MANAGING CHALLENGING BEHAVIORS IN PERSONS WITH DEMENTIA: A RETROSPECTIVE CHART REVIEW AND DESCRIPTIVE ANALYSIS OF A UNIQUE HOSPICE PALLIATIVE CARE UNIT SPECIALIZING IN DEMENTIA CARE

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Study Title:
Managing Behaviors in Persons With Dementia; A Retrospective Chart Review and Descriptive Analysis of a Unique Palliative Care Unit Specialized in Dementia Care.

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Abstract:

Background

Patients with behaviors arising from dementia are often rejected for hospice admission because hospices are not equipped to manage these acute symptoms. In addition, patients with dementia on home teams are discharged to geropsychiatric units due to behaviors. These symptoms are often most distressing for family members and the staff that care for them. Despite this, there are no FDA approved medications or interventions for the management of these behavioral symptoms. In 2013, Hospice of the Valley decided to change a standard inpatient unit into a unit devoted to managing persons with dementia to meet this need.

Methods

A convenience sample of 102 charts of Generalized Inpatient (GIP) admissions of patients with dementia admitted over 5 years for behaviors of hitting, screaming, paranoia/delusions/hallucinations, insomnia, pain, or agitation were reviewed. Pharmacologic and non-pharmacologic interventions, length of stay, oral intake, ambulation, and time to death or discharge were recorded and analyzed.

Results

Behaviors leading to admission were agitation (62), pain (53), hitting (37), screaming (35), paranoia/hallucinations (34), and insomnia (20). Psychoactive medications used were antipsychotics (76%), benzodiazepines (36%), morphine (86%), trazodone (42%), and antidepressants (33%), with no clear patterns of use with different behaviors. Non-pharmacologic interventions were documented for 77% of admissions. 51% of patients died within 2 weeks of admission, with pain and screaming most lethal (66% of each).

Conclusion/implications

In conclusion, pharmacologic interventions showed no specific patterns, and non-pharmacologic interventions were not documented for 23% of patients despite 100% actual usage per staff. In addition, the availability of the unit enabled direct admission or retention of challenging hospice patients. To our knowledge this is the only hospice inpatient unit in the country focusing on persons with dementia. We believe this research will be beneficial to other hospices, and will contribute to knowledge regarding managing behaviors in patients with dementia at end of life.

Research Objectives/Question:

The goals of this project were two-fold: 1) review admissions from the last 5 years to better understand and explore the management of such behaviors using pharmacologic and non-pharmacologic means in this setting and 2) describe the specialized inpatient hospice unit model and explore larger implications of this type of center.

Introduction/Significance/Rationale:

Behavioral/Psychological symptoms are experienced by almost all patients with dementia. Unfortunately, these symptoms are also particularly difficult to manage and weigh heavily on caregivers and health care professionals. Dementia is an increasingly more prevalent problem in the US [5]. Considering that age is the biggest risk factor for developing dementia, it is inevitable that with an aging population this will continue to be a problem for the foreseeable future. Hospice patients with a primary dx of dementia often have severe symptoms which do not respond to simple interventions. There are currently no FDA approved medications for the management of behavioral symptoms in patients with dementia. [5] Of the data that does currently exist, it is suggested that behavioral symptoms in patients with dementia should be managed without drugs whenever possible, as treating patients with dementia with antipsychotic drugs have been shown to increase risks for falls, hospitalizations, and death [1,3,4,6].

Other research has made it clear that there doesn't seem to be a "one size fits all" method for treating behavioral symptoms in patients with dementia, but that pharmacologic treatments should be carefully considered in regards to the pros and cons/risks involved. Specifically, a 2015 article in the BMJ, suggests that non-pharmacologic interventions should be first line, focusing on unmet needs, environmental factors and triggers, interactions, caregiver factors, pain/discomfort, and underlying neurobiological related disease factors [2]. It is clear that this is a difficult topic of research without clear direction in how to best manage these symptoms. Gardiner Home, specializing in care of those with dementia and behavioral issues, provides a unique opportunity to enhance this knowledge.

Methods:

The site of this study was a specialized in-patient palliative care unit focused on providing care for patients with dementia and behavioral problems. We reviewed 102 charts for Generalized Inpatient (GIP) Admissions of patients with a primary diagnosis of Dementia over a 5-year period. Charts were reviewed initially by a trained research assistant and a 3rd year medical student, and then reviewed a second time by the Principle Investigator-A Hospice and Palliative Medicine boarded physician. Pharmacologic and Non-Pharmacologic interventions were recorded, and outcomes measured (length of stay for GIP care, eating habits, ambulation, date of death). This data was then input into a review form that described each patient in order to describe the course of individual patients as well as aggregate group data about use of

pharmacologic management, non-pharmacologic interventions, length of GIP stay, and date of death in relation to admission. Admissions were categorized by GIP reason (Hitting, Screaming, Paranoia/Delusions/Hallucinations, Insomnia, Pain, Agitation). Within those categories, the percentage of admissions using the intervention was calculated. For pharmacologic interventions, we included the average daily doses (+/- 1 SD) and number of GIP days the medication was given for.
In addition to chart review, staff were interviewed to determine challenges and solutions caring for persons with behaviors, the hospice census was analyzed over 5 years looking specifically at the proportion of patients with dementia, and surveys of medical students and residents rotating on the unit were analyzed.

Results/Data:

Average age 83.5 +/- 7.6 yrs. 55 males, 47 females, no data on racial/ethnic background. Behaviors leading to admission were agitation (62), pain (53), hitting (37), screaming (35), paranoia/hallucinations (34), and insomnia (20). Psychoactive medications used were antipsychotics (76%), benzodiazepines (36%), morphine (86%), trazodone (42%), and antidepressants (33%), with no clear patterns of use with different behaviors. Non-pharmacologic interventions were documented for 77% of admissions. 51% of patients died within 2 weeks of admission, with pain and screaming most lethal (66% of each). Information regarding discharge level of care for patients that did not expire was not consistently documented.

For all 102 admissions:

- Antipsychotics were given 76.5% of the time, average dose: 4.4 mg Haldol +/- 3.5 mg for 3.75 GIP days
- Benzodiazepines were given 36.3% of the time, average dose: 3.74 mg Lorazepam +/- 5.95 mg for 3.5 GIP days
- Morphine Equivalents (MSEq) 86.3% of the time, average dose: 26.88 MSEq +/- 28 MSeq for 4 GIP days
- Non-Opiods were given 52.9% of the time, Tylenol average dose 1680 mg +/- 860 mg APAP for 3.75 GIP days
- Trazodone was given 42.2% of the time, average dose 85 mg +/- 65 mg for 3.75 GIP days
- 33.3% of patients were treated with an Antidepressant
- 3.9% of patients were on an Anticholinergic medication
- Non-Pharmacologic interventions were documented for 77.5% of admissions
- Average length of GIP stay: 5.5 +/- 2.5 Days, 77.5% stayed at facility for less than 2 weeks, 51% died within 2 weeks of admission.
- Of patients admitted with GIP-pain as well as behavior symptoms(53 admissions), 66% died within 2 weeks of admission.
- In 5 year period, Hospice Census rose due to increase in dementia patients (less than 20% in 2013 to 30% of census by 2017)

Discussion:

Analysis of pharmacologic interventions, primarily with antipsychotics, benzodiazepines, and opioids, were used often without clear patterns, and often with the effect of sedation rather than specific desired outcomes. Non-Pharmacologic interventions were not documented on close to 25% of patients despite almost 100% universal "real-world" usage. Having a specialized facility for caring for patients with dementia may allow hospices to meet the rising prevalence of dementia.

The current state of literature suggests that the best way to manage behavioral problems in patients with dementia is a multidisciplinary approach (nurses, aides, physicians, family members, caretakers) and with the use of both pharmacologic and non-pharmacologic agents. Despite this recommendation there is little healthcare infrastructure available for or capable of delivering this. Gardiner Home is an example of a site that follows these recommendations- however up until this point, very little time/effort had been spent looking back in-depth at what was being done on a day-by-day basis. The primary purpose of this study was to gather basic background information on what was being performed at this center and to describe the current status and future direction for the management of behavioral symptoms in hospice patients with a primary diagnosis of dementia.

It is impossible to take this data and attempt to extrapolate effects or statistical significance of prescribing antipsychotics, benzodiazepines, morphine, or non-opioid pain medications. However it was useful in seeing that a majority of patients admitted to this facility were given these medications despite there being no FDA approved indication for using these medications for the management of behaviors. It shows that there currently exists a sense of desperation from many healthcare providers, caretakers, and family members for us to do anything to help. This will only continue to become more prevalent as the population of persons with dementia is expected to triple over the next 30 years [5].

To our knowledge this is the only hospice inpatient unit in the country focusing on persons with dementia with behaviors. Despite that, there is still significant room for improvement in pharmacologic intervention, documentation surrounding non-pharmacologic interventions, as well as how to best quantify behavior symptoms and the responses from interventions. These findings are now being applied to patients in other inpatient units and facilities with future plans to study interventions more directly/in a prospective manner. An example of a future direction would be studying whether scheduled Tylenol may help reduce in patients with GIP-Behavior and GIP-Pain. We believe that this knowledge will be beneficial to other hospices as well as contributing to the foundation for future studies surrounding managing behaviors in patients with dementia.

Resources/Funding/Conflict of Interest:

Special thanks to Hospice of the Valley staff for support throughout this project. No funding, no conflicts to disclose.

Compliance:

IRB Approval gained from Hospice of the Valley IRB Review Board.

References:

[1] Macfarline, Stephen et al. Managing Behavioral and Psychological Symptoms in Dementia. Australian Prescriber. August 2016.
[2] Kales, Helen et al. Assessment and Management of Behavioral and Psychological Symptoms of Dementia. BMJ 2015
[3] Iaboni, A et al. Detecting and Managing Neuropsychiatric Symptoms in Dementia. Can J Psychiatry 2017.
[4] Cerejeira, J et al. Behavioral and Psychological Symptoms of Dementia. Front Neurology 2012.
[5] Langa K et al. A Comparison of the Prevalence of Dementia in the United States in 2000 and 2012. JAMA IM 2017.
[6] Novais T, Mouchoux C. Pharmaceutical care for patients and their caregivers in Alzheimer's disease and related disorders: a review and new perspectives. Geriatr Psychol Neuropsychiatr 2019.

Submission statement: This was submitted to the AAHPM Journal (American Association of Hospice and Palliative Medicine) They do not have published guidelines for their peer review guidelines and rather this format was done under the direction of Dr. Gillian Hamilton MD PhD who has had several other publications through this journal in similar format.