Relief of Sufferings Across the Disease Trajectory: Dementia

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Introduction

Palliative care in dementia

WHO definition of palliative care extends to incorporate non-malignant life limiting disease as: “an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness by treatment of pain and other problems, physical, psychosocial and spiritual”. Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

BPSD in dementia

• Behavioral disturbances among patients with dementia, including agitation, aggression, and psychosis, form a constellation of symptoms referred to as behavioral and psychological symptoms of dementia (BPSD). These impact heavily on resident’s quality of life, caregiver stress, and management options for the team [1].

• In the United States, Center for Medicaid and Medicare services (CMS) launched the National Partnership to Improve Dementia Care, [2] and established a goal of reducing the use of antipsychotic medications in long-stay nursing home residents by providing person centered comprehensive care.

Objectives

• Implement CMS regulatory standards to improve Dementia Care.
• Improve the quality of care of residents with diagnosis of Dementia by providing Palliative care programs.

• Reduce the usage of antipsychotics in Dementia related behavior (BPSD) by implementing nonpharmacological Approach [3].
• Key elements and outcomes of Palliative care programs at NYC Health +Hospitals /Coler.

Prevalence of Alzheimer’s disease in US

• In US 5 million people have Alzheimer’s disease [4].
• 2 million people with Alzheimer’s disease live in a Nursing home in USA [5].
• Over 60 % of Nursing home residents with dementia present with behavioral and psychological symptoms of dementia (BPSD) [6].
• 75% of people with dementia will spend time in nursing home, most typically in the moderate to advance stages.

Manifestations of BPSD (behavioral and psychological symptoms of dementia BPSD)

• Wandering
• Impulsive; Pulling, pushing, grabbing
• Verbal; Disinhibited language
• Hallucinations and Delusions
• Sleep and appetite disturbance
• Apathy/Withdrawn/Depression
• Sun downing
• Anxiety/Pacing
Use of Antipsychotic medication for BPSD: Not FDA approved

CMS standards (Center of Medicare and Medicaid Services)
- Drug regimen is free from unnecessary drugs; Residents on Antipsychotic receive gradual dose reduction and behavior intervention unless clinically contra indicated, in an effort to discontinue these drugs [7].
- Activities; The facility must provide ongoing activities and services to maintain highest physical, mental and psychosocial wellbeing of the residents.
- Quality of care; The facility must provide care and services to attain or maintain highest physical, mental and psychosocial wellbeing.

CMS standards: palliative care
- Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering.
- Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

Background
Initiated a grant Project on “Building Palliative Care in Dementia at Coler” in February 2018.

Methods/Intervention
This study was conducted in six Memory care units with 150 residents at an 815-bed long-term nursing care facility. All residents in Memory Care Units from May 2018 to May 2019 were individually assessed for usage of psychotropic, Physical Altercations, Falls, ER admission. Transfer to acute hospital, Pain Management, rejection of care, Weight loss usage of supplements and 1;1 observation.

Learning points related to palliative care in dementia
- Behavior in dementia is way of communication, behavioral expressions are almost always signs of distress, and as the disease advances, behavior rather than words become the primary mode of communication for most people living with dementia [8].
- Antecedent ←→ Behavior ←→ Consequence: Antecedents can be loneliness, Pain, hunger, soiled, constipation, urinary tract infections, delirium, dehydration etc.
- Identify and manage Delirium in Dementia: For all new onset behaviors, consider if this could be delirium. Early identification will help the resident’s health and reduce care giver burden, Delirium is caused by disturbance in brain functioning due to an underlying medical problem such as:
  a) Infections are the most common cause: UTL, pneumonia (tests: CBC, U/A, CXR)
  b) Dehydration, sleep deprivation
c) Medication interactions
d) Fracture
e) Systemic illnesses: e.g. heart, lung, liver dysfunction
f) Environmental changes
  - Depression syndrome in people with dementia: non-pharmacologic and pharmacologic strategies for treating these mood disorders, Use PHQ 9, observation to identify depressive symptoms.

Managing dementia related behavior: non-pharmacological approach:
- Go-with-the-flow if others are not disturbed/affected and safety is not jeopardized.
- Distract attention by verbally presenting other topics or presenting with distracting stimuli.
- Negotiate: e.g. “if you stop this, I will play your favorite music right now”.
- Try an environmental change.
- Assess for needs such as toileting and pain.
- Offer water and comfort food.
- Offer to hold their hand and take a little walk.
- Get family’s input if available: call the family by phone or talk about their family.
- Comfort items, Rocking chairs, lollipops, doll therapy etc.

Key concepts in dementia care
- Comfort Care: Refers to the care required to meet broad spectrum of needs of persons with Dementia, includes medical, physical, social emotional and spiritual needs.
- Comfort Focused Approaches in Dementia Related Behavior.
  - Assessing and Addressing Pain.
  - Magic of making Connections.
  - Know the person: individuals important life events, past daily routines and vocation, as well as family members and friends.
  - Staff Empowerment: give staff members “go ahead “to do what is best for individuals with Dementia. Staff members who are empowered become the voice of the person with Dementia.

Palliative care programs:
Shift from Medical Model to Palliative Model in Dementia Care: Fundamental premise underlying all care for people with dementia.
is that behavior is communication. These behavioral expressions are almost always signs of distress, as disease advances behavior rather than words become the primary mode of communication. Palliation-relieving distress-becomes cornerstone of care for people with Dementia.

Created a “neighborhood’ culture

Where all services are integrated: Newly created Memory Care “Neighborhood” has a Coordinator to integrate the services, all interdisciplinary staff work in the memory care units report to the memory care coordinator on daily basis.

Consistent staff

Consistent assignment is an extremely important component of good care. In Coler, Memory care units have consistent trained interdisciplinary staff.

Modified job functions of interdisciplinary staff

To improve meaningful engagement: modified Job Functions of interdisciplinary staff and cross trained them to improve meaningful engagement, every departmental staff engage the residents in different activities, for example. Housekeeping staff have story telling sessions to the residents, Therapeutic Recreation staff set up the meal trays for residents, nursing staff do musical performances and dancing programs with residents, administrative staff play games with them.

Consistent huddle with interdisciplinary staff, in the unit’s interdisciplinary staff have consistent huddles of all tours, in the huddle team discuss about any changes in residents medical conditions, cognitive functions, ADL status, changes in behavior etc. This discussion with the interdisciplinary staff helps the team to develop person centered care plans.

Liberalized diet

Even when people with Dementia can’t remember the name of the food, If they like the food, they are much more likely to eat it. As per Academy of Nutrition and Dietetics “the quality of life and nutritional status of older residents in long tram care facilities can be enhanced by a liberalized diet.” In the Memory Care Units of Coler, 90% of the residents are on liberalized Diet.

Snack on demand

the units have a snack cart around the clock with different types of snacks, juice, ice cream, jell and more. The key element for residents with Dementia is for staff to offer individually preferred snacks directly to residents approximately every hour around the clock while awake. Because people with Dementia slowly lose the ability to initiate or tell someone if they are hungry.

Meaningful engagement

Distress may result when people are feeling lonely, bored or frustrated. When caring for people with Dementia, every interaction has the potential for meaning. Whether it is offering a snack or walk hand-in-hand. There is connection and potential for comfort. All staff regardless of disciplines have a crucial role in meaningful engagement of residents.

Resident centered structured programs

Meaningful activities for short duration and multiple activities in different stations by interdisciplinary staff; Activities must be customized to be meaningful. The residents with Dementia almost never engage in large group events. There are many options available and staff are familiar with what will work with a given resident on a given day.

Music and memory program, 24X7

Is the personalized music (iPod) project in the Memory Care Units. Music that is personally meaningful to residents has been found to evoke remote and recent memories, often helping the resident to feel calmer and more connected to other residents, staff, family and friends.

I glance/I care plan

This is about residents preferences, likes and strengths. I Glances are posted at bedside of the residents. When the residents are being transferred to acute hospitals, the unit team send copies of I Glance and I Care Plan to the facility as communication tools.

Enhancement of student volunteer’s participation in memory care

By encouraging student volunteers in Memory Care Units we were able bridge 2 generations, connected young generation to geriatric population and gave students an exposure to the Dementia world.

Structured training

90% of Interdisciplinary staff are Certified Dementia Practitioners by NCCDP (National Council for Certified Dementia Practitioners). Memory Care Co-coordinator provides ongoing structured standardized in vivo training.

Bathing without battle

Almost all residents with Dementia are resistant to take shower. Our team have created pleasant bathing experience and reducing the battle by providing person centered bath such as, no rinse bathing, singing bath, Recliner bath, Music in the shower room.

“Adopt a resident” program

Administrators and departmental heads adopted a resident from the Memory Care Units. By doing so they committed to spend time with residents in a meaningful way consistently.

Memory Care Programs/ Meaningful Engagement Includes

- Live musical performances by interdisciplinary staff and residents
- Weekly cooking programs in the unit/Sensory stimulation program
• Weekly bread and coffee program/Sensory stimulation program
• Weekly religious programs
• Monthly outdoor barbeque with Music
• Chair Zumba
• Doll therapy
• Pet therapy
• Sensory room/quiet room

**Results**

- Usage of Antipsychotics reduced from 20% to 9%
- Fall reduced from 12% to 2%
- 1:1 Reduced from 6 to 1
- Pain Management Improved
- Reduction of hospitalization
- Reduced Rejection of Care
- Reduction of Physical Altercations from 20% to 0
- Improved Advanced Directives/MOLST
- Significant reduction in transfer to ER
- Increased number of residents on palliative care
- Improved morale of the units
- Improved family involvement and satisfaction
- Increased staff satisfaction
- Decreased staff call out

**Acknowledgement**

None.

**Conflict of interest**

No Conflict of interest.

**References**


