Dementia-Related Psychosis Symptoms and Impact from the Patient and Care Partner (Caregiver) Perspective: An Observational Study to Describe the Patient Experience

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INTRODUCTION

Dementia-related psychosis is a high-symptom condition characterized by hallucinations and delusions that are due to dementia and not to an unrelated cause. 1

1 The prevalence of hallucinations and delusions in dementia is often progressive and can disable the course of the disease.

Dementia-related psychosis increases the burden placed on individuals already suffering from debilitating diseases such as Parkinson’s disease (PD), Alzheimer’s disease (AD), and dementia with Lewy bodies (DLB). 2

2 Much of the responsibility for caring for individuals with dementia falls on family members.3

The patient and family experience of dementia-related psychosis can provide valuable information about the impact of psychosis symptoms on patients with dementia. However, there are no studies that describe dementia-related psychosis from a patient and care partner perspective.

OBJECTIVE

To collect data on the patient experience of symptoms and impact of dementia-related psychosis from the patient and care partner (caregiver) perspective.

METHODS

Qualitative Interviews

The qualitative component consisted of a prospective, observational, noninterventional, single-site study involving qualitative interviews approximately 60 minutes in length with eligible English-speaking participants in the United States.

In-depth interviews were conducted with patients or care partners of patients who have a diagnosis of all cause dementia with psychotic symptoms (for at least 2 months), recruited through physician referrals.

Care partners participating in the qualitative interviews included individuals who provided at least 20 hours per week of direct, in-person care for an individual with dementia-related psychosis.

The semistructured interview was conducted via telephone and was based on concepts included within previously available patient and Social Life, Emotional State, Independence, and Safety. These impacts substantiated a need for greater education among care partners.

DISCLOSURES

This study is limited in that most patients had AD or DLB and data may not reflect all subtypes of dementia. In addition, results of survey data are subject to recall bias.

However, the consistency of results from the qualitative interviews and the larger quantitative survey supports the reliability of the findings.

Patient experience data demonstrate that there is need for treatments to reduce the symptoms and impacts of dementia-related psychosis. For additional details on treatment, see poster 47153 (Brandt T et al., AAIC 2020).

REFERENCES


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