Keeping Care Complete
Caregivers' perspectives on mental illness and wellness
AN INTERNATIONAL SURVEY

The Caregiver Perspective

Caregivers of Individuals with Bipolar Disorder, Schizophrenia and Schizoaffective Disorder

- In the past 50 years, a shift toward community care and the deinstitutionalization of psychiatric patients has resulted in transferring of responsibility and day-to-day care to family members.[1] In part, this shifting of responsibility has been caused by a deficit in community support services.

- The profound psychosocial, physical, and financial impact on the family of individuals with severe mental illness is comparable to that of persons with other illnesses such as Alzheimer's disease or cancer. [2, 3]

- Recent estimates indicate that in the United States between one-third and two-thirds of persons with long-term psychiatric disabilities currently reside with family members.[4] Available data show that the proportion of persons with schizophrenia living with their relatives ranges between 40% in the United States to more than 90% in China.[5]

- Caregiver burden associated with mental illnesses refers to negative responses that occur when caregivers assume an unpaid and unanticipated responsibility for the person for whom they are caring who has disabling mental health problems.[6] The intensity of caregiver burden may be influenced by the duration and frequency of hospitalizations and relapse.

- A cross-European study (EPSILON) found caregiver burden in schizophrenia to be almost identical across England, Denmark, the Netherlands, Italy and Spain. Caregiver burden increased when caregivers had more contact with patients and when patients lived with their families.[7]

- *Worried, Tired and Alone*, a 2003 report analyzing the issues affecting caregivers of people with mental illness in Western Australia, found that as a result of long-term caregiving, the majority of caregivers surveyed experienced personal, emotional and physical strain on their lives and the loss of their personal freedom.[8]

Emotional impact

- Guilt, loss,[9] helplessness, [10] fear, vulnerability, [11] and cumulative feelings of defeat, anxiety, resentment, and anger are commonly reported by caregivers.[12]

- Caregivers may feel isolated, restricted from pursuing their own activities, and may be overwhelmed by a lack of support from friends, family and treatment providers.[13]

- Frustration in ensuring medication adherence;[14] coping with disturbed or awkward interpersonal behavior[15] and fatigue from continuous supervision of a family member have also been reported to add to caregiver burden.[16] In addition, caregivers have reported great anxiety due to fear that their relative may attempt suicide.[17]

- *Worried, Tired and Alone* found that many caregivers feel a deep and pervasive sense of fear and uncertainty as well as powerlessness and helplessness, often exacerbated by the unpredictable behaviors of the individual with mental illness experiencing a relapse. Most commonly reported behaviors were the reactions of violence, volatile mood swings, alienation, abusive language and the capacity of the individual to appear normal one minute and on the edge the next.[18]

Financial impact

- A loved one's mental illness may lead to a disruption of household and work routines [19] and a loss of productivity for the family unit. [20]

- Family members are often put in a position where they are required to pay for medical treatment for their loved one with a mental illness, as well as bear the brunt of a potential increase in medical costs for other family members. [21]

Physical impact

- Physical and mental health problems of caregivers increase for those providing the highest levels of care. Rates of caregiver depression have been estimated to range from 38% to 60%. Caregivers of family members with a higher number of symptoms and level of cognitive impairment experience more depression. [22]

- Similarly, there is a link between caregiver burden and symptoms of infectious illnesses (primarily upper respiratory illness) experienced by caregivers. The more severe the loved one's symptoms, the greater the number of infectious illnesses contracted by the caregiver.[23]

- Additionally, *Worried, Tired and Alone* found that many caregivers of individuals with mental illness reported feeling very tired, drained, emotionally stressed and sick from their caregiving responsibilities; some of them had also developed physical illness. [24]

- In another study, family members living with a person with bipolar disorder reported poorer physical health, more limited activity, and greater health service utilization than non-caregivers. [25]

- While studies have shown that people with severe mental illness are more likely to become victims of violent crime,[26] violence is a stressor that affects family caregivers both emotionally and physically. Among patients admitted to psychiatric hospitals who had physically attacked someone, research shows that family members were the targets more than 50% of the time.[27]

Successful treatment helps reduce relapse and ease caregiver burden

- Caregivers of patients with bipolar disorder, schizophrenia and schizoaffective disorder often struggle emotionally when their loved one doesn't comply with treatment.[28] Conversely, proper treatment can relieve symptoms, prevent or delay relapse [29, 30] and help individuals with bipolar disorder, schizophrenia and schizoaffective disorder lead productive and fulfilling lives. [31, 32, 33] This may also reduce caregiver burden and allow caregivers to focus on other aspects of their lives.

- Family therapy and other programs that involve and support families early in the treatment process have been found to reduce relapse and decrease stress and disruption in the family.[34] Studies show that family interventions have repeatedly demonstrated reductions in illness relapse, negative symptoms, and inpatient service utilization. [35]

- Family members of individuals with mental illness should seek support from friends and family members, or if they feel that they cannot discuss their situation with these individuals, they should find a self-help or support group. Such groups provide an opportunity for caregivers to speak with other people who are experiencing the same type of problems.[36]

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