Treatment Patterns and Needs for Dementia-Related Psychosis Described by Patients and Care Partners (Caregivers): An Observational, Prospective Study to Describe the Patient Experience

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INTRODUCTION

- Patients with dementia commonly experience dementia-related psychosis, which is associated with increased care partner burden, accelerated cognitive decline, and worse patient outcomes relative to dementia without psychosis.[1,2]
  - Hallucinations, in particular, are associated with a 1.6- and 1.5-times higher risk of institutionalization and death, respectively.[3]
- Affected individuals are faced with limited treatment options for dementia-related psychosis. No therapies are currently approved by the US Food and Drug Administration (FDA) for treating dementia-related psychosis, and patients are often treated on a short-term basis with existing antipsychotic medications with known risks and uncertain benefit.[4]
- Second generation atypical antipsychotics are commonly utilized off-label for the treatment of dementia-related psychosis and are associated with a number of side effects, such as extrapyramidal symptoms, orthostatic hypotension, hematologic abnormalities, and metabolic, gastrointestinal, thrombo-embolic, and sedative effects. These agents are also associated with an increased risk for falls (and associated fractures), infection, aspiration pneumonia, and other serious complications in this vulnerable patient population.[5-12] The majority of these risks are serious and are communicated to prescribers and patients as Warning and Precautions in their FDA-approved labeling.
- American Psychiatric Association (APA) practice guidelines recommend that after an evaluation of the potential benefit and harm of therapy to the patient, antipsychotic medication should only be used for the treatment of psychosis when symptoms are severe, are dangerous, and/or cause significant distress to the patient, and patients who do not respond should be taken off the treatments, minimizing exposure to ineffective treatment.[13]
- Understanding the patient experience of dementia-related psychosis, as reported by patients and their care partners, can help characterize treatment needs, clinically important outcomes, and preferences for benefits and risks of treatment.

OBJECTIVE

- To collect data on current treatments and unmet treatment needs associated with dementia-related psychosis from a patient and care partner perspective.

METHODS

Qualitative Interviews

- The qualitative component consisted of a single-visit study involving in-depth, approximately 60-minute interviews with eligible English speaking participants in the United States.
- In-depth interviews were conducted with patients or care partners of patients who have a clinical diagnosis of all-cause dementia with psychotic symptoms (for at least 2 months), recruited through physician referrals.
- The semistructured interview was conducted via telephone and participants were asked to describe any current treatments being taken for hallucinations or delusions and to discuss their perspective related to expectations for potential new treatments.

Quantitative Surveys

- The quantitative online survey was completed by persons with self-reported dementia-related psychosis or their care partners; they were recruited through direct outreach by the advocacy groups UsAgainstAlzheimer's and the Lewy Body Dementia Association.

METHODS (CONT)

- The online questionnaire included questions on medical history and potential and current treatments for dementia-related psychosis.
- Persons with dementia-related psychosis and care partners of persons with dementia-related psychosis reported the effectiveness of current treatments with a visual analog scale (VAS) of 0 ("not at all well") to 5 ("extremely well") and ranked benefits of an ideal treatment.
- Care partner burden was beyond the scope of this study.
- Participants in the interview portion of the study were not invited to participate in the survey portion. Pairs of patients and care partners completing the survey were not recruited; however, care partners of patients completing the survey were not explicitly excluded from participating.
- For additional details on the study design and characterization of symptoms and burdens of dementia-related psychosis, see poster 47164 (Brandt T, et al. AAIC 2020).

RESULTS

Qualitative Results

- The qualitative interview was completed by 1 patient and 15 care partners (10 family members and 5 friends).
- Six of the care partners were not aware of current medications for the patient's dementia-related psychosis; the remaining 9 reported that the patient's treatment included atypical antipsychotics, antidepressants, anxiolytics, and/or benzodiazepines.
- Participants commonly expressed concern about side effects and indicated a need to improve patients' symptoms and ability to know what is real versus not real (**Table 1**).

Table 1. Selected Qualitative Accounts of Current Treatments and Treatment Needs

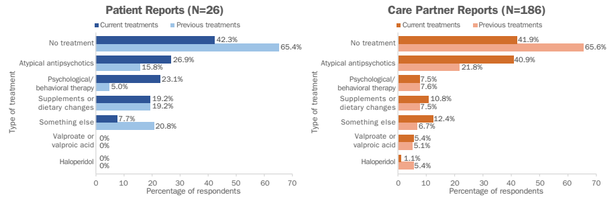
Comments on Current Treatment/Side Effects of Current Treatment
"He is sleeping in longer than usual." [Care partner - family friend]
"But then it has all these other side effects that…whoa, I'd rather not take it. So you're saying you're going to help me, but then I'm going to have nightmares or I'm going to have this. I'm going to have that. And it's like, 'Never mind. I think my dad was right. Don't take it.' Because there's so many side effects that these medications have. That you take it for one thing, and then it just disrupts another thing." [Care partner - niece]
"[Do] any of them work? I don't know. It's almost like people with dementia, they really don't fit into a category of mental illness. It's like they're their own little entity." [Care partner - wife]
"It was controlling his sleep, has a lot to do with it. So if he sleeps, he's more rested, he's more calm. But the days that he doesn't sleep, he gets more agitated during the day." [Care partner - wife]
Descriptions of How an Ideal Treatment Would Help
"I think his emotions. He gets very stressed. He gets very antsy in his episodes […]. It'll help him not having to go through that stress." [Care partner - family friend]
"Stop the repetitive thoughts, like the same thing over and over […] break the cycle and stop the thoughts that get him there in the first place. Oh, God, it would be like you could actually keep your loved one at home and wouldn't have to put him into a home. And bankrupt the family […]. Because I think everything else you can pretty much keep them at home." [Care partner - wife]
"When he's having these delusions, there are days when he's really sad […]. Well I think just seeing him happy and being normal a little bit again. Coming back to being himself again. I know that this is a disease, and it's a sickness, and it's not his fault. But I would love to see him come back as himself. And even if it's not 100%, but be my husband again." [Care partner - wife]
"Well, we would live better. We would be able to go out more, we'd be able to get along better. You know what, I would take him more often to my kids' house. Sometimes, I go there and I worry because I don't want him lashing out or anything. So I think our social life would be better." [Care partner - wife]
"Well, if he could realize it's himself in the mirror and if he could rest at night […]. I mean, we're up every night a couple of times at night and sometimes that's when he gets…that's when he can get aggressive because that's when he feels like he needs to do something, go get gas, go to work, go help somebody, and he gets frustrated when he can't get out of the house. And then he's mad at me because I'm the one. I'm the one that's doing all of this and so that's when it gets ugly." [Care partner - wife]

RESULTS (CONT)

Quantitative Results

- In total, 26 patients and 186 care partners participated in the quantitative online survey.
  - Care partners who answered the survey on behalf of patients (care partner reports) reported that patients were a mean 78.1 years old, and 51% were female.
  - Patients who answered the survey were a mean 64.6 years old, and 42% were female.
- For additional details on participant demographic information, see poster 47164 (Brandt T, et al. AAIC 2020).
- Many participants reported no current treatment (42.3% of patient reports, 41.9% of care partner reports) (**Figure 1**).
- Common treatments used included atypical antipsychotics (reported by 26.9% of patients and 40.9% of care partners) and psychological/behavioral therapy (reported by 23.1% of patients and 7.5% of care partners) (**Figure 1**).

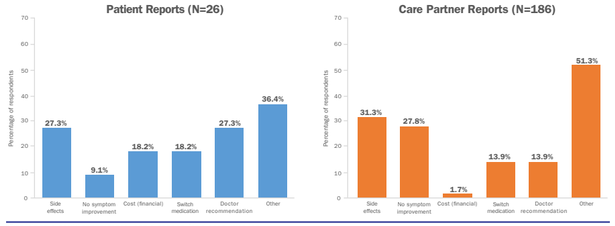
Figure 1. Treatment History and Current Treatments for Patients with Dementia-Related Psychosis[a]



[a]Participants could report more than 1 treatment.

- Participants reported that current treatment methods were less than moderately helpful in treating patients' most impactful symptoms, with a median visual analog scale (VAS) score of 2 out of 5 reported by patients and care partners (VAS range=0 [not well at all] to 5 [extremely well]).
  - The mean VAS score (standard deviation) was 2.33 (1.0) for patient reports (n=15) and 2.4 (1.3) for care partner reports (n=104).
- Discontinuation of a treatment was reported by 11 patients (42.3%) and 115 care partners (61.8%).
- Among those who reported discontinuation, common reasons given were side effects (27.3% of patient reports, 31.3% of care partner reports), doctor's recommendation (27.3% of patient reports, 13.9% of care partner reports), or lack of symptom improvement (9.1% of patient reports, 27.8% of care partner reports) (**Figure 2**).

Figure 2. Reasons for Discontinuation of Treatment[a]

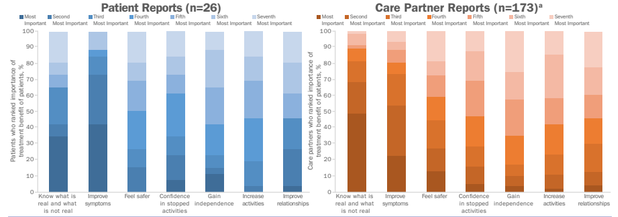


[a]Participants could report more than 1 reason for discontinuation.

RESULTS (CONT)

- Participants ranked the ability to distinguish what is real versus not real (34.6% of patient reports, 49.1% of care partner reports) and overall symptom improvement (42.3% of patient reports, 22.5% of care partner reports) as the most important benefits of an ideal treatment (**Figure 3**).

Figure 3. Ranking of Benefits of an Ideal Treatment for Dementia-Related Psychosis



[a]Thirteen care partners did not respond to questions on the benefits of an ideal treatment.

CONCLUSIONS

- Patient experience data presented here indicate that safe and effective therapies are needed to treat patients with dementia-related psychosis.
  - Patients and care partners rated current treatments as less than moderately helpful in treating the patient's current symptoms.
  - More than 40% of patients and care partners reported no current treatment for dementia-related psychosis, and for those that discontinued a therapy, many were from side effects, poor tolerability, and lack of efficacy.
  - Further research is needed to better understand reasons for discontinuation of treatments in these patients.
- An ideal therapy would have the primary benefits of improving symptoms of dementia-related psychosis and allowing patients with dementia to better distinguish reality from psychotic experiences.
- This study is limited in that the results of survey data are subject to recall bias. Furthermore, most patients in the current study reported having Alzheimer's disease or dementia with Lewy bodies, and results may not generalize to all subtypes of dementia.
  - However, the consistency of the results from the qualitative interviewing and quantitative survey (see poster 47164, Brandt T, et al. AAIC 2020) supports the reliability of these findings.

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