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

Survey Results - United States

Keeping Care Complete is the first international survey to shed light on experiences and insights of family caregivers of individuals with bipolar disorder, schizophrenia and schizoaffective disorder. Two hundred caregivers in the United States were among the 982 caregivers from around the world to participate in this survey.

Family caregivers are at the heart of the recovery process

The greatest percentage of caregivers surveyed (46 percent) were the parent of an individual with a serious mental illness. Of the other caregivers, 28 percent were the spouse, 7 percent were a sibling and 6 percent were an adult son or daughter.

A majority of caregivers (80 percent) said they were the primary caregiver for their loved one. In addition, 83 percent said they weighed in on treatment decisions and 80 percent said they accompanied their family member during visits with doctors.

Family caregivers want complete care and long-term wellness for their loved ones

Almost all caregivers (97 percent) said the goal of treatment should be to maintain wellness, defined as the condition of both good physical and mental health.

Forty percent of caregivers said family support is a key factor in keeping family members well. Other factors contributing to wellness were social support (22 percent), talk therapy (24 percent) and exercise and diet (11 percent). A majority of caregivers (72 percent) said doctors should focus on long-term care rather than managing crisis situations. In addition, 83 percent agreed that wellness programs are valuable in helping their family member manage their symptoms.

Relapse is devastating for families

Of the caregivers who said their family member experienced a relapse, 68 percent said that their loved ones were unable to work, 49 percent said they were hospitalized, 27 percent said they tried to commit suicide and 19 percent said their family member was imprisoned as a result of a relapse.

More than half of caregivers (61 percent) said they always or often worry about their family member experiencing a relapse and 43 percent said their own mental and physical health worsened following their family member's relapse.

Effective treatment benefits the whole family

Caregivers who said their relative is currently satisfied with their medication said that their family member is now able to re-engage with family and friends (81 percent), perform daily tasks more independently (85 percent), stay out of the hospital (82 percent), learn a new skill/attend a class (53 percent) and hold a steady job/volunteer (35 percent).

Family members' wellness and improvement of symptoms helped decrease caregivers' stress levels (67 percent) and interpersonal tension (69 percent), while also increasing the amount of quality time spent with the family (74 percent).

Nine hundred and eighty two caregivers from United States, Australia, Canada, Germany, France, Italy, Spain and the United Kingdom participated in the survey, which was developed by the World Federation for Mental Health (WFMH) and Eli Lilly and Company. To view survey findings across countries represented in the survey, as well as additional fact sheets on the caregiver perspective and serious mental illness, please visit www.wfmh.org.