SCHIZOPHRENIA –
BRINGING THE
BURDEN OF CARE
INTO THE SPOTLIGHT

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According to the World Health Organization, more than 21 million people worldwide suffer from schizophrenia, with only half of patients receiving proper care. Schizophrenia is a debilitating brain disorder. Patients diagnosed with schizophrenia may hear voices or believe that others are reading their minds, plotting to harm them or controlling their thoughts. These symptoms greatly affect patients’ abilities to perform routine daily tasks. Therefore, those caring for adults diagnosed with schizophrenia are required to be heavily involved in day-to-day activities, which affect their own mental and physical well-being.

The extent and impact of caring for an individual with schizophrenia are not well recognized in society, and caregivers do not have adequate support and resources. While previous studies indicated that significant costs are associated with caring for a patient with schizophrenia, large-scale studies are not available in Europe. These financial estimates are needed to guide treatment and care decisions related to schizophrenia.

**Demand of Caring for Schizophrenia Patients**

To address the humanistic and economic burden of caring for schizophrenia patients, our study sought to profile informal caregivers and communicate the burden to help integrate them into society. This study used data from the 2010, 2011 and 2013 5EU National Health and Wellness Survey (NHWS). The NHWS is a nationally representative, cross-sectional patient-reported general health survey of adults (18+) conducted in the 5EU (France, Germany, Italy, Spain and the UK), the United States, Japan, Brazil, urban China and urban Russia and covers topics including patient demographics, health history, health status, attitudes, behaviors and health outcomes.

As schizophrenia impairs mental functioning, patients are highly reliant on their caregivers. They are often unable to hold a job or care for themselves. Many patients live with caregivers who provide assistance with their daily activities. These tasks include managing finances; making treatment decisions; managing transportation, meals, housework and medications; arranging for outside services; and helping with bathing/grooming. According to data from NHWS, over half of schizophrenia caregivers reported they regularly manage finances and make treatment decisions for the adult with schizophrenia they are caring for (Figure 1).

**Impact of Caring for Schizophrenia Patients**

The 5EU NHWS respondents who reported caring for an adult with schizophrenia were further compared with those caring for individuals with other conditions (e.g., Alzheimer’s disease, cancer or stroke) as well as non-caregivers. The current study matched demographics and health characteristics across the three respondent groups via propensity scoring methodologies. Separate matching criteria were implemented to compare schizophrenia caregivers with other caregivers, as well as to compare schizophrenia caregivers with non-caregivers. The matched samples were subsequently reanalyzed to confirm appropriate balance between the groups. Additionally, the matched samples were compared on health-related quality of life (HRQoL) using the Short-Form (SF)-36v2 (a general health quality of life validated scale), stress-related comorbidities, resource utilization and associated direct costs. Respondents also completed the Work Productivity and Activity Impairment (WPAI) questionnaire, a validated instrument that

+ THOSE CARING FOR PATIENTS WITH SCHIZOPHRENIA EXPERIENCE A LOWER MENTAL HEALTH-RELATED QUALITY OF LIFE THAN NON-CAREGIVERS AND THOSE CARING FOR PATIENTS WITH OTHER CONDITIONS.
assessed work and activity impairment due to one’s health in the past seven days. Absenteeism, presenteeism, overall work impairment, and activity impairment and associated indirect costs were calculated via the WPPI and public sources.3,5

Overall, results from NHWS showed that those caring for patients with schizophrenia experience a lower mental HRQoL as measured by the Mental Component Summary from the SF-36v2 and higher direct and indirect costs and overall activity impairment than other caregivers and non-caregivers.3,5

Schizophrenia caregivers and other caregivers reported similar rates of work-related productivity loss and physical HRQoL, as measured by the Physical Component Summary of the SF-36v2.3,5 The analysis found that those caring for adults with schizophrenia reported more healthcare provider visits, emergency room visits and hospitalizations than non-caregivers and slightly more physician visits than caregivers of adults with other

**FIGURE 1. CAREGIVER INVOLVEMENT WITH PROVIDING CARE TO ADULTS WITH SCHIZOPHRENIA IN THE 5EU**

- I am not involved at all: 25.5% (61.2%)
- I help out occasionally: 16.6% (24.8%)
- I help out regularly, but another family member or friend is more involved: 6.4% (14.0%)
- I share responsibilities in equal parts with another family member or friend: 8.3% (10.8%)
- I am mainly responsible: 7.6% (24.8%)

- Bathing or grooming, toileting, feeding, etc.
- Transportation, meals, housework, medication management, arranging for outside services
- Making treatment decisions (including nursery home placement)
- Managing finances

+ WITHOUT THE PROPER SUPPORT IN PLACE, THE BURDEN OF SCHIZOPHRENIA CAN MAKE PROVIDING ADEQUATE CARE DIFFICULT.
conditions. Respondents who cared for adults with schizophrenia reported estimated medical care costs more than three times higher than non-caregivers and nearly twice as high as other caregivers.3

The greatest differences in comparing schizophrenia caregivers with other caregivers and non-caregivers were seen in mental HRQoL. In particular, caregivers of adults with schizophrenia saw the greatest impact to their HRQoL in the areas of mental health (feelings of nervousness and depression), role emotional (problems with work or other daily activities as a result of emotional problems), and social functioning (interference with normal social activities due to physical and emotional problems) based on the SF-36v2 domain scores when compared with the total 5EU population. All of the domain scores were below the population average [normed mean=50], with many exceeding a minimal important difference [> 3 points different] [Figure 2].6

**FIGURE 2. AVERAGE SF-36V2 DOMAIN SCORES FOR CAREGIVERS OF ADULTS WITH SCHIZOPHRENIA**

- **Mental Health:** 40.6 vs. 45.9
- **Role Emotional:** 41.9 vs. 47.7
- **Social Functioning:** 42.8 vs. 48.0
- **Vitality:** 45.6 vs. 49.3
- **General Health:** 46.0 vs. 48.9
- **Bodily Pain:** 45.3 vs. 49.3
- **Role Physical:** 45.6 vs. 49.4
- **Physical Functioning:** 46.7 vs. 51.3

**Legend:**
- ■ Caregiver of Adult Relative with Schizophrenia
- □ Total 5EU Adult Population
A prior study indicated that the burden of providing care increases as schizophrenia patients’ symptomatology increases and they become less able to care for themselves. In addition to having a decreased mental and physical HRQoL, schizophrenia caregivers were substantially more likely than non-caregivers to experience stress-related comorbidities including sleep difficulties, insomnia, pain, headaches, heartburn, anxiety and depression. These results were consistent across all 5 EU countries (France, Germany, Italy, Spain and the UK), implying that schizophrenia caregivers reported greater burden than non-caregivers reliably across all five countries (Figure 3).

**PREVIOUS STUDIES HAVE SHOWN THAT FAMILY-FOCUSED INTERVENTIONS REDUCED CAREGIVER BURDEN AND PATIENTS’ SYMPTOM SEVERITY.**

**BURDEN OF CAREGIVING AFFECTS THE LEVEL OF CARE PROVIDED**

This study shows the burden of caring for an individual with schizophrenia is significant. Caregiving has a major impact on daily routines as well as mental, physical and economic outcomes. The burden of a demanding condition such as schizophrenia is extensive and, without the proper support in place, can make providing adequate care difficult.

Yet despite this burden, caregivers’ reactions to providing care for schizophrenia patients were more often positive than negative. More than half of caregivers indicated that providing care was important to them and that they wanted to care for the patient. At least 40% of caregivers also commented that they were healthy enough to provide care, had enough physical strength, felt privileged to care for the patient and enjoyed providing care, and that caring for the patient made them feel good.

While many caregivers were positive toward providing care for individuals with schizophrenia, a significant percentage also indicated that the experience could be burdensome and they had inadequate financial and family support. Only 32% reported that their financial resources were adequate to cover the costs of caregiving. Further, 36%
commented that it was difficult to get family members involved in helping care for the patients.\textsuperscript{5}

It is evident that greater support and family services are needed to enable caregivers to provide quality care and alleviate the physical, mental and economic burdens of providing care. Improved community and family support systems may provide an outlet for caregivers, improving morale and addressing the issue of abandonment that many caregivers experience. Previous studies have indicated that family-focused intervention reduced caregiver burden, patients’ symptom severity\textsuperscript{6} and hospitalizations and improved social resources for caregivers.\textsuperscript{9,10} Medication management for schizophrenia patients must be a continued focus and is as important to the caregiver as it is to the patient because studies have shown that burden is reduced for those caring for higher functioning patients.\textsuperscript{11}

Although caregivers’ experiences were similar across the 5EU, implementing support resources for caregivers will need to be addressed at the local level. It is important for the local policy makers and the local healthcare communities to be aware of these caregiver issues so that they can provide optimal support, resources and treatments at the individual patient level that would adhere to local regulations and standard policies.
REFERENCES

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Ms. Gupta’s responsibilities include conducting cross-sectional and longitudinal research based on the National Health and Wellness Survey (NHWS) and custom surveys (both patient and physician data collection). Ms. Gupta engages in consulting, programming, statistical analysis (including multivariable analyses, structural equation modeling, item response theory and classic test theory analyses), producing abstracts, posters and manuscripts across a range of therapeutic areas and health outcomes. Ms. Gupta has authored over 100 publications and has presented her research at medical conferences.

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