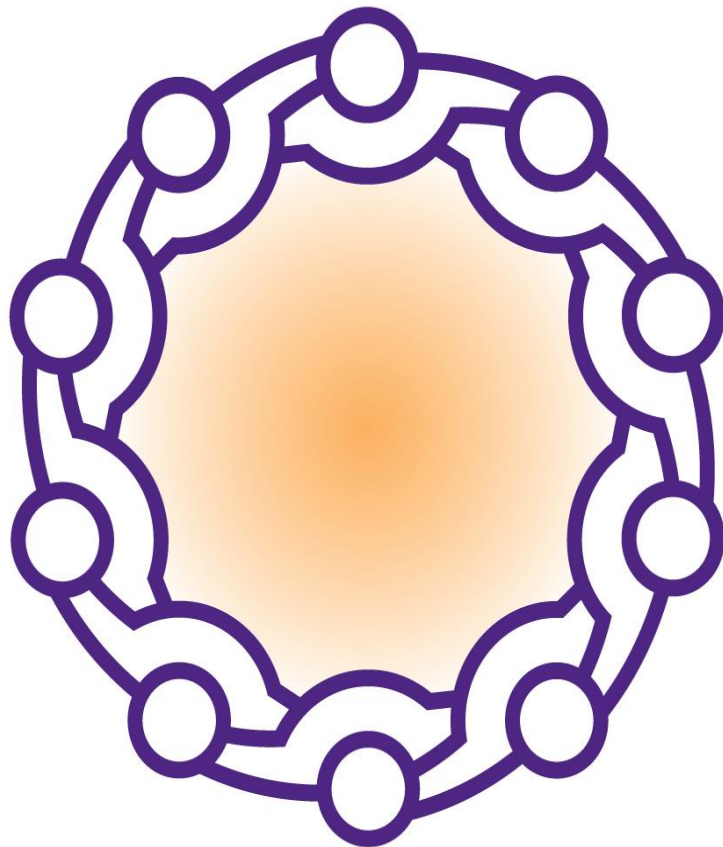
- Although the educational program was positively rated by participants, caregivers needed it to be individualized or customized to their particular issues and concerns.
- Face-to-face, personal contact was the participants' preferred strategy for learning about how to eliminate stigma.
- Many of the situations and problems addressed in the program were identified as actually happening to the participants.
- The identification and discussion of potential problems allowed participants to be prepared if the particular problem occurred.

# Implications

- Information and education through the use of face-to-face personal interaction was useful to family caregivers.
- The support group and discussion components of the program were the essential factors that facilitated the program's success.
- Education, guidance and discussion of action strategies were integral to facilitating caregiver engagement in the program.
- The group format worked well for this program and met the participants' needs.

# Research Recommendations

- Review and replicate this study after revisions are made to the program.
- Develop follow-up studies on the effectiveness of the strategies caregivers used to address the experience of stigma in family members with mental illness.
- Perform longitudinal studies on the effectiveness of interventions used to address stigma.
- Plan further studies to evaluate interventions related to educating clients and caregivers.



# Stand Against Stigma

*Changing minds about mental illness.*