Case Report

The Behavioral and Psychological Symptoms of Dementia in Palliative Care: Caught in the Middle with a Challenging Decision

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Abstract

Dementia is a progressive condition and in contrast to other chronic illnesses, the terminal phase can be prolonged and difficult to recognize making palliative care elusive and often inadequate. The Behavioral and Psychological Symptoms of Dementia (BPSD) are common and can progress over time adding to an increased symptom burden at the end of life. Both non-pharmacological and pharmacological management options are the cornerstone of therapy along the continuum of progressive symptoms of BPSD. When the latter fails to achieve the desired goals of care, consenting to using medications at the end of life involves understanding and appreciating both risks and alternatives on the part of the Substitute Decision Maker (SDM). Why certain SDMs choose not to use medications at the end of life with increasing burden from BPSD, is challenging and complex. Being able to identify and understand the SDM’s specific relationship with the patient for whom they are the representative, and working through their anticipated grieving under the framework of total symptom burden, goals of care and prognosis may aid in the bridge of aligning decision making at the end of life.

ABBREVIATIONS

BPSD: Behavioral and Psychological Symptoms of Dementia; SDM: Substitute Decision Maker; EPS: Extra Pyramidal Side effects; NMS: Neuroleptic Malignant Syndrome

INTRODUCTION

Dementia is a progressive condition and in contrast to other chronic illnesses, the terminal phase can be prolonged and difficult to recognize [1]. In the advanced stages, behavioral and psychological symptoms of dementia (BPSD) such as wandering, agitation, delusions, depression, physical aggression and sleep disturbances are common affecting up to 80% of patients over the natural disease trajectory, and can result in a progressively decreased quality of life for patients and their caregivers [2,3]. Palliative care provides physical, psychological, social and spiritual care along disease progression, not just when death is perceived as being imminent. Reconsidering, withdrawing and adding interventions at the end of life becomes a part of the continuum of quality care and most health care providers and families believe that palliation in advanced dementia is appropriate and effective [4,5]. However, the literature suggests that patients with advanced dementia often receive inadequate palliative care and experience high symptom burden [6]. With escalating symptoms of BPSD at the end of life, the decision of whether or not to investigate a possible underlying or contributing cause and then how to best manage those symptoms can be complex, challenging and burdensome for the Substitute Decision Maker (SDM) [7].

CASE PRESENTATION

Mrs. D is an 82 year old female living at home with advanced dementia; she is bedbound, speaks a few coherent words at a time, requires assistance with all her activities of daily living and eats primarily protein shakes via a straw. She has a dedicated husband and 2 daughters who visit regularly – both daughters...
have shared Power of Attorney for medical decision making; there is no advanced directive. Her past medical history includes hypertension and degenerative disc disease. She is on scheduled acetaminophen, ramipril and donepezil.

She presented to acute care with several days of increasing confusion, agitation and refusal to take in food or drink. She was started on IV fluids for dehydration and her medical work-up was negative for other reversible causes of delirium. Mrs. D’s family gave the history of progressive apathy, agitation and delusions over the previous six months. In the Emergency Room when personal care was attempted, Mrs. D refused and would strike out. After a geriatric consultation, she was eventually diagnosed with Behavioral and Psychological Symptoms of Dementia (BPSD) and was transferred to a Geriatric Mental Health Unit where her behaviors were managed non-pharmacologically. Mrs. D was eventually discharged to a Nursing Home.

Over the ensuing three months Mrs. D declined and spoke incoherently. There was very attentive family involvement: Daughter-A was present every day with the patient’s husband, and Daughter-B came 1-2 times a week. Mrs. D became more somnolent, could not swallow her medications and was restless. The possibility of pain was raised and a trial of low-dose subcutaneous opioids was scheduled twice a day and every hour if needed. Despite this and maximized non-pharmacological strategies, Mrs. D cried-out and was combative with any approach, making personal care impossible. The medical team, through observations and behavioral mapping, felt that pain was not a significant contributing factor to Mrs. D’s distress.

A multi-disciplinary family meeting was held to discuss goals of care. As Mrs. D’s prognosis was estimated to be likely less than 6 weeks, the family chose a palliative approach to care which embodied preservation of dignity and relief of symptoms such as pain and agitation. The family accepted comfort feeding and no life prolonging interventions. The two daughters consented to a trial of low-dose scheduled antipsychotics to manage her agitation. However, over the next week, discord developed between the two daughters which culminated in Daughter-A and the patient’s husband abruptly stopping Mrs. D’s nurse from administering her scheduled medications - they both felt that Mrs. D was “too sedated from the medications.” Mrs. D’s behavior quickly escalated and the multi-disciplinary team was disillusioned. The disagreement amongst both daughters who equally shared medical POA now had turned to their father to “tie-brake” on the use of medications. Although Mr. D had seemingly acknowledged that Mrs. D had entered the terminal phase of her disease and was at the end of life, he struggled to accept the risks medications carried even if they provided comfort.

**DISCUSSION**

At the end of life, effective treatment strategies for BPSD include various non-pharmacological and pharmacological approaches. Non-pharmacological approaches such as behavior therapy, cognitive stimulation therapy and psycho-education of caregivers should ideally be first initiated with pharmacological strategies reserved for behaviors that are severe, persistent, and resistant to non-pharmacological treatments [8]. At the end of life in advanced dementia and significant BPSD, the use of medications can play an integral role in providing comfort from symptom burden - this is inherently morally challenging because the patient him/herself cannot appreciate their disease severity and the management of its complications, and clinically distinguishing between BPSD and pain as in this case, continues to be challenging and poorly understood [9]. Even so, the use of medications such as antipsychotics, antidepressants, mood stabilizers and cognitive enhancers to control symptoms of BPSD at the end of life must be target-based and carefully balanced with the potential of adverse reactions from drug-drug interactions and drug-disease interactions under the framework of the patient’s goals of care and prognosis.

**Risk Tolerance at the End of Life in Advanced Dementia**

In light of recent media attention and scrutiny of antipsychotic use in nursing homes and concerns with safety and efficacy, usually some risk needs to be tolerated when searching for improved quality of life in patients with progressing BPSD not responsive to non-pharmacological approaches [10,11]. With physical aggression and agitation at the end of life, when pain and delirium are not thought the be major underlying causes or contributors, it is not uncommon for clinicians to have discussions specifically about risks and benefits of antipsychotics and the trade-off that exists between quality of life and risk tolerance. Adverse effects with antipsychotics in general are sedation, metabolic syndrome, QTc prolongations, extra pyramidal side effects (EPS), neuroleptic malignant syndrome (NMS) and the increased risk of stroke and a smaller risk of mortality [12]. As a class, antipsychotics generally should have a time limited use and planned discontinuation after a period of behavioral stability - but a detailed discussion with the SDM regarding the clinically relevant risks and benefits at the end of life, specifically taking into account a short prognosis, including alternatives, must be held within the context of symptom burden and goals of care. In this case, even though both SDMs were in agreement about goals of care, there was disagreement over the risk tolerance from medication as the patient progressively declined - this is perhaps contrary to intuition which is that as dementia progresses to its terminal phase, that the family would tolerate more risk to obtain the benefits of treatment for quality of life reasons [13]. Understanding why the two SDMs accepted risks differently under the framework of palliative care is complex with reasons that are sometimes elusive.

**Factors that influence Caregiver’s decision to Risk-Take**

Multiple factors directly influence risk tolerance regarding medication intervention at the end of life. Factors that are associated with less risk tolerance in advancing dementia include increasing age of the caregiver, lower caregiver education, and less personal disease experience whereas a higher level of education, previous experience with dementia, and being an adult child with work demands are associated with more risk tolerance [13,14]. For the most part, these factors are not modifiable but helpful in appreciating decision making. Important to note is that the caregiver’s assessment of the patient’s severity of disease and the patient’s quality of life also influence risk tolerance with advancing dementia. If the caregiver’s perception of overall
health status of the patient is poor, the caregiver may decline risk in treatments for fear of incurring harm to the patient. Exactly how a caregiver interprets quality of life in advanced dementia is not well understood, but is known to be influenced by factors such as personal levels of burden and depression [13]. To what extent a caregiver’s interpretation of quality of life and disease severity are modifiable requires special attention by the multidisciplinary team including those knowledgeable in family dynamics.

**Distinct Caregiver Portraits within the same Family**

Each individual in Mrs. D’s family was coping with advancing BPSD in different ways and had a different tolerability of risk at the end of her life. When there is one SDM or many, understanding the SDM’s distinct coping strategy may contribute to moving forward in achieving the desired goals of care.

Research from Sanders et al., (2009) used “caregiver portraits” to represent how individual caregivers coped with end stage dementia - four distinct character portraits representing caregivers to patients with end-stage dementia were described including the disengaged caregiver, questioning caregiver, all-consuming caregiver and the reconciled caregiver [15]. For different reasons, the disengaged and reconciled caregivers were prepared for their relative’s death. The disengaged caregiver had physical and/or emotional distance while the reconciled caregiver remained involved in patient care - both being realistic about the disease process and not feeling the stress and burden of care giving. On the other hand, the questioning and all-consuming caregivers were involved in the care of their relatives, but care giving in these two portraits was associated with more burden, anxiety and grief as the death approached. Questioning caregivers struggled with understanding of disease progression and had anxiety because of skepticism, whereas the all-consuming struggled with the feelings of loss, and focused on concrete care tasks to help cope. In the above case, both SDMs and husband were involved in the patient’s care; Daughter-A was questioning, Daughter-B was reconciled and the husband was all-consuming. Identifying and understanding caregiver portraits at the end stage of dementia serves as a useful tool not only in understanding an SDM’s decision-making, but then ultimately in creating a practical strategy in aiding him/her move towards the patient’s goals of care.

Lastly, it is also not uncommon that denial in that a loved one is slowly transitioning through the diagnosis and progression of BPSD, can continue and worsen. Families of dementia patients who are in denial often feel unprepared about what to expect at the end of life - this can become exacerbated if distressing symptoms such as agitation or combative worsen [7]. Traditionally, anticipatory grieving is the process whereby terminally ill patients and their caregivers prepare for death, and thus serves as a tool in coping with denial. With advancing BPSD, traditional grieving on the part of the patient is lost and anticipatory grief counselling focuses on the caregiver, not only on impending death but also on past and present losses. In using anticipatory counselling as a strategy throughout progressing dementia care, some caregivers with repeated forewarnings from chronic illness exacerbations may be able to transition to unconditional acceptance of the patient with his/her growing symptom burden and allow one to cope and reconcile in graduated phases -yet other caregivers may find this difficult and remain in denial throughout [16].

How an individual caregiver or SDM copes with advancing BPSD must be taken into account when discussions involving the balance of risk-tolerance and quality of care at the end of life are held. The goal to have all family members or SDMs reconciled with the disease of advancing dementia may be the ideal from the clinician’s perspective, but the process of getting there is complex, challenging and sometimes unachievable. When all the “caregiver portraits” are not congruent, individual support in addition to addressing the caregivers or SDMs as a unit is sometimes required.

**Back to the case**

The focus of attention rested on Mr. D; although legally not a decision-maker had significant influence over his daughters’ decision making. The potential of harm from Mrs. D’s symptoms being now considered greater than the potential risks from the medication and overall quality of life were discussed – Mr. D wanted to see his wife “die naturally and not from medication side effects.” The Attending Physician discussed that medications would not alter the natural course of her BPSD and that with or without medications, Mrs. D would progressively become somnolent. Greater emphasis was placed on the distinct roles that each caregiver had with Mrs. D and that the SDM’s final decision should reflect the general philosophy and ideals of Mrs. D and not their personal ones.

After discussions, Mr. D was able to compromise what he felt was acceptable tolerance from medication side effects in order to achieve better symptom control – he spoke to Daughter-A about using medications at the lowest-possible dose and as needed only so that Mrs. D’s personal care plan was congruent with the agreed goals of care. Ultimately, opioids were re-ordered as needed, but the entire family consented to scheduled Haldol® at 0.5mg subcutaneously twice a day and every 4 hours as needed as the patient would not accept medications orally. Different strategies for each caregiver were then discussed including establishing a more trusting relationship with Daughter-A by having a care plan created and re-visited with her involvement and incorporating anticipatory grief counseling for all. Back on her scheduled medications, Mrs. D tolerated personal care and appeared more comfortable. Surrounded by all her family, Mrs. D passed comfortably in her sleep two weeks later.

**CONCLUSION**

The combination of dementia complicated by BPSD in the setting of palliative and end-of-life care is often a daunting task. It is relatively recent in the history that dementia has become one of the dominant players, competing with malignant disease, as one of the common foci for palliative approaches to end-of-life care being pursued. This has presented programs and practitioners that previously focused mainly on symptom management on those for whom pain and other manifestations of late-stage malignancies were the cause of the adoption of palliative care, to a patient population that is often older than those with malignant disease, and whose dementia-related symptoms are more challenging to address especially when BPSD becomes a dominant manifestation of their symptoms. For many family
members, coping with the challenges of cognitive decline is a major challenge and becomes even greater when combined with agitation, aggression, unusual and threatening actions. These behaviors may cloud the recognition on the part of family members that the person they love is no longer recognizable to them and yet they want very much that their care and dignity be assured. At the end of life, the development of a variety of approaches to BPSD must include non-pharmacological and pharmacological modalities of care within the framework of total symptom burden, prognosis and goals of care, as well as the engagement in a mutually cooperative and respectful manner between individual family members and the medical team for whom BPSD may be very difficult for them to understand.

REFERENCES