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Effective Dementia Care Management: Essential Strategies for Nurses

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I have no financial disclosures

Objectives

At the conclusion of the presentation the participant will be able to:

- Describe the components of patient centered dementia care management.
- Develop patient centered care management care plans.
- Collaborate with care partners and community resources to implement dementia care management.

Why my interest in this topic?

- Clinical Nurse Specialist background with emphasis on system level & team approach with community resources
- Over my nursing career community based care, with vulnerable populations
- Better outcomes with team approach and connection to community resources
- I was a care partner 10 years, father lived with me 3.5 years
- Dementia is a long journey involving the family and have seen the benefits of care management and coordination.

- What brought you here? What do you want to learn?

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Dementia Prevention

- The underlying brain changes associated with dementia happen many years prior to onset of symptoms.
- Dementia continuum spans decades-requires life course approach (Olivari et al., 2020)
- The Lancet (2020) identified 12 potentially modifiable risk factors for dementia which “account for **around 40% of worldwide dementia.**”
  - Excessive alcohol intake, traumatic head injury, air pollution, **less education**, **hearing loss**, hypertension, obesity**, smoking**, **depression, social isolation**, physical inactivity, diabetes

Case Study

- Linda is 67 year old female seen with her husband Butch for check of memory changes. Linda has a hx of significant depression & being withdrawn and unable to work for the past 15 years due to her depression.
- They live in a small rural community, Linda is home all day by herself, spends time with her multiple cats, smokes and has been going with a male friend reason unknown. Her husband drives school bus & checks on her mid-day.
- Linda's MOCA score is 15/30, she is unable to dial the telephone, does not remember her address, hides things and does not always eat properly. She has not wandered. Butch thinks she is doing pretty well.

Care Management Definition

- “Care management is a promising team-based, patient-centered approach ‘designed to assist patients and their support systems in managing medical conditions more effectively.’ It also encompasses those care coordination activities needed to help manage chronic illness” (AHRQ, 2018)

- Include coordination of care, self-management support, and outreach (AHRQ, 2018)

Dementia Course-The Reason for Care Management

- "On average, a person with Alzheimer's lives **four to eight years after diagnosis, but can live as long as 20 years**, depending on other factors.
- Other types of dementia journey can be up to 6-8 years" (Alzheimer's Association, 2022).
- "Multiple studies have shown that quality of care for dementia in primary care is poor with physician adherence to dementia quality indicators (QIs) ranging from 18-42%" (Jennings et al., 2016)

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Nursing Education & Care Management

- AACN Essentials (2021)—Domains-Person Centered Care; Quality & Safety; Systems Based Practice; Interprofessional Partnerships; Informatics & Health Care Partnerships.

  -Crosses all spheres of care.

-NCLEX Test Plan (2019)- Safe & Effective Care Environment including Management of Care, Case Management, Advocacy, Client Rights, Collaboration with IDT, Continuity of Care, Referrals; Safety and Infection Control-Home Safety; Health Promotion and Maintenance-Aging Process,

Developmental Stages and Transitions; Psychosocial Integrity

Typical Appointment for Dementia Dx

- Framed within the medical model, no cure, no treatment to fix it.
- Often diagnosed too late- due to stigma, lack of awareness, lack of specific diagnostic test, concern about placing label.
- Sense that there is not a lot of hope, perhaps some medications, given brochures, call the Alzheimer's Association.

Care Management at Dementia Diagnosis

- Recognize this is a life-changing diagnosis for patient and family/care partner.
- View as a **chronic illness which is life limiting.**
- This is where **nursing steps up**—person centered care, walking with the patient and family, helping to navigate the journey
- Develop an effective patient centered plan of care moving forward at the pace the patient and family want to pursue.
- More than education and brochures.

- "…the majority of healthcare delivery does not happen in the doctor's office or hospital: It happens at home" (Markwood, 2020)

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Reasons for Dementia Care Management

- Improved quality of life and reduced fear/anxiety
- Maintain cognitive and physical abilities
- Slow progression of cognitive decline
- Reduce hospitalizations
- Safe medication management
- Reduce injuries and safety problems
- Reduce caregiver stress and burnout
- Maintain person with dementia longer in the community
- Care provided according to patient preferences/goals

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Dementia Care Management Interventions/Models

- Components of Dementia Care Management Interventions have been identified in the areas of assessment and screening, counseling and treatment (American Medical Association, 2011; Wenger, 2007).
- Several models for Dementia Care Management have been developed with positive results and recommendations.

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UCLA Alzheimer's & Dementia Care Program

- NP Dementia Care Managers assessment & care approach with individualized dementia care plans, ongoing care management with active monitoring every 4 months, & variety of interventions to support caregivers, including support, education & referral to community agencies. (Reuben et al., 2019)
- Clinical benefit was demonstrated with patients and caregivers
- Results in very high quality of care for dementia, especially for assessment, screening and counseling (Jennings et al., 2016)
- May reduce the number of admissions to long-term care facilities, and depending on program costs, may be cost neutral or cost savings (Jennings, 2018)

Dual Eligible Dementia Care Coordination

- Dementia screening and diagnosis; caregiver identification, assessment & involvement; referral to community resources; collaboration with aging services network; and care coordinator training & qualifications.
- Managed care organizations can include more dementia-capable care coordination practices in health plan contracts (Hollister, et al., 2018).

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Dementia Care Management in Primary Care

- Four major features of primary care practice have been identified which influence decisions to utilize the emergency room:
  - Clinic & organizational structure
  - Emphasizing proactive approaches to anticipate needs & avoid acute problems
  - Health care provider knowledge & skills of dementia
  - Engaging appropriate community services/resources (Beck et al, 2021)

Reimbursement & Dementia Care Management

- Health Outcomes, Planning, and Education for Alzheimer’s (HOPE) Act effective in 2018 allows eligible providers (MDs, NPs, PAs & CNSs) to bill for comprehensive care planning service. The Alzheimer’s Association has a COGNITIVE IMPAIRMENT CARE PLANNING TOOLKIT-A guide to conducting a reimbursable clinical visit under CPT® code 99483 (Alzheimer’s Association, 2020).

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- Medicare Chronic Care Management (CCM)," non-face-to-face services provided to Medicare beneficiaries who have multiple (two or more) chronic conditions expected to last at least 12 months, or until the death of the patient " (American Academy of Family Physicians, 2022).

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Person Centered Focus Dementia Care

(Alzheimer's Association, n.d)

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Essential Elements of Dementia Care Management

- Diagnosis and optimization-Exercise, Nutrition, Sleep, Routine
- Strengths/Assets based approach
- Education and identification of care team members, Caregiver support/respite
- Strategies to maintain independence-Community Referrals, Handicapped Parking Permit, FMLA
- Advance care planning-health care directive, financial planning
- Medication Management and Safety
- Home and Safety Planning
- Dementia Communication Changes
- Behavioral & Psychological Symptoms of Dementia
- Follow-up Planning, Resource for Questions

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Cultural Care Considerations

- Dementia is more than a biological disorder, it is also a social disorder which needs to be viewed from different cultural perspectives (Gunderman & Wolf, 2018).
- “Dementia itself is, in part, a culturally determined phenomena, one that relies upon biomedicine’s ability to name and give form to a collection of changes, behaviors, and experiences” (Hillman & Latimer, 2017)
- Significant inequalities in dementia across cultures & need for additional research and support.
- Historical factors and trauma inform key care considerations

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Cultural Care Considerations

- Cultural traditions, religious practices & language are key variables
- Important to identify cultural norms and patient/family decision making
- Referral to culturally supportive services
- Culturally Responsive Caregiver Support and Dementia Services
- Caregiving for Older Adults--A Part of Our Culture

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Rural Dementia Considerations

- Recent studies have shown differences in dementia diagnosis populations is narrowing in rural -5.1% and urban-4.4%
- Strengths—neighbor support, local linkages,
- Social isolation, lack of family supports, transportation challenges, difficulty with getting a diagnosis, broadband access problems
- Specific issues to be addressed- driving, firearm security
- May need to look at long term living plan for safety
- Area Agencies on Aging experts on providing rural care

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Diagnosis & Tracking of Cognitive Changes

- Early diagnosis allows for time for planning and optimizing health.
- Accurate tools required for screening—Mini-Cog, MOCA or SLUMS
  - MMSE is not as accurate in detecting MCI or mild dementia, 10 points from orientation, dependent on language and educational level
- Consider neuropsych testing for MCI and mild dementia
- Staging of dementia & cognitive functioning--annually
- Functional Assessment evaluation -annually
- Need regular follow-up for cognitive & health monitoring

Identify Patient & Family Goals

- What is important to patient and family. What are their worries & fears, what are they hopeful for?
- **Strengths/Assets based approach**
- At what rate do they want to receive care & information.
- Sometimes the patient/family lacks insight into degree of cognitive impairment or limitations—overly preserved social skills

  -ADL performance is preserved into moderate stage dementia
- Sooner rather than later, address health care directive, financial power of attorney, completing a will
- Consider meeting with an attorney and financial advisor

Identify Who is on the Support Team

-Important to identify who is on patient's support team, collateral contacts

-Signed release of information, access to electronic health record

-Also clarify phone numbers and appropriate contacts for appointments and follow-up communication.

-Consider need for family meeting to discuss new diagnosis & goals of care

Advance Care Planning (ACP)

- Goals of care as the disease progresses is important to discuss-life limiting, progressive disease
- Barriers to addressing ACP in dementia include: " failure in acknowledging dementia is a terminal/life-limiting illness; the potential for loss of decision-making capacity early on in the disease trajectory; a lack of knowledge of the course of dementia (prognostication) in families" (Denning, Sampson & DeVries, 2019)
- Advance Directive for Dementia--A Simple Way to Document the Medical Care You Would Want If You Had Dementia

Care Partner Evaluation & Support

- Regularly assess caregiver well-being and strain
- Provide referrals to support groups, caregiver consultants and community resources
- Need to develop team for support-dementia requires more than 1 person to provide successful support
- Need for regular and planned respite
- Planning ahead & Emergency Planning
- “Evidence-based interventions for carers can reduce depressive and anxiety symptoms over years and be cost-effective“ (Livingston et, al. 2020).

Health Promotion/Optimization

- Encourage regular physical exercise-evidence based health programs; healthy diet (Mediterranean Diet), adequate sleep including sleep study if needed; balance of activity and rest.
- Optimize management of comorbidities which impact dementia — hypertension, DM, hyperlipidemia.
- Discontinue smoking, reduce or eliminate alcohol or drug use
- Continue dental care
- Immunizations—shingles
- Discuss role of periodic screenings—colonoscopy, mammograms

Community Resources

- Active and warm referrals
  - Instead of handing brochure or phone number, case navigator make referral on behalf of patient/care partner
  - Emphasize importance of developing care team and community partners to successfully manage the dementia journey
  - **Refer early and often.**
- Alzheimer's Association—24 Hour Help Line 800.272.3900

Community Resources

- Area Agencies on Aging, Aging & Disability Resources in WI
- Local Organizations—Senior Centers, Meals on Wheels, Adult Day Programs and Respite Providers
- National Institute on Aging
- Veteran Services Officer
- Parish Nurses and Congregations
- Home Health Care and Hospice
- Physical, Occupational and Speech Therapy
- Mental Health

Community Resources

- Wisconsin ASSISTIVE TECHNOLOGY FOR ALL
- Blind and Visually Impaired Support
- Deaf, Hard of Hearing, and Deaf-Blind Support

- Tribal Health
- Wisconsin Family and Caregiver Support Alliance(link is external)
- National Alliance for Caregiving

Socialization & Purpose

- Essential to avoid social isolation
- Social interactions are key, tailor with patient’s abilities at each stage of dementia
- Work with family to help communicate about diagnosis with friends and family.
- Opportunities for person with dementia to feel purpose and productive.
- Consider use of technology for socialization.

Maximize Abilities

- Optimize independence as much as possible
- Hearing and visual aides
- Referral to occupational therapy to maximize self care abilities and caregiver education
- Graded support and cueing, moving from verbal, visual, touch cueing
- Physical therapy to reduce fall risk
- Continue physical exercise (ACT on Alzheimer’s, 2015).

Communication

- Face the patient, maintain eye contact,
- Verify the message was received & understood-more than yes, no
- Simplify the message, use less words; avoid multiple step directions
- Avoid abstract concepts, concrete messages

    -Instead of it is time to eat, say it is time to eat your soup

- Recognize executive dysfunction which impacts insight, recognition of limitations, sequencing and planning
- Person with dementia is not choosing to ignore communication, may not be able to process messages

Home & Personal Safety

- “Refer to an occupational therapist and/or physical therapist to address fall risk, sensory/mobility aids and home modifications
- Obtain MedicAlert® + Alzheimer’s Association Safe Return® (call 1-800-272-3900 or visit www.alz.org/care/dementia-medic-alert-safe-return.asp)
- Alarms and devices to reduce wandering risk
- Lock up chemicals, unplug stove, smoking safety,firearms
- Use of technology to assist in maintaining safety, consider referral to local agency working with assistive technology for older adults.

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Driving Safety

- **Driving is a responsibility, not a right**
- Driving retirement is plan that we need to normalize for all of us as we age
- Refer to occupational therapy for driving evaluation (http://myaota.aota.org/driver_search/index.aspx)
- Educate patient and care partner about safe driving (see At the Crossroads at www.thehartford.com/advance50/publications-on-aging or Dementia and Driving Resource Center at www.alz.org/driving" (ACT on Alzheimer's, 2015)
- Transportation Alternatives need to be explored

Medication Therapy

- Certain medications can worsen dementia symptoms, .i.e. anticholinergics Tylenol PM, Oxybutinin; sleeping meds; muscle relaxant
- Medications can address some dementia symptoms and use can be reviewed with patients and families, i.e. acetylcholinesterase inhibitors
- Antipsychotic medication use in dementia patients have a Blackbox warning due to increased death rates from cardiovascular problems such as heart attack and stroke.
- Minimize polypharmacy; refer to pharmacist for medication review.

Medication Safety

- Moderate to late stage dementia will require supervision and assistance with medications.
- Develop a medication management plan, review prescribed & over the counter medications.
- Safety issues can include over use or under use of medications.
- Technology can be utilized to support medication management

Behavioral & Psychological Symptoms of Dementia (BPSD)

- Up to 80% of persons with dementia experience some form of BPSD- usually in moderate or late stage
- BPSD is a form of communication, not refusal or chosen behaviors
- Strategies to address BPSD- rule out delirium or physical health problem; treat for pain; identify triggers; consider hx of trauma; progressively lowered stress threshold-balance between stress and abilities; expectations are often too high for capacity of person with dementia; non-pharmacological treatment is first line—validate feelings, distract, provide comfort, reduce distress;
- Caregiver education is KEY to effectively managing BPSD

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Transitions of Care & Hospital Care

- Transitions of care, including hospitalization, can trigger delirium or worsening of dementia symptoms.
- Carefully evaluate antecedents to hospitalization
- Importance of the 4 M’s –What Matters, Mobility, Mentation, Medications (Institute for Health Improvement, 2020)
- Importance of Prior Functional Health Status
- About Me—person centered plan, who they are, hx, preferences
- Discharge Planning-importance of cognitive assessment, home health referral
- May trigger need for higher level of care.

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Case Study

- Linda is 67 year old female seen with her husband Butch for check of memory changes. Linda has a hx of significant depression & being withdrawn and unable to work for the past 15 years due to her depression.
- They live in a small rural community, Linda is home all day by herself, spends time with her multiple cats, smokes and has been going with a male friend reason unknown. Her husband drives school bus & checks on her mid-day.
- Linda's MOCA score is 15/30, she is unable to dial the telephone, does not remember her address, hides things and does not always eat properly. She has not wandered. Butch thinks she is doing pretty well.

Case Study Linda & Butch

- What dementia care management interventions would you recommend?

Case Study Linda & Butch

- Linda was formally diagnosed with Alzheimer's dementia.
- Completion of health care directive & recommendation for financial POA
- Discussed need for more supervision & vulnerable adult—need for 24 hour supervision & intervention with male who was visiting
- Referral to caregiver consultant
- Referral to adult day program
- Follow-up visits addressed risk of wandering, in home safety when up at night

- Activation of health care directive one year later
- Education on brain changes with dementia, reduced ability to understand communication
- Evaluation and management of visual hallucinations, medication management
- Expanding care support team, increase respite including over night respite
- Discussion of goals of care, health care decisions which need to be addressed
- Developing plan for out of home care

- Family coordination, expectations about care as disease progresses
- Referral for primary care management for hypertension, immunization update
- Periodic regular follow-up appointments

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