Aging Parents as Caregivers to Adult Children with Serious Mental Illness: Patterns of Vulnerability & Resiliency

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Serious Mental Illness

Schizophrenia
Bipolar Disorder
Major Clinical Depression

Significant impairment in daily life
Work
Ability to live independent in the community without supports
Interpersonal Relationships
Prevalence of SMI Among U.S. Adults (2012)
Three Major Research Questions

What is the nature of stress experienced by aging parents who provide lifelong care and support to an adult child with a serious mental illness?

What are the long-term effects of caregiving on parental physical and psychological well-being?

What are the pathways to risk and to resiliency?
Types of Stressors

Societal Stressors

Individual Stressors
Societal Stress
Historical Context
Aging Parents Lived Through

Mendota Mental Health Institute

Winnebago Mental Health Institute
Deinstitutionalization
Locus of Treatment: Hospital to Community

Mendota

Winnebago

1960 1980

1960 1980
Lack of Community Supports

- System of care based on “acute” conditions
- Shortage of trained mental health professionals
- Lack of housing
Schizophrenogenic mothers: rejecting, domineering, critical, over demanding, controlling, smothering
“The schizophrenic is painfully distrustful and resentful of other people due to the severe early warp and rejection he encountered in important people of his infancy and childhood, ....mainly in a schizophrenogenic mother.” (Frieda Fromm-Reichman, 1940, 1948)
Societal Stigma

“ The hardest thing is when people make fun of Sam or look at us as though something’s wrong with us… “

“One time he was broke and ran into three of his former friends who had slept at our house when they were young and eaten at our family dinner table. They were in business suits and they were coming out of a restaurant...”
“Sam was dirty and hungry and had no money for the bus. One of the guys had a new car and my son went over and said “I’m going to my folk’s house, can you give me a lift.” It was the end of the day. And they looked at my son, and said ‘Get a life.’ They got into the car, made some offensive remarks, and drove away.

And Sam came home and cried.”
The Media: Schizophrenia & Violence

James Holmes
Aurora, Colorado

Adam Lanza - Newtown, Connecticut, Sandy Hook Elementary School

One Goh, Oakland, CA shooting

Elliot Rodgers, Santa Barbara
More Likely to be Victims

2.7 to 10 times more likely to be victims of violence than in the general population
“He’s very vulnerable. A few years ago, he was working and he was making all kinds of money. He wasn’t interested in spending it. And he’d give it away to folks who promised that they would pay him back, which of course they never did.”
Individual Stressors
Here was somebody who was a National Merit Scholar and on his way to really contributing to society, so active and an all around gifted person.....To see that gone because of the illness. It was so hard. And I spent a lot of nights crying. It was just like he had died and somebody else had moved in. And I missed the old Steve. “
“When she came home, she was deep in debt I bailed her out to the tune of $40,000 paying credit cards and hospital bills and all kinds of delinquent taxes and so forth. But when she went off her meds in 1998, she ran away and was gone for a week, She ran up another $6000 on her credit card. And this time, I’m 70 years old, I’m living on a limited income…”
What will happen when I’m gone?

“I am gonna be 75 this next year. I don’t know what’s gonna happen to her if I pass away. I have a very big concern on that. What’s gonna happen to her? When I talk to her sometimes about this, she says ‘Oh, I’ll just move in with my brother.’ I say No, you got to learn to live on your own. They have their own problems.”
The toll of long-term caregiving on the well-being of parent’s in later life
Research Studies

- Studies of Wisconsin Families who have an adult child with SMI receiving treatment in publicly funded mental health programs. Recruited through CSP and NAMI
- Wisconsin Longitudinal Study from Robert Hauser (PI)
- Midlife in the United States (MIDUS) Carol Ryff (PI)
Number of Physical Symptoms

Depressive Symptoms

Alcohol Symptoms

F (type of case) = 3.81, p < .05

F (type of case) = 4.18, p < .05

F (type of case) = 3.45, p < .05
Multiple Caregiving Responsibilities

Depression

Social Participation

Financial Strain

Depressive Symptoms

Spouse Healthy: 7.4
Spouse Disabled: 8.2

Social Participation

Spouse Healthy: 3.1
Spouse Disabled: 2.5

Financial Strain

Spouse Healthy: 1.4
Spouse Disabled: 1.8
Summary

- More health problems
- Higher levels of depression for mothers, fathers higher rates of alcohol use
- Married couples caring for adult child with SMI and a spouse disabled are particularly vulnerable
Heterogeneity in Experience

Wear and Tear Effect

“The problems with my daughter were like a black hole inside of me into which everything else had been drawn. The pain is so intense sometimes that I barely get through the day.” (Marsh et al., 1996)
Heterogeneity in Experience

Wear and Tear Effect

“My daughter’s mental illness wrecked my marriage. Her father was weak and could not take it.” (Marsh et al., 1996)
A Process of Growth

“There is absolutely nothing each of us wouldn’t do for one another. We celebrate the high points and come together in times of trouble. Along with mental illness, we’ve dealt with divorce, alcoholism, and the routine ups and downs of life. In every instance, .... we come up triumphant.” (Marsh et al., 1996)
A Process of Growth

“I feel stronger and better able to meet life’s challenges. My husband and I have become closer and more loving…” (Marsh et al., 1996)
Pathways to Resiliency
Resiliency

Ability to maintain a sense of positive well-being even in the face of enduring long-term life challenges
Is the behavior due to an underlying illness or within the individual’s control?

“He needs to be told quite a few times before it sinks in, and I don’t know if it’s just because he’s being lazy, or if he is not just getting what we are trying to say because of his illness. This illness is so hard to understand.”
Resilient Parents are able to:

Understand it is an illness

Separate the person from the illness.
“We are people and not a diagnosis. We are separate from the illness. We have much respect for our son for being able to deal with this.”

“When bad things happen, remember the person and remember that it is the illness that is causing the behavior.”
Information Seeking Coping

Information about serious mental illness and its treatment

Psychoeducation programs
Accommodative Coping

Ability to change expectations; to accommodate to a new reality
“...Don’t expect a miracle overnight. Don’t expect them to never get sick once you see them getting better. “
Importance of Optimism

“Even the bad days are learning experiences. The bad days turn out to be a good thing because you learn a way to help and how to help.”
“I’ve been very active in my son’s life in the Alliance for the Mentally Ill, and in the Community Support Program. … I feel I’ve accomplished something for my son and for others with mental illness.”  (Marsh et al., 1996)
“Imagine seeing a beloved son regain his ability to smile, to laugh at a joke, to be socially acceptable....To see him able to live independently once more, with a part-time job and the pride of being more like others. And to feel we have helped this process.” (Marsh et al., 1996)
Persons with Mental Illness as a Family Resource

“I got a bad hip—he does all my vacuuming, washing windows. He keeps up all the yard work here and he’s very, very thoughtful with me if I’m sick.”
What Doesn’t Work: Vulnerabilities
Emotion Focus Coping

Denying a problem,

Psychologically or Behaviorally Disengaging

Venting Frustration and Anger
Detachment

“I live my own life, and detach from the situation. When I detach, I feel stronger”
Having friendships with parents who do not share your difficulties is just as important as being with people who know what it is like to walk in your shoes.
Concluding Tips

 Practice optimism
 Be flexible in your expectations
 Try to separate out the person from the troubling behavior
 Seek ways to enhance reciprocity in the relationship
 Don’t rely on emotion-focused coping
 Have a diverse group of friends
Research Support

❖ National Institute of Mental Health
❖ National Institute of Aging
❖ Graduate School, University of Wisconsin-Madison