

Caregivers Of People With Schizophrenia Need Support, Not Stigma

(NAPS)—An estimated 2.4 million Americans are living with schizophrenia. However, the condition impacts many more than those patients alone. It also impacts the people who love those patients, care for them and worry about them. It takes courage, compassion, and a commitment to stand and face this serious condition together. May is Mental Health Awareness Month, and it's an ideal time to recognize this often overlooked caregiver population.

Caregivers act as advocates, collaborate with treatment team members and often are the main support in the daily life of their loved one with schizophrenia. Results of an online survey* among 302 unpaid caregivers to adults with schizophrenia reveal that many caregivers face challenges in caring for their loved ones, yet they strive to maintain a positive outlook.

“Caring for a loved one with schizophrenia has considerable challenges because of the stigma associated with the disease. Many people don't understand schizophrenia and they may fill those gaps with fear. It's a unique caregiving experience in that sense,” said Randye Kaye, mental health advocate, actress and author of “Ben Behind His Voices: One Family's Journey from the Chaos of Schizophrenia to Hope.” Kaye is the primary caregiver for her son, who was diagnosed with schizophrenia about 12 years ago. Her book is a memoir of her experience as a mother and caregiver to her son, from the onset of his battle with schizophrenia along the hopeful road to managing his disease.

Results from the survey suggest that caring for someone with schizophrenia can be associated with significant challenges. Of caregivers surveyed, 79 percent felt their loved one has experienced isolation and 57 percent felt they have experienced isolation as a result of their loved one's schizophrenia.



Randye Kaye

Perhaps because of the perceived stigma and social isolation, caregivers may feel they lack support from others. Seventy-nine percent of those surveyed said they wish there were more opportunities to talk to others about caring for someone with schizophrenia and more than half (57 percent) have felt nobody understands what they are going through.

Despite challenges, 94 percent of caregivers surveyed said they try to maintain a positive outlook and 68 percent would likely be as involved in their loved one's care even if someone else was willing and able to be a caregiver. Kaye knows firsthand how important the caregiver's role is in contributing to successful outcomes for a loved one with schizophrenia.

“I know from experience the physical and emotional burdens of caring for someone with schizophrenia, but I also know how critical my involvement is to my son's success,” said Kaye. “I've learned that a caregiver's informed input can be an incredibly valuable contribution to an effective treatment team. That's why it's important to develop strong and trusted relationships with members of your loved one's treatment team.”

Feeling supported is key for caregivers, said Kaye. There is a notable difference between caregivers who feel satisfied by the support that's available and those who do not, according to results of the survey. Compared to those who are dissatisfied by available support, caregivers who are satisfied are more likely to feel grateful (39 percent v. 23 percent), content (27 percent v. 11 percent) and proud (38 percent v. 24 percent) about being a caregiver for their loved one. They are also less likely to feel stressed (36 percent v. 66 percent), challenged (40 percent v. 58 percent), frustrated (25 percent v. 54 percent), overwhelmed (28 percent v. 40 percent), and sad (25 percent v. 40 percent), and they're less likely to feel that nobody understands what they're going through (49 percent v. 65 percent).

This reinforces that action is required to help provide caregivers with the support and resources they need.

“If you are caring for someone with schizophrenia, you are not alone. There are others out there who are going through what you're going through, and there are resources that can help,” said Kaye.

If you or someone you know is struggling to provide care for a loved one with schizophrenia, visit WeLiveWithSZ.com to register for resources and find the support you deserve.

*The survey was conducted by Harris Poll on behalf of Otsuka America Pharmaceutical, Inc. and Lundbeck. The survey was administered online within the United States between January 20 and 27, 2014, among 302 adults who provide unpaid care for an adult with schizophrenia. Data were not weighted and are only representative of those who completed the survey. Certain percentages include net values (such as those who selected “somewhat agree” and “strongly agree” on a four-point agree/disagree scale).

References:

1. *The Numbers Count: Mental Disorders in America*. National Institutes of Mental Health Website. <http://www.nimh.nih.gov/health/publications/the-numbers-count-mental-disorders-in-america/index.shtml> Accessed Mar. 17, 2014
2. Suresky, M. J., Zauszniewski, J. A. and Bekhet, A. K. *Factors Affecting Disruption in Families of Adults With Mental Illness*. *Perspectives in Psychiatric Care*. 2013; 49.
3. Chen, F. & Greenberg, J. *A Positive Aspect of Caregiving: The Influence of Social Support on Caregiving Gains for Family Members of Relatives with Schizophrenia*. *Community Mental Health Journal*. 2004; 40: 423-435.
4. Shor, R. & Birnbaum, M. *Meeting Unmet Needs of Families of Persons with Mental Illness: Evaluation of a Family Peer Support Helpline*. *Community Mental Health Journal*. 2012.
5. González-Torres, et al. *Stigma and Discrimination Towards People With Schizophrenia and Their Family Members*. *Social Psychiatry and Psychiatric Epidemiology*. 2007, 42: 14-23.
6. *Understanding Schizophrenia and Recovery*. NAMI. 2008. Available at: http://www.nami.org/Template.cfm?Section=By_Illness&template=/ContentManagement/ContentDisplay.cfm&ContentID=7279