Palliative Care for People Living with Dementia: Why Comfort Matters

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Learning Objectives

Participants will:

1. Describe two expectations for people experiencing mild, moderate and advanced dementia
2. Identify and describe at least three comfort-focused approaches for people with dementia
3. Identify key strategies for implementing these practices in your setting

The Beatitudes Campus Story

When I knew what I knew, I did what I did. Now that I know better I do better."

Maya Angelou

alzheimer's association New York City Chapter

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Progression of Dementia

	Mild	Moderate or Mid-Stage	Severe or Late Stage	Terminal
INDEPENDENCE	Impaired memory; Personality changes; Spatial disorientation	Confusion; Agitation; Insomnia; Aphasia; Apraxia	Resistiveness; Incontinence; Eating difficulties; Motor impairment	Bedfast; Mute; Intercurrent infections; Dysphagia

ADVANCED DEMENTIA

TIME

(Hurley & Volicer, 1998)

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The resilient brain

- People with dementia are experts on their own comfort
- Emotions are intact-so we can change how a person feels even if we can't change how they think
- Information about the world around us can get into our brain through our 5 senses
- When verbal communication is compromised we communicate through our behavior/actions

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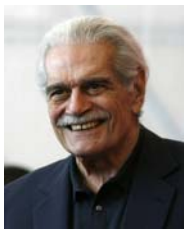
Looking at dementia differently


What to expect from me, Matilda

- I look normal and act as though I have no trouble thinking most of the time
- I have difficulty remembering upcoming events or learning new information
- I know there is something wrong with my thinking but I don't want everyone else to know
- I have gotten lost while driving but I'm afraid to give up my car and my independence

What to expect from me, Enrique

- I look like I always have but sometimes I don't act like myself
- I struggle to be understood and to understand verbal language
- I have great difficulty learning anything new but others expect me to learn
- I can't take care of myself like I used to and can become fearful when you try to help me with everyday tasks

What to expect from me, Amelia

- I look like myself but I act completely different all the time now
- I can no longer communicate verbally
- I can no longer learn new information but everyone doesn't know this
- I tire easily and need to rest often
- I struggle to engage with the world around me

Why does comfort matter to people with dementia?

- How important is being comfortable to us?
- What happens if we're uncomfortable?
- Are people with dementia different?

Defining Comfort

Merriam-Webster's definition

1. *"To give strength and hope to"*
2. *"To ease the grief or trouble o*

Synonyms:

assure, cheer, console, reassure, soothe

Antonyms:

Distress, torment, torture, trouble

Kolcaba's Theory of Comfort

The three senses of comfort:

Relief

If specific comfort needs of a person are met, for example, the relief of pain by administering prescribed analgesia, the individual experiences comfort in the relief sense.

Ease

If the person is in a comfortable state of contentment, the person experiences comfort in the ease sense, for example, how one might feel after having issues that are causing anxiety addressed.

Transcendence

If person is comfortable enough they will be able to rise above their challenges, this is described as the sense of transcendence.

Evidenced-based comfort assumptions

- Being comfortable is a benefit to people with dementia
- People with dementia communicate comfort and discomfort through their actions
- Everyone with dementia can be comfortable
- Comfort includes body, mind and spirit
- Comfort is **NOT** just for end-of-life circumstances

Barriers to comfort

- Everyone but the person with dementia struggles to understand why comfort is so important
- Most staff and families have unrealistic expectations for the person with dementia
- Comfortable living is confused with end-of-life circumstances

Traditional versus comfort models of care

Traditional Model	Comfort Model
Focused on the physical body and cure	Focused on body, mind and spirit
Care/service is driven by the medical provider	Care/service is driven by the person receiving care/service
Emphasis on staff for task completion	Tasks are scheduled according to a person's needs and wants
Staff members are instructed not to get close to "patients"	Staff members are encouraged to "know the person"

So what has to change if comfort is the priority

What comfort looks like for people with dementia

- They are free from pain
- They sleep when they're tired and wake when refreshed
- They eat what they enjoy when they're hungry
- They receive care on their own terms
- They are engaged in things that make sense to them
- They experience an environment which meets their needs at every level

Beatitudes Campus evolution of care models

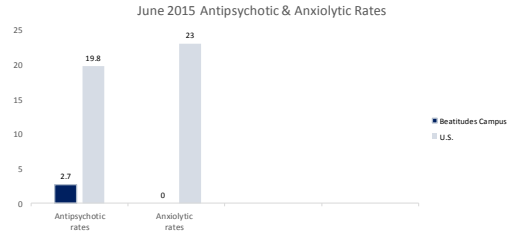
Traditional Model

- All people used physical restraints
- All people received an antipsychotic and anxiolytic
- 25-40% of population lost weight every month
- Strict adherence to therapeutic diets
- Spent 30,000 annually on supplements
- Most people rejected care
- Sleep/wake were staff-driven
- Everyone showed Sundown symptoms
- Total focus on medical needs

Comfort Model

- No physical restraints
- Antipsychotic & anxiolytic medication use in minimal
- Weight loss is rare
- NO therapeutic diets
- NO supplements used
- Resisting care/service is rare
- People sleep, wake & eat as they desire
- NO ONE exhibits Sundown symptoms
- Total focus on mind, body, spirit

Comparison of Beatitudes Campus and US antipsychotic & anxiolytic medication rates



Support for comfort

- Center for Medicaid & Medicare Service
- Institute of Medicine
- Center for Advancing Palliative Care
- AARP
- New York Times
- The New Yorker Magazine
- Chicago Tribune
- Boston Globe

Margie's comfort

Using the MDS and QAPI to Improve Care and Bring Comfort to People with Dementia

Ann Wyatt
Alzheimer's Association,
New York City Chapter

MDS 3.0

Four specific items from the 'behavior' section:

- E0200 A. Physical symptoms directed towards others
- E0200 B. Verbal symptoms directed towards others
- E0200 C. Other behavioral symptoms not directed toward others
- E0800 Rejection of Care (Did the resident reject evaluation or care?)

Care Planning

- Quarterly Care Plan Meetings
- Meeting Preparation: Detective Work
- “What Comforts Me” Care Plans

QAPI

- Use the four specific items from the ‘behavior’ section to zero in on areas of need
- Useful as starting point for unit-based QAPI
- Focus on specific residents to identify root causes (which may then lead to unit-wide or facility-wide improvement projects)
- Identify and test specific interventions
- Test for interventions should measure both (1) effectiveness of intervention for residents, and (2) fidelity of implementation process itself
- Plan for on-going monitoring of effectiveness and of process

Pain Projects

Potential areas for focus:

(1) Behavioral Expressions (MDS Section E)

(2) Implementation of behavior-based pain assessment tool

Potential Measures:

(1) Behavioral Expressions (MDS Section E)

(2) Medication Usage Patterns

Sleep/Rest

Potential areas for focus:

(1) Customary routines

(2) Observations (AM care, afternoons/early evenings, activity engagement)

Potential Measures:

(1) Falls

(2) Behavioral Expressions (MDS Section E)

Food

Potential areas for focus:

(1) Snack

(2) Meal presentation

(3) Meal content

(4) Mealtime ambiance

Potential Measures:

(1) Weight Loss

(2) Supplement Use

(3) Costs (Supplements vs. food)

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THANK YOU!

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