Background & Methods

Background

An online survey was administered to self-identified, unpaid, informal caregivers of adults diagnosed with schizophrenia or schizoaffective disorder for at least one year. The survey was developed after conducting a literature review and interviews with experts in the field of schizophrenia and caregivers. The survey included questions about caregiver characteristics, out-of-pocket (OOP) costs, and the impact of caregiving on family, work, and social life.

Methods

The survey was administered to caregivers of individuals with schizophrenia or schizoaffective disorder. The survey included questions about the number of major life events (MLEs) reported by the caregiver in the past 12 months, and the impact of caregiving on family, work, and social life. The survey also included questions about the number of days the care recipient spent in the hospital, and the number of contacts the caregiver had with mental health professionals.

Results

The survey was completed by 229 caregivers, with an average age of 55.8 years and a majority (89.2%) were female. Most caregivers (86%) reported at least one MLE in the past 12 months. The average number of MLEs reported was 4.0 (SD = 3.0). The most common MLEs were financial problems (32.3%), substance use (18.1%), and personal health issues (15.8%). The impact of caregiving on family, work, and social life was common, with 57.7% reporting at least one impact on family life, 43.5% reporting at least one impact on work, and 50.3% reporting at least one impact on social life.

Conclusion

Caregiving to those with schizophrenia or schizoaffective disorder is a significant burden, with impacts on family, work, and social life. Caregivers of individuals with schizophrenia should receive support and resources to help them manage the burden of caregiving.

Additional Information

Limitations

Caregivers responding to the survey may differ from the general population of caregivers of individuals with schizophrenia. Some evidence suggests that caregivers who devote more time to caregiving and report higher burden are more likely to experience burnout. Therefore, results should be interpreted with caution.

Disclosure

The authors declare no conflict of interest. All authors have reviewed and approved the final version of the manuscript.

About Schizophrenia & Psychotic Action Alliance (S&PAA)

S&PAA has launched a transformative initiative to lead a system-wide movement for change to improve care, support, and equity for the millions of people living with schizophrenia and psychosomatic disorders. Learn more at sampa.org and follow us on Twitter @SPPAAAction.