COMPREHENSIVE CAREGIVER TRAINING TO FACILITATE AGING IN PLACE FOR PATIENTS LIVING WITH DEMENTIA
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Blue Ridge PACE

Blue Ridge PACE opened in March of 2014 in Charlottesville, Virginia. Our service area covers 5+ counties and is a mix of very rural, suburban, and urban areas. Currently, we have a census of 144 with an expected max enrollment of 200+ participants.
Why did we decide that we needed a dementia management program?
Our program did not provide appropriate care

- Participants with dementia were not able to participate fully in the activities offered in the day center.
- Large group activities were increasing behaviors such as agitation, aggression, wandering. Other participants were distracted by these behaviors.
- Participants with dementia were resistant to personal care attempts from our Universal Care Partners (UCP’s).
- Family caregivers were reaching out to us reporting significant stress and difficulty with providing care at home.
Classic LTC Environment

Program Expectations

- We hope to see
  - Decreased agitation
  - Decreased apathy
  - Decreased caregiver strain
  - Increased participation in activities
  - Increased engagement with the environment
  - Increased socialization
  - Increased ability to adhere to daily routines
  - Positive impact on medication needs
  - Positive impact on overall health and wellness
  - Decreased utilization

- Increased quality of life for participants and caregivers
Issues Managing Dementia Care in LTC

- Staffing Levels
- Staff Attitudes toward dementia care
- Limits on Environment
- Time to do it all
- Lack of Sufficient Funding
- Lack of Adequate Training
- Regulations
Risks associated with poor management

- Increased in residents who have a decline in ADL status on MDS
- Increased risk for CMS citations at survey time
- Increased cost related to hospitalizations / ED admissions
- Increased time allocated to care
- Decreased staff morale
Implementation

- Interprofessional Approach
- Staff Training
- Assessment
- Environment
- Activities
- Routines
Interprofessional Approach

- A multidisciplinary group that makes group decisions, usually based on a consensus model

- Providers
- Administration
- Rehab Staff
- Nursing
- Recreation Therapy or Activities Department
- Dietary
- CNA / Restorative Aids
- Housekeeping
Training
Case Study – Inappropriate expectations by caregivers

■ Case: 80 y.o. male
Hx: Senile dementia with delusions, Anxiety, urinary retention, post polio
Ptcp had indwelling catheter d/t urinary retention. He frequently became agitated and pulled at the catheter d/t discomfort.

RN Response to frequent injury d/t above:
“He’s just going to have to learn.”
(regarding implications of pulled at catheter)
- “He’s just being stubborn.”

- “I just told you to sit down! Don’t you remember??”
Caregiver training

- Skills based
- Ongoing
- Individualized
  - To caregiver abilities and roles
  - To the population you are serving
Staff training at BRP

- Formal training provided by OT and SLP to each new hire and all staff yearly
- Informal mentoring provided continuously
- It’s important to be aware of current issues and provide training and mentoring opportunities to address them as they come up
- In other words...1 training is not going to cut it and you have to modify what you’re doing for the specific population you have at any given time
Key topics for staff training

- Understanding Dementia
- Behavioral Management
- Positive Communication
- Adapting Activities
- Modifying the Environment
- Learning How to Assist to Facilitate Participation
- Benefits of Routines
- Hydration Program and Toileting Schedule
Assessment and Intervention
Logistics

- How do you assess for changes in status?
  - Regular screening (who does this?)
  - Monitoring health outcomes (falls, weights, labs)
  - Listening to your CNAs

- PT, OT, SLP will need orders. They will follow residents under Part B when a need has been identified. Generally, this is when there is a change in status or function. Assessment and interventions will be limited by Medicare regs. However, re-refer when you see a new change or decline.
Monitoring

- Monitor cognitive decline
  - Regular cognitive screening – example Global Deterioration Scale, Blessed Dementia Scale, FAST, Brief Cognitive Rating Scale, Montreal Cognitive Assessment (MoCA), St. Louis University Mental Status Exam (SLUMS)

- Monitor functional decline
  - ADL performance, mobility, leisure engagement, appearance

- Monitor behaviors
  - Aggression, agitation, apathy, social skills, sleep routines
Environment
Environment

- Quiet, Calm, Comforting
- Appropriate stimulation/music
  - *Upbeat during active times of day, quieter during calm times of day*
- Appropriate activities available
- Safe for wandering, disguised exits
- Homey, personalized
- Cues available (e.g. calendars, clocks, schedules, signs)
- Snoezelen (multisensory)
- Montessori
https://www.snoezelen.info/who-can-benefit/snoezelen-for-the-elderly/

http://health.wusf.usf.edu/post/multisensory-approach-memory-care#stream/0
Complete with a Main Street, a barber shop and hardware store, this village-in-a-box is designed to make elderly patients with memory loss feel at home in an unexpectedly interior small-town setting.

Effects of environmental modifications

- Improvements with behaviors
- Improvements with participation
- Decreased falls
- Decreased exiting behaviors

- Research does not find long-term benefits with moving residents out of traditional nursing home units and into specialty care units
The power of engagement

- Right activities
- Right amount of support
- Available throughout the day

- Utilize your rec department, OT, and ??
The power of engagement

- Decreased agitation
- Decreased anxiety
- Increased engagement in the activities
- Increased social engagement
- Slows functional decline
- Improves nighttime sleep
Proper Engagement
Falls

- Implement regular routines for
  - Toileting
  - Hydration and snacks
  - Activities

- Consider medications

- Stop using alarms as a fall prevention measure

- Regular exercise

- Environmental considerations
  - Typical safety (e.g. lighting, clutter, trip hazards)
  - Montessori, Snoezelen, Wander Gardens
  - "noise reduction and temporally appropriate" music may help
Falls

Statistics:
- 391 total reported falls from PACE participants from January 2017-June 2018
- 62 of those falls were from Dogwood participants (16% of falls for ~10% of population)
- 48 of these total falls occurred in the PACE center
- 0 of those falls were in the Dogwood room

Conclusion? These participants are more likely to fall in general. BUT they are not falling when in the Dogwood room with appropriate stimulation and supervision.
Healthy routines
Routines

- Schedule
- 0830 Breakfast
- 0930 Hydration and Toileting
- 1030 Activity
- 1130 Clean up for lunch
- 1200 Lunch
- 1300 Toileting
- 1400 Activity / Exercise
- 1500 Rest
- 1630 Hydration and Toileting
- 1700 Dinner
The battle to prevent dehydration

Dehydration was diagnosed in 6.7% of hospitalized patients age 65 and over, and 1.4% had dehydration as the principal diagnosis.

Behaviors and Communication
Behavioral Communication

- Nonverbal communication
  - Gestures
  - Changes in mood
  - Pacing
  - Facial expressions
  - Fast breathing
  - Spitting, hitting, kicking
  - Nonsensical yelling

- Pay attention! Each person communicates differently.
Agitation and Aggression

- Many people with dementia will at some point become agitated and/or aggressive. WHY?!

THEY ARE TRYING TO TELL US SOMETHING!
Agitation and Aggression

- What do I do when this happens?
  - Stay calm
  - Make sure everyone is safe
  - Try to figure out why this person is so upset?! Many likely reasons include:
    - Having to go the bathroom
    - Being hungry
    - Being hot/cold
    - Being in pain
    - Being bored or tired
    - Being overstimulated or overwhelmed
    - Just being upset! We all get angry at times.
  - Redirection
Medical Management in Dogwood

- Hydration program
  - Improves overall health and decreases risk of UTI
- Toileting schedule (when appropriate)
- Coordinating with med-nurse and clinic for med management and other medical needs
- Regular exercise
- Pain management
- Swallowing and diet

(Easterling, & Robbins, 2008; Faces, et al., 2007; Lavizzo-Mourey et al.,1988; Warren, et al., 1994)
Transitions
Transitions of Care

- Delirium
- Functional Decline
- Cognitive Decline
- Emotional impact
- Error
Transitions of Care

- Minimize the number of transitions
- Minimize time away from home (hospital LOS, SNF days)
- Get all team members on board to support a smooth transition
- Be patient
- Focus on a consistent routine
Follow up care post hospitalization

- Schedule a follow up visit with primary care asap
- Review medications
  - Were any inappropriately added or d/c’ed?
- Review hospital discharge instructions
  - Are follow up specialty appointments or recommendations in line with the goals of care?
- Review Labs / Tests
  - Was there anything to indicate that needs were not met prior to admission?
- Prepare the home (DME, etc)
Hospital at Home

- John’s Hopkins: http://www.hospitalathome.org/

- When possible, provide treatment within the person’s familiar environment. Some hospitalizations can be avoided by treating the person earlier and in the home.
- Pneumonia outcomes
- Can we provide more clinical oversite or caregiver training to identify issues early on?
- How can you set up your facility to manage more in-house?
Advanced Care Planning

- Have the difficult discussions. Then encourage the POA to have these discussions with their families.
- Curative versus Palliative
- Focus on goals of life, not just death
- Discuss medical recommendations including
  - Feeding tubes – not recommended for people with advanced dementia
  - CPR – survival rate (near 0%) for this population – what are the expected outcomes should someone go through CPR?
  - Ventilators – consider how someone with dementia would respond to intubation
  - When to hospitalize – when to not
Case Study - Peggy

- PM is a 92 yo female who joined PACE 4 years ago. She was a professional singer, has 5 children though only has contact with 1 currently (her daughter with whom she lives). She lived in Italy, NJ, and now Virginia. Her medical history includes: hip fracture with failed ORIF (2015) and active issues include: healed sacral pressure ulcer, end-stage COPD, vascular dementia, chronic pain, muscle weakness. She is a DNR and receives comfort care. While a PACE participant, she has been followed from home, to the hospital s/p fall with hip fracture, to the SNF for therapy, to respite for therapy, and back home.
Hospital transition

- Hospitalization for hip fracture s/p fall, complicated by blood loss anemia and kidney injury. LOS 6 days, procedure: ORIF
- ACP provided to hospital and coordination of care provided by PACE staff
- Room for improvement
  - Staff training/communication regarding PLOF and dementia care
  - delirium prevention strategies
  - minimize LOS
SNF transition

- ACP provided to SNF and coordination of care provided by PACE staff
- Seen by PCP for med rec and to review/schedule follow-ups
- De-prescription, d/c’ed narcotics

- Room for improvement
  - delirium prevention strategies
  - pain management
  - visits to facility to improve routine
Respite transition at LTC Facility

- Consistent routine, staff, activities
- Consistent meals and hydration
- Pain management: scheduled Tylenol
- Follow up care with ortho – failure of ORIF, decision to not pursue further tx (consistent with ACP)
- Assessed agitation, pain, and function at PACE
- Environment/task/caregiver modifications to minimize agitation and maximize engagement at PACE
- Room for improvement: nighttime routine and sleep
Home transition

- Consistent routine, staff, activities
- Familiar environment
- DME, home care, respite for caregiver strain (additional services and DME added during the expected decline)
- Caregiver training for daughter and staff, ongoing
- Palliative care for symptom management particularly with COPD exacerbations – initially utilized steroids, nebulizers, and supplemental O2. After review of ACP, antibiotics not used.
- Regular assessment and contact with caregivers familiar with ptcp
- Regular PT, OT, SLP for maintenance of function (not currently supported by traditional Medicare/Medicaid)
Results of consistent support and providing appropriate levels of care

No Readmissions to ER or Hospital since 2015
Utilization
ER Utilization per 1000 ptcp days

Q1 2016
Q2 2016
Q3 2016
Q4 2016
Q1 2017
Q2 2017
Q3 2017
Q4 2017
Q1 2018
Q2 2018
Q3 2018

Dogwood
All Other PACE ptcps
- **Q3 2017:**
  - 1 UTI
  - 1 End of Life
  - 2 falls

- **Q1-2 2018:**
  - 1 Participant outlier with 6 ED visits and 4 hospitalizations
  - 2 End of life
Research links a dementia diagnosis with higher utilization

But

Participants in the Dogwood program are utilizing the ED and hospital less than all other participants
Why?

- Comprehensive care approach
- Caregiver involvement and ongoing training and support
- Assessment of changes and early treatment
- In-home hospital options
- Advanced Care Planning
Take-home

- Residents with dementia require a different approach to care – this type of care is possible in long-term care settings
- Ongoing training and support of caregivers is essential
- Support from the top (i.e. you) will help with buy-in and success
- ACP is a must
- Minimize the transitions, maximize care at home
- Good care = better outcomes = lower costs (Triple Aim)
- It takes a village
References


