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Challenges of Agitation in Dementia: A Plea for Early Discussion

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Abstract: Behavioral and psychological symptoms of dementia (BPSD) occur frequently among people with dementia and are known precipitants for placement in care facilities. Despite the social, financial, and psychological impact on dementia care, education and discussions on BPSD have not been routinely included in advance care planning (ACP). As a result, families can face great challenges in making complex medical decisions when their loved ones are admitted to the geriatric psychiatric inpatient unit with refractory BPSD. We present the case of an 83-year-old gentleman with BPSD to illustrate universal struggles in dementia care experienced by many families, which could have been alleviated by education and discussions around BPSD earlier in the patient's dementia course. A literature search did not yield any articles that mention discussions of BPSD in ACP. The lack of literature referencing BPSD in ACP supports our clinical experiences with the case and highlights the need for improvement in current dementia care. We propose a guideline for providers to facilitate conversations around BPSD as an integral part of ACP, including discussions of four key points related to the progressive nature of dementia, the commonality of BPSD, the lack of FDA-approved treatment for BPSD, and the difficulty in balancing agitation and sedation to allow safe placement. We firmly believe it is important to start discussion on BPSD as part of ACP as early as possible. Early education and discussion will help to facilitate meaningful care decisions as patients and families navigate the challenges associated with this progressive disease.

Keywords: dementia, behavioral and psychological symptoms of dementia (BPSD), advance care planning (ACP), agitation, geriatrics

THE CASE OF MR. L*

Mr. L is an 83-year-old gentleman with a history of dementia, probable Alzheimer's type with behavioral and psychological symptoms of dementia (BPSD) including wandering, intrusive behaviors, paranoia, and impulsivity that at times has led to physical aggression. He was transitioned from home to a long-term care facility due to inability to safely reside in the community. Within six months of arrival, Mr. L was admitted twice for inpatient psychiatric treatment and stabiliza-

tion. In both residential and inpatient settings, an interdisciplinary team that included nursing, social work, rehabilitation services, psychiatry, internal medicine, and palliative care struggled to manage his refractory BPSD.

Given Mr. L's advanced dementia, the family became responsible for making decisions around his care. Although advance care planning (ACP) had previously occurred with respect to end-of-life care as well as financial and legal decision making, the care team had not discussed management of BPSD with the patient and the family. Despite Mr. L's having been diagnosed with a dementing illness and being placed in a nursing home, his family remained uninformed about and surprised by the emergence of BPSD symptoms. The family initially strenuously resisted the diagnosis of BPSD and recommended management strategies. The treatment team continued to engage in intense conversations around goals of care and treatment, contacting the family multiple times a week. The absence of plans for BPSD management resulted in emotional distress among the family, the treatment team, and the patient.

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INTRODUCTION

Dementia is an umbrella term for a variety of diseases affecting cognition and behavior that significantly interfere with an

* The case of Mr. L represents a composite of several cases.

individual's functioning.¹ It is estimated that in 2021 among the 58 million people of age 65 or older in the US, 6.2 million people had Alzheimer's dementia.² Individuals with dementia can present with changes in cognition and function as well as behavioral disturbances. BPSD is defined as signs and symptoms of disturbed perceptions, thought content, mood, or behaviors.³ This heterogeneous group of clinical phenomena is largely unpredictable and varies widely within subtypes of neurocognitive disorder as well as among individuals with dementia. Though there have been attempts to profile BPSD into subsyndromal categories across dementia and some symptoms may be more likely to occur in specific dementia types, there is no uniform presentation.⁴ Studies suggest that 80–90% of patients with dementia present with BPSD.⁵ Agitation, aggression, and psychosis related to BPSD are the leading causes for placement in assisted living facilities and nursing homes.⁶ According to the World Health Organization, the total global societal cost of dementia was estimated to be \$1.3 trillion US in 2019 and is expected to exceed \$2.8 trillion US by 2030.¹ Because dementia affects one's cognitive function, advance care planning (ACP) can help the patient and family navigate the complex decision-making process they face. ACP is a dynamic process of discussing possible healthcare management needs to ensure that medical decisions align with the individual's values, wishes, and preferences.⁷ Commonly used resources for ACP in dementia—including those of the Alzheimer's Association, Alzheimers.gov, the National Institute on Aging, and The Conversation Project—offer guidance to providers and patients on discussions about end-of-life care and legal and financial planning. Despite the prevalence of BPSD and its associated financial and social cost, it has been our clinical experience that BPSD management generally is not part of ACP or discussions of prognosis.

Though ACP for dementia is usually conducted by primary care providers, and the literature offers general guidance to aide such discussions, we feel that additional recommendations are needed to educate caregivers and others specifically about BPSD and its management.

METHODS

We conducted an English language literature search and review through MEDLINE, CINAHL, Cochrane Reviews, EMBASE, PsycINFO, PsycArticles, Web of Science. The search focused on articles published from the start of each database to April 22, 2022. Keywords included major neurocognitive disorder, dementia, behavioral and psychological symptoms in dementia, and advance care planning.

MEDLINE Mesh terms were as follows:

("Major Neurocognitive disorder"[tw] OR "elder"[tw] OR "geriatric"[tw] OR "Dementia"[Mesh]) AND ("Behavioral and psychological symptoms of dementia"[tw] OR "behavioral and psychiatric symptoms of dementia"[tw]) AND ("Patient care planning"[Mesh] OR "Advance care planning"[Mesh]). CINAHL terms were as follows: ("Major neurocognitive disorder" OR "elder" OR "geriatric" OR "De-

mentia") AND ("behavioral and psychological symptoms of dementia" OR "behavioral and psychiatric symptoms of dementia") AND ("Patient care planning" OR "Advance care planning").

Cochrane Review terms were as follows:

("Major neurocognitive disorder" OR "elder" OR "geriatric" OR "Dementia") AND ("behavioral and psychological symptoms of dementia" OR "behavioral and psychiatric symptoms of dementia") AND ("Patient care planning" OR "Advance care planning"). EMBASE/Emtree terms were as follows: ('Major neurocognitive disorder' OR 'geriatric' OR 'geriatric patient'/exp OR 'dementia'/exp) AND ('behavioral and psychological symptoms of dementia'/exp OR 'behavioral and psychiatric symptoms of dementia'/exp) AND ('Advance care planning/exp' OR 'patient care planning/exp'). PsycINFO terms were as follows: (DE "Major neurocognitive disorder" OR DE Geriatric Patients" OR DE "Elder Care" OR "older adults" OR "elderly" OR "seniors" OR "geriatrics" OR "Dementia") AND (DE "behavioral and psychological symptoms of dementia" OR DE "behavioral and psychiatric symptoms of dementia") AND (DE "Patient care planning" OR DE "Advance care planning").

PsycArticles terms were as follows:

(DE "Major neurocognitive disorder" OR DE Geriatric Patients" OR DE "Elder Care" OR "older adults" OR "elderly" OR "seniors" OR "geriatrics" OR "Dementia") AND (DE "behavioral and psychological symptoms of dementia" OR DE "behavioral and psychiatric symptoms of dementia") AND (DE "Patient care planning" OR DE "Advance care planning")) Web of Science terms were as follows: (TS = ("Major neurocognitive disorder" OR "elder" OR "geriatric" OR "Dementia") AND TS = ("behavioral and psychological symptoms of dementia" OR "behavioral and psychiatric symptoms of dementia") AND TS = ("Patient care planning" OR "Advance care planning").

We also reviewed the resources available through the Alzheimer's Association, Alzheimers.gov, the National Institute on Aging, and The Conversation Project.

RESULTS

The literature search did not yield any articles that mention discussions of BPSD and its management in ACP.

Standard ACP templates, including advance directives and medical or physician orders for life-sustaining treatment (MOLST/POLST), as well as the process of discussing goals for care and planning, are often not designed for individuals with dementing illness, who slowly and progressively lose the ability to guide their own care and therefore are less likely to occur.⁸ The need to adjust goals and interventions as disease progresses often proves very challenging for both family and providers.⁹ Though it is recognized that ACP for those with dementia is valuable and important, there is no single standard practice or clear evidence base for addressing the dynamic process of dementing illness.¹⁰ The need for individualized care is clear.

Piers and colleagues¹⁰ conducted an extensive literature search for existing guidelines and used their findings as well as expert opinion to develop recommendations for health care providers. They provide 32 recommendations divided into 8 domains:

- initiating ACP as early as possible,
- evaluating decision-making capacity,
- holding regular ACP conversations to explore fears, goals, values, and preferences,
- acknowledging the role and importance of persons close to the person,
- continuing to ensure maximal participation of the person and those close to them when communication is difficult or impossible,
- documenting wishes and preferences,
- discussing end of life care, and
- providing training and support to health care providers.

ACP is associated with improved outcomes for both people living with dementia and their caretakers and is associated with fewer hospitalizations, increased concordance between care received and stated prior wishes, and increased satisfaction with care.¹¹ ACP creates a shared understanding among people living with dementia, their care providers, and health-care professionals.¹²

Barriers to ACP, both in general and specifically for individuals living with dementia, include concerns about when and who should initiate such conversations,¹³ worry about causing increased distress,¹⁴ and lack of training. Healthcare providers describe needing a knowledge of dementia, resources and confidence to engage in such discussions.¹⁵ Research indicates that training and education about ACP improved confidence and reduced uncertainty in decision making.^{16,17}

There are several resources available to support ACP for individuals with dementia and their caregivers. The Alzheimer’s Association Dementia Care Practice Recommendations offer updated guidance for dementia care based on a current review of evidence and expert opinion. The recommendations encourage caregivers to participate in ACP discussions early in the patient’s dementia course, in order to designate durable healthcare power of attorney (DPAHC) and clarify the patient’s wishes in end-of-life care including code status.¹⁸ Under the Medical Management section, they discuss the use of pharmacological treatment for BPSD to protect a patient’s safety, well-being, and quality of life. Recommendations for care of behavioral and psychological symptoms of dementia list management of BPSD as a critical part of dementia care and further include a section focusing on care of BPSD and advise identifying triggers, implementing nonpharmacological practices, adhering to protocols for administration of pharmaceuticals, and developing systems for evaluating effectiveness of practices. It does state that there are no FDA-approved medications for the treatment of BPSD. While they recommend discussion with caregivers on the treatment options for BPSD, they do not include BPSD management as part of ACP.

Alzheimers.gov has information on living will, DPAHC, code status, MOLST, organ and tissue donation, brain donation, financial planning, and long-term care planning.¹⁹ It encourages patients to start discussions of these topics early with their family members, prepare appropriate documentation, and give involved physicians or lawyers permission to speak directly with a caregiver. The section on Long-Term Care Planning brings up problematic behaviors as potential symptoms of dementia and possible needs for placement to provide more support to ensure safety and

Table 1	
Key Points for Primary Care Providers to Discuss in APC in Regard to BPSD and its Management	
Key Points	Providers should discuss:
Dementia is progressive.	<ul style="list-style-type: none"> • Dementia can have fluctuating and prolonged course • Expect overall deterioration in cognition, behaviors, and function without significant improvement
BPSD is common.	<ul style="list-style-type: none"> • BPSD include affective symptoms, anxiety, psychosis, agitation, aggression, disinhibition, wandering • Up to 80-90% of people with dementia can develop BPSD • BPSD is a leading cause of placement in a care facility
There is no FDA-approved treatment for BPSD.	<ul style="list-style-type: none"> • Treatment is for symptomatic management • No disease-modifying treatment currently available for BPSD • May have to use antipsychotic medications which have a black box warning for increasing mortality in people with dementia
The balance between agitation and sedation needs to be achieved to provide the most appropriate and safest care setting.	<ul style="list-style-type: none"> • It is often clinically not possible to achieve a balance between aggression/alertness and sedation/calmness • BPSD can make placement in a care facility extremely difficult • Resources may be even more limited due to the pandemic

well-being but does not include specific information on managing BPSD.

The National Institute of Aging offers online guidance in its Advance Care Planning page that addresses advance directives (living wills), code status, MOLST/POLST, goal of care discussion, legal and financial planning, DPAHC, organ and tissue donation, and brain donation.²⁰ The website provides information on ACP especially in the context of emergency treatment such as CPR, ventilator use, and artificial nutrition and hydration, as well as decisions for end-of-life care. However, it does not provide information on BPSD and its management as part of ACP.

The Conversation Project provides a guideline for caregivers of people with Alzheimer's or other forms of dementia to help with designating a health care proxy (HCP) and clarifying patients' values and preferences in dementia care.²¹ This resource defines dementia as a terminal illness and educates caregivers and patients that dementia is a progressive disease that affects thinking as well as behavior. Guidance on talking with dementia patients encourages caregivers to discuss general goals of care and preferences in medical decisions but does not delve into concrete details on potential medical decisions associated with dementia care, including BPSD management.

In summary, current mainstream resources and literature recognize the progressive nature of dementia and universally recommend initiation of ACP as early as possible, ideally before patients develop signs of significant cognitive impairment. Our literature search yielded the current recommendations with key elements for health care providers to navigate through ACP in dementia, such as designation of HCP, code status, and financial and legal planning. While Alzheimer's Association Dementia Care Practice Recommendations specifically highlight the significance of BPSD in dementia care and encourage discussions of treatment options with caregivers, none of the above resources and current literature explicitly recommend education and discussion of BPSD and its management to be routinely included in ACP.

DISCUSSION

The lack of literature with specific reference to BPSD in ACP was not surprising given our clinical experiences with patients and families with advanced dementia. The composite case of Mr. L provided a framework for some of the challenges which early education and ACP might help to address.

Often, providers are unsure of how to engage in discussions around BPSD due to lack of knowledge, lack of expertise, and difficulty broaching such an uncomfortable topic with patients and families. Avoiding such discussions, however, does not change the fact that BPSD is common, complex, and can be clinically, logistically, and emotionally demanding to manage.

While admitted to the hospital, Mr. L continued to demonstrate problematic behaviors refractory to multiple trials of therapy with psychotropic medication. Discussions with family

around realistic treatment options and possible outcomes were challenging. The family's understanding of the disease course and care options was limited and further complicated by unrealistic beliefs and insufficient information. Complex decisions had to be made expeditiously, leading to discomfort, shame, and embarrassment among family as well as providers. Considerations for what the patient himself would have wanted were ambiguous and overshadowed. The disparity between the family's understanding and expectations and providers' knowledge of the reality of the disease course and treatment options often led to heightened emotions and difficulties building rapport and improving the therapeutic alliance.

Although Mr. L had access to resources that included financial means and familial support, this is certainly not the case for many patients struggling with dementia. As cognitive decline progresses, patients often lose the capacity to make or express decisions on their treatment and care, and surrogate decision makers need to be engaged. When there is no such decision maker, or it is unclear what the person with dementia would have wanted, it falls on the treatment team to make such decisions. This can often become legally and ethically complex, leading to delays in care and significant burden to all involved. This painful and potentially harmful situation can be mitigated by ensuring early and ongoing discussions to clarify the wants and needs of patients and their caregivers.

Mr. L's case is representative of struggles faced by countless families and providers caring for those who exhibit BPSD. Our goal is to provide a framework for primary care providers to begin conversations around the dementia disease course including BPSD in order to allow for holistic care planning. We highlight four key points to be included in such conversations (Table 1):

1. *Dementia is progressive.* Patients and their families may not be aware of the progressive nature of dementia. In the case of Mr. L, the family had expectations for stabilization or even improvement in symptoms of dementia and BPSD during times of relative stability and became deeply disappointed and frustrated when BPSD persisted and continued to be difficult to manage. Small fluctuations in presentation are expected in the course of dementia, while the overall trajectory is deterioration without improvement. The lack of understanding of dementia as a progressive disease may serve as a barrier for the family to have realistic views of the patient's prognosis and treatment options.
2. *BPSD is common.* BPSD is extremely common among people living with dementia, yet most patients and family members have minimal or no knowledge of the fact that BPSD is part of dementia. Mr. L's family did not know that his problematic behaviors including wandering, agitation, aggression, and disinhibition were due to dementia and often attributed those behaviors to his personality, lack of self-discipline, or other medical, neurological, or psychiatric conditions. Attribution of BPSD to one's personality and ability for self-discipline can provoke an intense sense of embarrassment, shame, and even anger in the family,

potentially leading to counter-therapeutic dynamics between the patient and the family or providers. Once other causes for behaviors have been appropriately ruled out, attribution of BPSD to such medical, neurological, or psychiatric conditions can lead to unrealistic expectations and prompt unnecessary workups and therapeutic interventions.

3. *There is no FDA-approved treatment for BPSD.* Perhaps the most distressing aspect of BPSD for the patient and their family is that there is no cure and no FDA-approved treatment for BPSD. Families have certain expectations for clinical outcomes based on a lack of understanding of treatment options for BPSD. They are frequently unaware that they will likely have to make complex medical decisions around BPSD management, including the use of antipsychotic medications, which carry a black box warning for increasing mortality when used in people living with dementia. Discussion should include risks and benefits of antipsychotic use and other medications while emphasizing the goal of treatment, which is symptomatic relief. Having open and honest conversations on realistic expectations of treatment for BPSD can significantly help the patient and their family prepare for the potential challenges and decision-making points in the dementia course.
4. *The balance between agitation and sedation needs to be achieved to provide the most appropriate and safest care setting.* Placement of patients with dementia who are not safe in the community into appropriate care facilities can be complicated. For those with BPSD, the challenge can be even more pronounced. Problematic behaviors associated with BPSD can interfere with care and cause disruption in the facility. The availability of memory care units that can handle such behaviors is limited, and resources have become even more scarce due to the COVID-19 pandemic. Management of BPSD for placement into these facilities is further complicated by the necessity of achieving a balance between agitation and sedation. Medications used to treat agitation can cause sedation, but not treating the agitation leaves open the possibility of injury to self or others. Having discussions about what is wanted in the context of what is actually possible early in the course of treatment helps to orient families. Clarity of actual availability of placement options and realistic expectations of treatment outcome with BPSD management is crucial in helping the family make the most optimal decisions in dementia care.

CONCLUSION

Providing education on dementia, including BPSD and facilitating ACP is essential and can potentially improve the quality of life for patients and their families. Due to the lack of subspecialty providers, patients often do not interact with psychiatry until they are admitted to an inpatient setting for acute stabilization. All too often, the conversations around BPSD do not occur until the patient with dementia is admitted

to a geriatric psychiatry unit. However, an inpatient psychiatric unit does not provide the platform suitable for the providers and the family to have ACP in the most comprehensive way. Many times, as in the case of Mr. L, there is not enough time for the family to fully absorb and process the information before having to make critical medical decisions that are often time sensitive. This can result in a traumatic experience for the family and can heighten the risk of decisions rooted in fear or overwhelming emotions. We firmly believe in the value of starting education and discussions on BPSD as part of ACP as early as possible, in order to facilitate the patient and their family make the most meaningful care decisions as they go through their already challenging journey with this relentless disease. We provided the framework for relevant areas of discussion to facilitate the process. As the medical system adapts to manage this growing problem, our hope is that the treatment and resources continue to evolve.

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