

# Educational needs of caregivers of patients with schizophrenia: results of a national survey study

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## Introduction

- Schizophrenia is a chronic, severe, and disabling mental disorder that affects how an individual thinks, feels, and behaves<sup>1</sup>
- Over time, the care of patients with schizophrenia has shifted from psychiatric hospitals to outpatient treatment and caregivers who are responsible for managing the well-being of these patients<sup>2</sup>
- Caregivers of patients with schizophrenia are an often-overlooked target for education, but may be a key resource to promote therapeutic adherence and patient education<sup>3</sup>

## Objective

- To determine specific educational needs of caregivers of patients with schizophrenia

## Methods

- A survey instrument was developed and fielded to caregivers in the United States in September/October 2019 via online communities and caregiver newsletters
- Results were organized into specific topics, including:
  - Symptoms exhibited when diagnosed
  - Current treatment options and use of long-acting injectable (LAI) antipsychotics
  - Treatment adherence attitudes
  - Barriers for caregivers and patients with schizophrenia
  - Informational resources utilized
  - Caregiver information and education topics
- Data were analyzed using a combination of qualitative and quantitative methodology

## Results

### Characteristics of caregivers

- The study sample consisted of 96 caregivers of patients with schizophrenia (Table 1)
  - The mean age of the caregivers was 58, and the mean age of the patients they care for was 45
  - Caregivers reported a mean of 17 years since symptom onset and 14 years since diagnosis
  - Most caregivers (57%) were parents of patients with schizophrenia, with the majority residing in a suburban area (54%)
  - The type of support provided by the caregivers included coordinating medical care (74%), taking patients to medical appointments (73%), performing household tasks (71%), and managing finances (71%)

**Table 1** Characteristics of caregivers

Characteristic	Caregiver (N = 96)
Age of caregiver, mean (SD)	58 (11.5)
Age of patient, mean (SD)	45 (19.6)
Years since symptom onset, mean (SD)	17 (13.4)
Years since diagnosis, mean (SD)	14 (14.3)
Relationship to patient, %	
Parent	57
Family (non-parent)	25
Spouse/partner	12
Paid caregiver	6
Type of support provided by caregiver, %	
Coordinating medical care	74
Taking to medical appointments	73
Household tasks	71
Managing finances	71
Driving for errands	67
Medication supervision	67
Shopping	66
Participating in recreational activities	49
Other	32
Residence, %	
Urban	21
Suburban	54
Rural	25

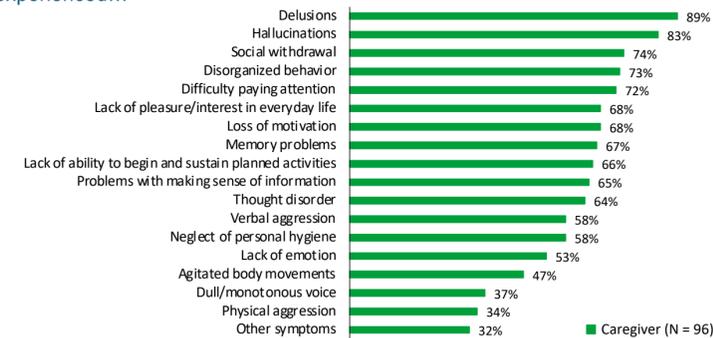
SD, standard deviation.

### Symptoms exhibited when diagnosed

- Caregivers reported that most patients had experienced delusions (89%) and hallucinations (83%) (Figure 1)
- When asked which symptoms are most worrisome when the individual needs to be admitted to the hospital, caregivers identified delusions, hallucinations, disorganized behavior, thought disorder, verbal aggression, and physical aggression
- When asked which symptoms are most worrisome when the individual is not in the hospital, caregivers identified delusions, hallucinations, social withdrawal, disorganized behavior, lack of pleasure/interest in everyday life, loss of motivation, verbal aggression, and physical aggression

**Figure 1** Symptoms exhibited when diagnosed<sup>a</sup>

Survey statement: The individual with schizophrenia for whom I provide care has experienced...



<sup>a</sup>Survey included definitions for hallucinations, delusions, disorganized behavior, and thought disorder.

### Current treatment options and use of LAI antipsychotics

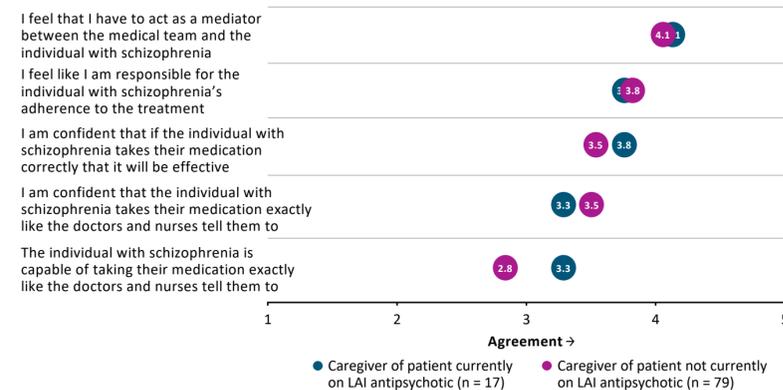
- The most common current treatments were oral antipsychotics (79%), psychotherapy (43%), and LAI antipsychotics (18%)
- LAI antipsychotics
  - 33% of caregivers reported having a conversation with a doctor or other healthcare provider about an injectable medication to help the patient with symptoms and relapse prevention
  - Caregivers of patients with no LAI antipsychotic treatment history identified cost of injectable medication as the most significant barrier to use
  - Caregivers of patients with LAI antipsychotic treatment history identified lack of information about what the medication does as the most significant barrier to use

### Treatment adherence attitudes

- Most caregivers feel that they act as a mediator between the medical team and the patient, and that they are responsible for the patient's therapeutic adherence (Figure 2)

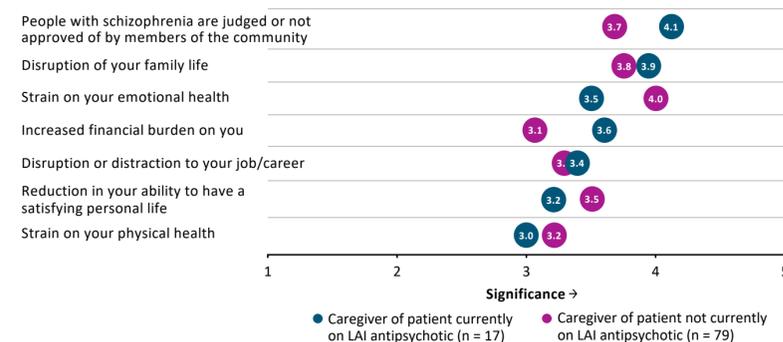
**Figure 2** Treatment adherence attitudes

Survey instructions: Please rate your agreement with the following statements



**Figure 3** Barriers for caregivers and patients with schizophrenia

Survey instructions: Please rate the significance of the following issues when caring for the individual with schizophrenia



### Barriers for caregivers and patients with schizophrenia

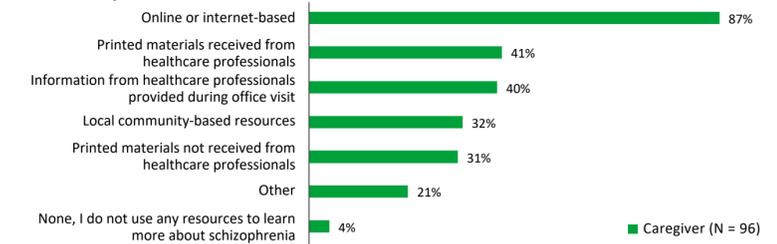
- The most significant barriers when caring for an individual with schizophrenia were judgment or lack of approval by members of the community, disruption in family life, and strain on emotional health (Figure 3)
- Caregivers generally have fewer barriers caring for patients on LAI antipsychotics than for those not on LAI antipsychotics

### Informational resources utilized

- Most caregivers (87%) use online or internet-based resources to learn about schizophrenia; other resources included printed materials received from healthcare professionals (41%) and information from healthcare professionals provided during office visits (40%) (Figure 4)

**Figure 4** Informational resources utilized

Survey question: What types of resources do you currently use to learn more about schizophrenia?



### Caregiver information and education topics

- Caregivers were interested in learning more about schizophrenia and its treatment (mean of 4.3 on a 5-point Likert scale) and about providing care for individuals with schizophrenia (4.2/5)
- When asked what informational or educational topic(s) related to schizophrenia and its treatment would be most valuable, caregivers indicated information on new medications, coping as a caregiver, understanding specific symptoms, housing and helping patients become independent, and establishing support groups in their areas

## Conclusions

- Symptoms that are most worrisome include positive symptoms such as delusions, hallucinations, disorganized behavior, thought disorder, verbal aggression, and physical aggression, and when the patient is out of the hospital, negative symptoms also become worrisome, including social withdrawal, lack of pleasure/interest in everyday life, and loss of motivation
- Most caregivers feel that they act as a mediator between the medical team and the patient, and that they are responsible for the patient's therapeutic adherence
- Caregivers generally have fewer barriers caring for patients on LAI antipsychotics than for those not on LAI antipsychotics
- Caregivers were interested in learning more about schizophrenia and its treatment, including information on new medications, coping as a caregiver, understanding specific symptoms, housing and helping patients become independent, and establishing support groups in their areas

