

Background & Methods

BACKGROUND

Individuals with schizophrenia generally require lifelong treatment focused on managing symptoms, improving functionality, and management of adverse effects of treatments. Access to coordinated and comprehensive care is limited by cost, psychiatrist scarcity, restrictive insurance arrangements, and fragmented systems of care in the United States.¹ Inadequate care and treatments are associated with a range of poor psychosocial, physiological, economic and environmental outcomes, including reduced quality of life, shortened life expectancy, interactions with the criminal justice system, incarceration, and psychiatric hospitalizations.²

Many individuals with schizophrenia rely on friends and family members as informal, unpaid caregivers to provide support and care. These caregivers manage various challenging responsibilities, including providing food, housing, transportation, coordinating care, and managing symptoms and behaviors.³ This provision of care has widespread impacts, including adverse effects on social relationships, finances, and work productivity.³⁻⁵ While multiple previous studies have described the humanistic burden of caregiving, associated unpaid labor, and work productivity loss, many characteristics of caregiving for individuals with schizophrenia have not been well-elucidated or explored. This study aimed to address the gaps from previous research by surveying informal caregivers of adults living with schizophrenia or schizoaffective disorder about these issues.

OBJECTIVE

To characterize the humanistic and financial burden for informal caregivers of individuals with schizophrenia in the United States (US).

METHODS

An online survey was administered to self-identified, unpaid, informal caregivers of adults diagnosed with schizophrenia or schizoaffective disorder in the US. Caregivers were recruited from survey vendor panels and advocacy organization mailing lists from December 2021 to January 2022. Adults serving as the primary caregiver of an individual with schizophrenia or schizoaffective disorder for at least six months and providing at least one hour of support per week received a survey instrument with seven modules. Questions included caregiver and care recipient characteristics, out-of-pocket (OOP) costs for major life events [e.g., arrest (MLE)] and everyday expenses, humanistic burden measured by the Burden Assessment Scale (BAS),⁶ and career, educational, and personal impacts.

Responses were summarized with descriptive statistics and logistic regression for predictors of caregiver impacts.

Impacts of Caregiving in Schizophrenia

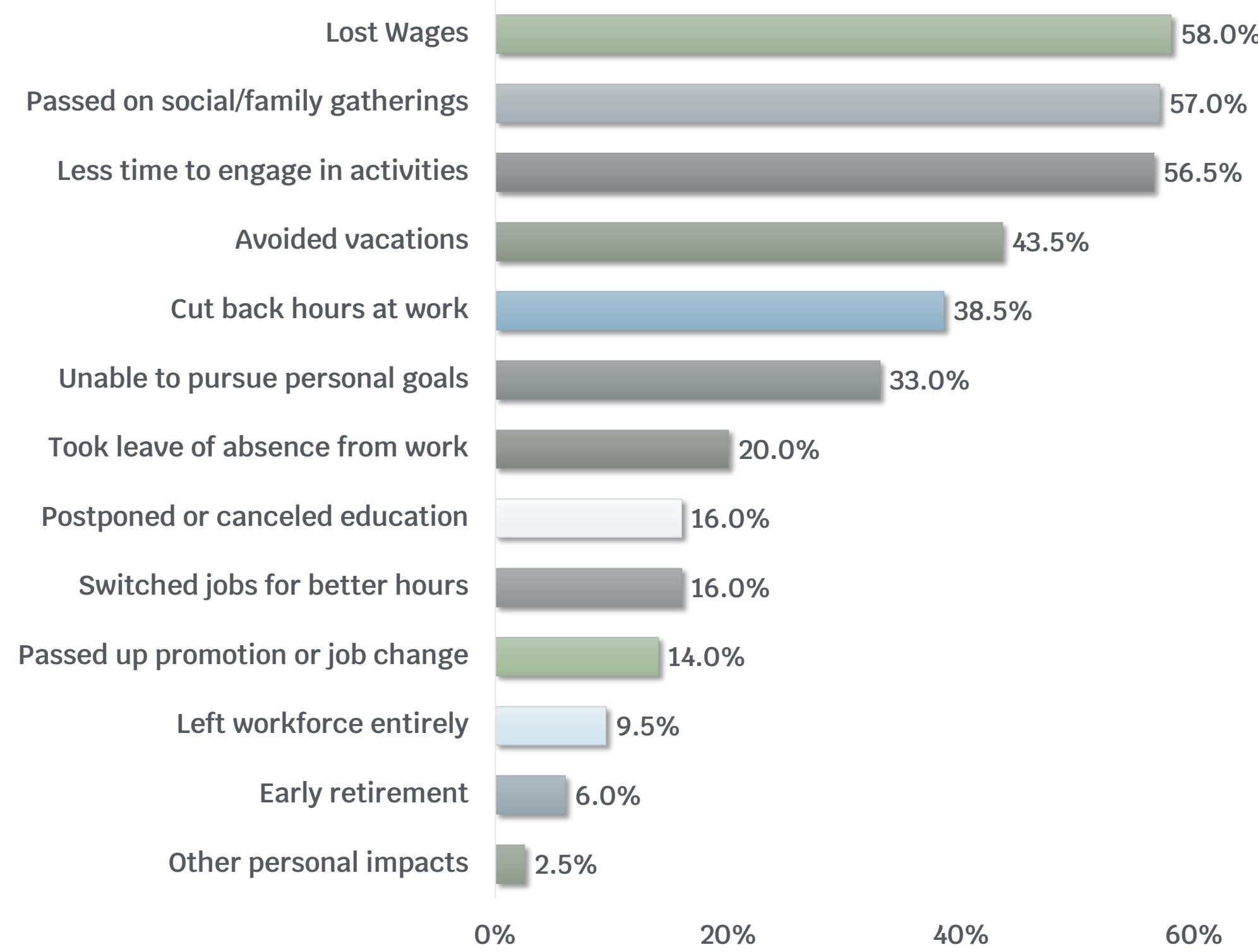


Figure 1. Frequency of work, career, and personal impacts reported by caregivers

Population

Two-hundred caregivers aged 42.3 ± 13.4, 54.0% male, 65.5% White, 24.5% Black or African American, and 11.0% Hispanic or Latino/a completed the survey. Caregivers reported an average of 36.1 ± 33 hours of care weekly, 49.5% of care recipients lived with caregivers. Moderate to severe symptoms in the past month (67.5%) and 6-months (72.5%) were common. (Table 1)

Table 1. Survey Population Characteristics

Caregiver Characteristic (N=200)	Care Recipient Characteristics – as Reported by Caregivers (N=200)				
Age, mean (SD)	42.3 (13.4)	Age, mean (SD)	49.9 (17.1)		
Male gender, n (%)	108 (54.0)	Diagnosis ≤ 5 years, n (%)	122 (61.0)		
Caregiving hrs/wk, mean (SD)	36.1 (33.0)	Diagnosis > 5 years, n (%)	78 (39.0)		
Race/Ethnicity, n (%)	Current Living Situation, n (%)		Primary Health Insurance, n (%)		
White	131 (65.5)	Living with caregiver	99 (49.5)	Commercial insurance	73 (36.5)
Black/African American	49 (24.5)	Independently, alone/others	77 (33.5)	Medicare	53 (26.5)
Asian, American Indian, Other	20 (10.0)	Supervised/supported home	21 (10.5)	Medicaid	54 (27.0)
Hispanic/Latino	22 (11.0)	Residential SU/LTC Facility	10 (5.0)	Other	11 (5.5)
Not Hispanic/Latino	171 (85.5)	Homeless	3 (1.5)	No health insurance	9 (4.5)
Annual Household Income, n (%)	30-day Symptom Severity, n (%)		Current Treatments or Interventions, n (%)		
\$34,999 or less	34 (17.0)	None/Very mild	22 (11.0)	Oral antipsychotic	134 (67.0)
\$35,000 to \$74,999	64 (32.0)	Mild	43 (21.5)	LAI antipsychotic	63 (31.5)
\$75,000 to \$149,999	67 (33.5)	Moderate	84 (42.0)	Other psychiatric medication	70 (35.0)
\$150,000 or more	35 (17.5)	Severe/Very Severe	51 (25.5)	Inpatient psychiatric care	34 (17.0)
Legal Responsibilities, n (%)	6-month Symptom Severity, n (%)		SUD treatment	37 (18.5)	
Conservator/guardian	80 (40.0)	None/Very mild	14 (7.0)	Outpatient psychiatric care	84 (42.0)
Healthcare POA	90 (45.0)	Mild	41 (20.5)	Housing support services	31 (15.5)
Mental health POA	91 (45.5)	Moderate	91 (45.5)	Vocational/education services	22 (11.0)
Financial POA	69 (34.5)	Severe/Very severe	54 (27.0)	No treatments/interventions	10 (5.0)

SD=standard deviation; hrs=hours; wk=week; POA=Power of Attorney; SU=substance use treatment; LTC=long-term care; SUD=substance use disorder; LAI=long-acting injectable

Humanistic and Economic Caregiver Burden

Work, Education, Personal and Humanistic Impacts of Caregiving

The majority (80.0%) of caregivers reported current employment, with 32.5% working in the same job as before they became a caregiver. Common work impacts include lost wages (58%), reduced work hours (38.5%), and leave of absence from work (30.0%). Some (16%) reported postponing or cancelling education and 14.0% reported they were passed up for promotions or job changes. Impact on family and social life was common including missing social/family gatherings (57%), less time to engage in activities (56.5%) and avoiding vacations (43.5%). (Figure 1)

High humanistic impacts were evident, as assessed by the BAS, where the mean BAS score 49.6 ± 13.3 (High burden defined as a BAS score >40).⁷ Living with caregiver, receiving substance abuse treatment, or attempting suicide in the past year, and higher 6-month symptom severity predicted high burden as measured by the BAS (p<0.05).

Care Recipient Major Life Events (MLE)

Caregivers reported that nearly all care recipients (84%) experienced at least one MLE and over half (58%) reported at least two MLEs in the past 12 months. The overall mean number events in the past 12 months was 2.0 (SD: 1.6, Range: 0–8), commonly reported events included psychiatric hospitalization (65%), substance use treatment (28%), and needing other legal services (24%). (Figure 2)

Caregiver Out-of-Pocket (OOP) Costs

Of the caregivers who reported paying OOP costs associated with MLEs and support needs in the last 12 months, 65.0% reported paying OOP for expenses related to an arrest, 64.3% for psychiatric hospitalization, and 60.7% for substance use treatment. Caregivers frequently paid for care recipient expenses for MLEs (n=110, 12-month OOP mean \$3,909 ± \$6,113; Range: \$12–44,440) without reimbursement. (Figure 2)

The majority (87.0%) of caregivers reported paying OOP for everyday needs across all domains in the last month (n=174, 30-day OOP mean \$1,810 ± \$3,492; Range: \$12–28,500). Caregivers most reported paying out of pocket for food (64.5% of caregivers), followed by transportation (59.0%) and clothing (43.5%). Living with caregiver, at least one MLE in the past year, and higher income predicted higher 30-day OOP costs (p<0.05).

Informal Caregivers Spend Almost \$2000/month on Everyday Needs to Support Care Recipients with Schizophrenia

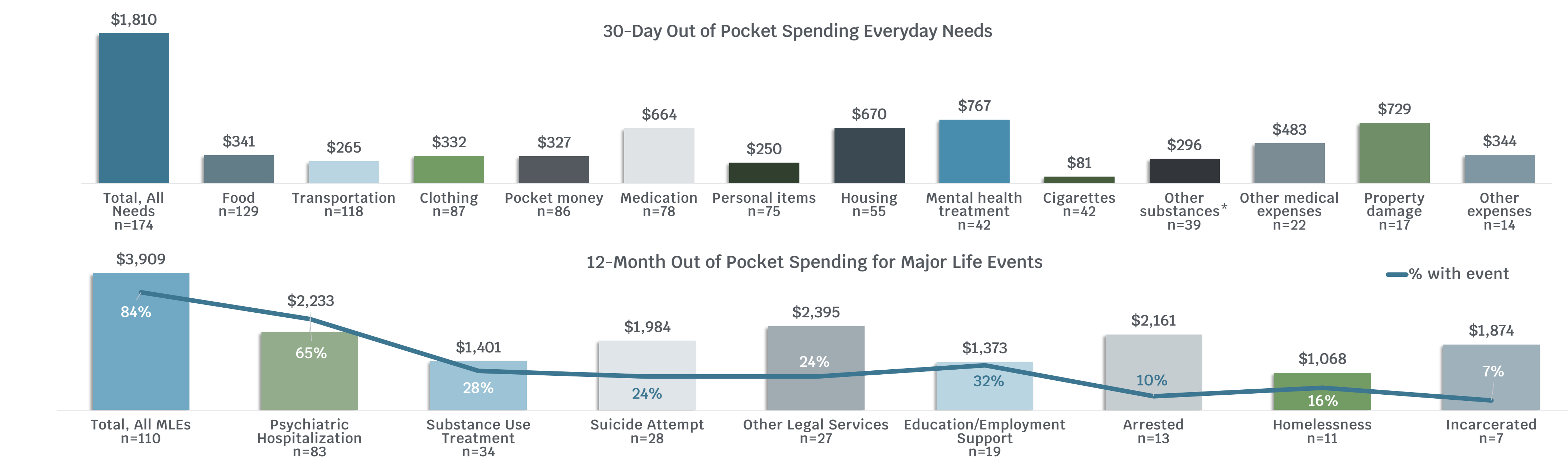


Figure 2. Economic Burden of Unpaid Caregivers of Schizophrenia in the United States

*Marijuana, alcohol, or other types of substances; MLE=Major Life Event

Conclusions

Caregiver Impacts in Schizophrenia

Caregivers to those with schizophrenia or schizoaffective disorder report significant financial impacts, humanistic burden, as well as career, educational and personal impacts independent of the number of hours per week they provide care. High economic and humanistic burden was predicted by living situation and MLEs. Caregivers frequently reported major life events and everyday support needs in care recipients. Reducing the burden of events and support needs should be considered for inclusion in outcome measures.

Considerations for Product Developers, Policymakers, & Health Systems

Caregiver expertise can provide vital information to help shape the development of drugs and devices and provide meaningful information about appropriate services, therapeutic benefits, risks, safety, efficacy, and program components.

Through lived experience, caregivers have a unique understanding of the current medical, behavioral health, and coordinating support services landscape, including deficits and areas for growth and expansion. Caregivers can draw upon their close relationship with someone with schizophrenia. This expertise can support product developers, policymakers, and health systems. Those interested in impacting the health and well-being of this high-risk population would be remiss to ignore the unique and invaluable perspectives that caregivers possess.

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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 high burden are more willing to participate in research, thereby potentially biasing the sample towards those with higher burden.⁸ Survey respondents qualified with only 1 hour of care per week, potentially mitigating this potential bias. Respondents to the survey were also highly educated, with 26.5% having obtained a graduate degree. Additionally, the web-based nature of the survey results in a respondent sample with the ability to access and use technology.

This caregiver-reported data may be subject to recall, and social desirability biases found in survey research and may be affected by respondent error. Caregivers may have struggled to recall the frequency of events, been unaware of some of the MLEs experienced by the care recipient, misinterpreted the intent of a question, or been unable to recall the precise amount of money spent on particular needs.

Acknowledgments

The authors thank the survey respondents for their participation, Kelly Talbot and Angela Babaev for their feedback on the content of the survey instrument, Frances Eskew for editorial and project support, and Gordon Lavigne for his support and feedback throughout this research.

Disclosures

Dr. Maravic and Ms. Birch are employees of PRECISIONheor who received funding for this research. Ms. Krasa, Ms. Frangiosa, and Mr. Palsgrove are employees of Blue Persimmon Group who received funding for this research. Ms. Krasa and Ms. Frangiosa are members of the board of directors for the Schizophrenia & Psychosis Action Alliance, the non-profit organization funding this research.

About Schizophrenia & Psychosis Action Alliance (S&PAA)

S&PAA has launched a transformational agenda to lead a system-wide movement for change to improve care, support, and equity for the millions of people living with schizophrenia and psychosis spectrum disorders. Join us and follow our progress @ www.sczaction.org.

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Measuring the Impacts of Caregiving in Schizophrenia

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