A new direction for research

Clinician – Family/Friend Caregiver Partnership as a Cornerstone of Dementia Palliative Care

Tatiana Sadak PhD, PMHNP, ARNP
Associate Professor of Geriatric Mental Health
Department of Psychosocial and Community Health Nursing
University of Washington, Seattle
Robert Wood Johnson Foundation Nurse Faculty Scholar 2013-17
DEMENTIA

> Life-limiting disease
> No curative treatment

~8 million people living with DEMENTIA
~15 million unpaid DEMENTIA caregivers
$216 billion+ value of yearly unpaid care
$1.2 trillion+ projected dementia costs in 2050
National Alzheimer’s Plan

Five Overarching Goals

• Prevent and effectively treat Alzheimer’s disease by 2025
• Enhance public awareness and engagement
• Enhance care quality and efficiency
• Expand supports for people with Alzheimer’s disease and their families
• Improve data to track progress
Palliative Dementia Care

actively assesses and treats distressing symptoms: physical, psychological, emotional, to optimise the quality of life for the person with dementia and their family

knowing that the underlying cause cannot be cured

(Australian Clearing House, 2009)

Our Approach

• Integrating caregivers into the health care environment
• Supporting partnerships between clinicians, caregivers and patients
Why Caregivers?

- Almost half of all family/friend caregivers regularly perform **medical/nursing tasks** for care recipients who have multiple chronic physical, cognitive, and neuropsychiatric conditions.

- Caregivers have different degrees of knowledge, readiness and willingness to do these tasks.

- **Clinicians need strategies to:**
  
  - Sustain ongoing partnership with dementia patient/caregiver dyads
  - Assess and nourish caregivers’ capacity for comprehensive home management of patient’s health
  - **Promote caregiver activation**


Figure 1. Dementia progression and suggested prioritizing of care goals.
Model of Dementia Palliative Care
Moderate/Severe Stages
GOAL: Maximize Comfort

CHALLENGES

1. Lack of clinician’s time and perceived dementia expertise
2. Limited data about appropriate interventions for chronic and acute comorbidities at different stages of dementia
3. No models for structured assessment and engagement of family/friend caregivers in medical care planning
OUR SOLUTION

Family Caregiver Needs Assessment Battery

- **MYLOH**: Measure of Caregiver Activation
- **SERVICES MINI-SCREEN**: Behave 5+ and Stress Thermometer
- **READINESS FOR CAREGIVING**: Single item scale
- **MYOW**: Managing Your Own Wellness Assessment of caregiver self-care
- **KCSS**: Multi-domain measure of caregiver stress

**DEVELOPED AND VALIDATED**

**IN Development**

**VALIDATED**
CURRENT WORK: Employing Palliative Care Approaches to Reduce Potentially Avoidable Hospitalizations in Dementia

In Dementia, Hospitalization have significantly increased risks of:

- Death
- Falls
- Worsened Cognitive Impairment
- Difficult Behaviors
- Delirium
- Institutionalization
- Functional Decline

Significantly higher hospitalization-related costs
Hospitalizations

• People living with dementia (PWD):
  • 2-4 times more likely to be hospitalized
  • Have longer stays, more complications
  • More readmissions soon after discharge

• Two thirds of these hospitalizations can **potentially be avoided by:**
  • Preventing acute illness
  • Treating early
  • Managing chronic conditions effectively

• Potentially Avoidable Hospitalizations are referred to as **AMBULATORY CARE SENSITIVE CONDITIONS (ACSC)**

• CMS conducted several demonstration projects aimed at reducing ACSC in dementia
  • All demonstrated limited efficacy
CHALLENGES

Early symptoms not recognized and reported

Patient/caregiver do not comply with the prescribed treatment

Caregiver not instructed about proactive symptom monitoring

Health care provider does not respond promptly

Prescribed treatment is not effective
Why do hospitalizations happen?

Health System Failure

Patient/Caregiver Failure

Could not be avoided
SOLUTIONS:

- Save Lives
- Save Money

1. Identify Causes
2. Create Intervention
3. Minimize Avoidable Hospitalizations
Utilizing Palliative Care Approaches to Prevent ACSC Admissions in Dementia

**Aims:** N=30 (advanced dementia); N=100 (all stages)

- To set intervention targets for resilience coaching by identifying gaps in CG self-care during day-to-day caregiving as well as during PWD health crises
- To describe CG experiences, observations, decision making processes and actions prior to hospitalization of a PWD; and identify CG/PWD characteristics that indicate opportunities for mitigating future risk.
  - **Outcome 1:** Create a CG self-care inventory to identify and monitor CG self-care practices and how such practices change during PWD health crises.
  - **Outcome 2:** Map the chain of events leading to hospitalization, identify missed opportunities for prevention, and create a repository of CG descriptions of early symptoms of conditions that lead to PWD hospitalization.
  - **Outcome 3:** Stratify CG into those with high vs. low risk for experiencing difficulties in responding effectively to a PWD health crisis and detect intervention components that are most relevant for individual CG based on their identified needs (e.g., enhanced self-care, knowledge/skills, engaging health system).
Utilizing Palliative Care Approaches to Prevent ACSC Admissions in Dementia

Study Procedures

– In-depth caregiver interviews shortly after or during an ACSC related hospitalization of PWD
– Prompt caregivers to recall chains of events that lead to the index hospitalization
– Review EMR 60 days prior and including index hospitalization
– Compare caregiver report and EMR
– Assess caregiver: self-care, resilience, readiness, preparedness, depression, anxiety, stress
– Assess PWD: dementia stage, functional ability, behaviors, comorbidities and medications (as reported by caregiver and recorded in the EMR)
– Assess if Palliative Care Principles were applied
Utilizing Palliative Care Approaches to Prevent ACSC Admissions in Dementia

Palliative Care Principles

Shared Decision Making
Healthcare team should assess and address CG/PWD information/education needs, palliative care/other specialty needs & involve PWD/CG in setting care goals

Ex. questions: Did you feel like you were involved with the process of making a decision about care plan or care options? Did the healthcare provider ask you questions on priorities of care for PWD? Did you feel that all of your questions were adequately answered?

Continuity of Care
Care should be continuous, there should be no interruption

Ex. questions: Did the provider/PCP follow up with you while PWD was in the hospital? Did he/she (PCP) consult with the hospital doctors? For patients still in hospital: Does the PCP know that he/she is in the hospital?
Utilizing Palliative Care Approaches to Prevent ACSC Admissions in Dementia.

Work in progress update

- Current N=33 primary caregivers of PWD residing in community settings
  - Age, 61 (sd. 16); 53% male
  - 80% White, 16% Black; 4% Asian
  - 54% college education
  - 38% reside with PWD
  - 42% have some difficulty paying for basics (ex. food, electricity, medications)
  - 56% experience significant current stress
  - 73% experienced significant stress prior to index hospitalization
  - 72% have low to moderate activation for patient’s health management

- PWD N=33
  - Age 75 (sd. 11); 50% male
  - Dementia stages: severe 64%; moderate 23%; early 13%
  - ~ 7 comorbidities
Utilizing Palliative Care Approaches to Prevent ACSC Admissions in Dementia.

VERY Preliminary Findings

• Majority of hospitalizations likely COULD NOT HAVE BEEN PREVENTED due to vague symptom presentation for all ACSC in dementia
  – Caregivers and clinicians were not able to assess the severity of symptoms till crisis occurred
• Care coordination was poor
• Many caregivers were not aware that patient had dementia diagnosis or did not understand how this diagnosis affects manifestation of comorbidities and the need for additional care and support
• None of the PWD received formal palliative care services
• Majority of caregivers reported:
  – Poor self-care
  – Their information/care skills needs were not assessed
  – They were not engaged by clinicians in setting care priorities
NEXT STEPS

PARTNERSHIP

Patient coaching
Clinician coaching
Caregiver coaching

Explore in ACSC admissions are potentially preventable in older adults without dementia
Research Team

Primary Investigator, Tatiana Sadak, PhD, PMHNP, RN
Content and Clinical Mentor, Soo Borson, MD
Palliative Care Mentor, Ardith Doorenbos, PhD, FAAN
Career Development Mentor, Azita Emami, PhD, FAAN
National Nursing Mentor, Kitty Buckwalter, PhD, FAAN
Study Coordinator, Emily Ishado, MSW
Statistician, Anna Korpak, PhD
Research Assistant, Andrew Petitt, RN, DNPC
Research Assistant, Julie Steward, MSc
Research Assistant, Michelle Tempelton, MN

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Measuring Caregiver Activation

Managing Your Loved One’s Health [MYLOH]

Valid, reliable, culturally tailored measure

- 29 items - 21 knowledge; 8 skills; 4 domains
- Likert type 4-level response scale:
  - Lower scores = need for caregiver coaching, support, tracking
- 6th grade reading level; <20 min to complete
- Created with iterative input from caregivers and clinicians
- Culturally tailored with input from African American and Hispanic caregivers

Understanding and managing everyday symptoms and/or worrisome changes in health

Understanding and managing medications

Engaging providers and advocating for the patient in health care situations

Caring for one’s own needs as a caregiver