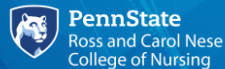


## Partnering with Families during Hospitalization of Persons with Dementia: Lessons Learned

Wisconsin Alzheimer's Institute's 19<sup>th</sup> Annual Update in Alzheimer's Disease  
and Related Dementias  
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## Purpose of this Presentation

### Discuss

Discuss the experiences and outcomes of the hospitalized persons with dementia and their care partner.

### Describe

Describe organizational approaches to partner with families of hospitalized persons with dementia.

### Discuss

Discuss implications for future research and practice to improve dyadic outcomes



## Why focus on persons with dementia in acute care?

- Older persons with Alzheimer's disease and related dementias (ADRD) are 2-3 x's more likely to be hospitalized as their peers who are cognitively healthy (Alzheimer's Association, 2021)
- They are at greater risk for:
  - Functional decline
  - Delirium
  - Nutritional problems, pain, falls
  - Emotional/psychological distress
  - increased care dependency after discharge.
- Their care has traditionally focused solely on the acute medical problem that led to admission



(Watkin et al., 2012; Boltz Galvin, 2013; Fox, Boltz et al., 2020; Fox, MacAndrew & Ramis, 2020)



## The Hospital Experience of Persons with Dementia

Persons with AD/ADRD have reported :

- feeling ignored, distressed, or uncertain
- rarely engaged in decisions about care and treatment
- negative encounters
- not receiving the same services as people without AD/ADRD, including attention to mobility, cognition, privacy, hygiene, and comfort

(Goldberg & Harwood , 2013; Innes A, Kelly F, Scerri C, Abela, 2016; Hung et al, 2017)

## The perspective of the person living with dementia: Hopes for care (Alzheimer’s Association® National Early-Stage Advisory Group)

### Get to know the person.

*“I want the opportunity to tell them (staff) about my life, my hopes, my dreams.”*

### Maximize independence.

*“ Let me do as much as I can and help when I need it or get confused.”*

*“Ask HOW I want you to help me.”*

### Assess carefully.

*“I ask you to be detectives to help figure out what’s troubling me.”*

### Practice patience and compassion.

*“I will most likely be resistant to help.*

*“I ask for patience, understanding and forgiveness for those with whom I will battle.”*

## The perspective of the person living with dementia: Family engagement

(Alzheimer's Association® National Early-Stage Advisory Group)



- **Expect that we (clinicians) get information from family**
  - “Make contact with persons who know me from their direct experience with me such as my adult children...”
- **Want us to include family in evaluation and decision-making**
  - “Keep in close contact with my caregiver to ensure knowledgeable parties are included in discussion.”

## Focus on family caregivers

### 75-80% of care provided by family caregivers

- Care delivery
- Care management

Approximately 15.5 million caregivers provide estimated 17.7 billion hours of unpaid care

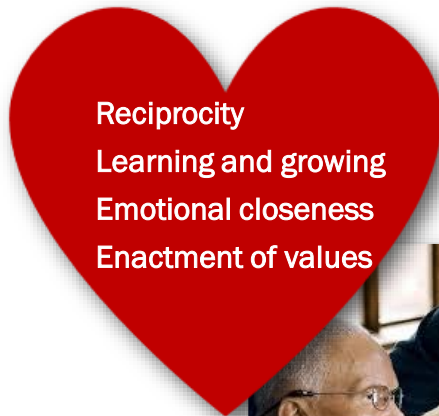
### Majority of caregivers are women (approx. 66%):

- 21% are 65 years old and older
  - average age 42
- 64% are currently employed, a student or a homemaker
- 71% are married or in a long-term relationship



(Alzheimer's Association, 2021)

## Rewards of Caregiving



(McGillick & Murphy-White, 2016)

## The challenges experienced by caregivers

Higher levels of perceived stress  
Greater employment complications  
Less family time  
Disrupted family and social relationships  
Less time for leisure  
Less self-care

Higher burden, strain,  
psychological morbidity

Impaired function

- Cognitive
- Immune

When depression present

- Increased vascular inflammation and altered clotting profiles

(Rowe et al., 2016)

## Family Experience in Acute Care

- Worry, anxiety, and stress
- Vulnerability predisposing to acute illness
- Limited information and engagement with care decisions
  - Staff attitudes
  - Staff time
- Increased burden during and after the hospital stay

(Bloomer et al, 2014; Boltz et al, 2010; 2014a, 2014b, 2015a, 2015 b; Clisset et al., 2013; Douglas-Dunbar, Gardiner, 2014, Li, 2005)



## Promoting Functional Recovery: Stakeholder Views

### The Views of Patients: Expect to “go home better not worse”

- Knowing the person critical to goal setting and engagement
- Fear of falling is a factor
- **Family support influences behavior**



### The Views of Nurses

- Lack of prioritization, measurement, accountability, and deployment challenges
- **Family role is key**



### The Views of Families: Fears/stress

- Fear of falling
- Fear of increased care needs
- Lack of information and involvement in decision-making, and preparedness

- **Boltz M, Galvin J.** Gerontologist. 2013;53
- **Boltz M, Resnick B, Capezuti E, Shuluk J.** Int J Older People Nurs. 2014;9(1):44-53.
- **Clisset et al.** The challenges of achieving person-centred care in acute hospitals: *A qualitative study of people with dementia and their families.* Int J Nurs Stud. 2013;50(11):1495-1503

## Why focus on family caregivers in acute care ?

As care partners they:

- Can provide vital information, emotional support, motivation, and assume responsibility in varying degrees for post-acute care delivery and coordination (Li, 2005; Boltz et al., 2015, 2016)
- Play an important role in promoting the functional recovery of hospitalized older adults (Boltz et al. 2015a,b)



### Why a dyadic approach?



## Patient factors influence caregiver status

### Mechanisms influencing physiologic changes in caregivers:

- Poor sleep, sustained vigilance, and interference with caregivers' health promoting behaviors

### Mechanisms influencing psychological changes in caregivers:

- Being a spouse, female, with poorer perceived health, smaller social network
- Role overload, captivity, or burden associated with depression

### Care recipient characteristics that are associated with caregiver depression and burden include:

- poorer cognitive function
- higher dependence in activities of daily living
- behavioral manifestations of distress

(Rowe et al., 2016)

## Family caregiver factors influence patient outcomes

Higher family efficacy support associated with better functional status. (Tao et al, 2012)

Caregiver strain affects ability to support the ADL needs of the person with dementia. (Tao et al, 2012; Boltz et al., 2015a)

Baseline function, depression, dementia severity, and caregiver strain were associated with preadmission loss of function. (Boltz et al., 2018)





Can goals of promoting functional recovery (cognitive and physical) align with improving family caregiver preparedness and sense of well-being?  
(UL1 TR000038, Alzheimer's Association 12-242090,)

## Family-centered Function-focused Care (Fam-FFC)



- This study examined the efficacy of Family-centered Function Focused Care (Fam-FFC)
- An approach to care in which family caregivers partner with nurses to prevent functional decline and other complications related to hospitalization in older adults with dementia
- Uses a systematic care pathway that includes information-sharing and decision-making to:
  - promote physical activity, function, and cognitive stimulation during the hospitalization and immediate post-acute period

**Design:** Cluster randomized clinical trial that tests the efficacy of Fam-FFC

**Setting:** Two hospitals: comparative medical units at each hospital

## Study Participants and Measures

### Patient inclusion:

- Age 65 and above with dementia (mild to moderate; CDR= 0.5-1.5), no neuro condition affecting cognition, no acute exacerbation of SMI
- Not on hospice
- Speak English or Spanish

**Descriptive data** demographics, co-morbidity (Charlson), cognition (MoCA), depression (Cornell Scale), baseline and admission physical function (Barthel Index) and length of stay

### Outcomes;

- Activities of daily living (ADLs)
- Delirium severity (CAM-5)
- 30-day hospital readmissions

### Family caregiver inclusion:

- Age 18 and above
- Identified as primary caregiver
- Able to recall 2 of 3 words

**Descriptive data:** demographics, relationship with the patient, whether they lived with the patient, employment status, and the number of hours worked per week

### Outcomes

- Preparedness for caregiving
- Strain
- Burden
- Anxiety

## Family-centered Function-focused Care Interventions

Intervention Components	Intervention Units	Control Units
Clinical Nurse Champions (1 day shift & 1 night shift)	X	
Environment and Policy Assessment	X	X
Education and Training for Nursing Staff	X	X
Equipment Provision	X	
<b>Nurse Interventionist</b>	X	
<ul style="list-style-type: none"> <li>• Development of <u>FamPath</u> with family and patient                             <ul style="list-style-type: none"> <li>• Family/patient education</li> <li>• Jointly developed goals and treatment plans in hosp</li> <li>• Post acute care follow-up by phone weekly for 8 wks then monthly for 4 months</li> </ul> </li> <li>• Supports Champions in their role</li> <li>• Coaches clinical nurses in application of evidence-based geriatric/dementia care principles; communicate FamPath to interdisciplinary team</li> </ul>		

# Implementing FamPath

## In-hospital engagement with patients and families

- \*Education – delirium, function, sleep, nutrition, family caregiver role in dementia care
- \*Conduct assessment/interview focusing on caregiver role, patient’s typical activities
- \*Co-Create function-focused goals (typically 2-4 goals)
- \*Daily follow-up

## Nurse Interventionist engagement with study champions and nursing staff

- \*Coaching and clinical support
- \*Observed nurse/patient interactions using behavior checklist



## Discharge assessment and goal planning


- \*Evaluated progress toward goals and created function-focused home plan

## Follow-up phone calls to caregiver (weekly x 8 weeks; then monthly x 4 months)

- \*Used goals to guide the conversation; sleep, nutrition, function and falls; check in on caregiver



# Partnering with Family Care Partners



**FamPath Information for Patients and Families**  
Patients and Families guide the decision-making and play an active role!

INFORMATION    SLEEP & REST    NUTRITION    FUNCTION, STRENGTH, MOBILITY    SKIN CONDITION    WHAT YOU CAN DO    DELIRIUM    FALLS    DISCHARGE PLANNING



### INFORMATION to share with the health care team:

- Medical and surgical history
- Normal abilities (examples include: transferring, ambulating, feeding, toileting, bathing, dressing, shopping, preparing food, doing laundry, medication administration)
- History of memory or thinking problems
- Daily routine at home
- Signs of stress (including behaviors and functioning)
- Ways to prevent or help cope with stress
- Use of health care or support services
- Living situation and plan for assistance at discharge

### WHAT YOU CAN DO as the Family Caregiver while in the hospital:

- Find out who the physician and nurse are and introduce yourself
- Always have paper/pen to write down information and any questions
- Arrange to meet (in person or on the phone) with patient and members of the healthcare team on a regular basis
- Have a friend or family member with you during conversations as support
- The bedside FamPath is a guide to prevent complications and discharge the patient in the best possible condition – please review, provide feedback, and keep current!
- Use the “Family Caregiver Report” with the FamPath to document any changes
- Provide as much information as you can about your loved one!

### FamPath Assessment and Plan

Name: \_\_\_\_\_

FAMILY ROLES	
The Family member or friend who is designated by the patient and/or legally authorized status to help make decisions and guide care planning is:	
Name Relationship:	_____
Telephone number:	_____
Email:	_____
Other family members who will be involved in care: if the patient is upset, this is the person to call:	
Name:	_____
Telephone number:	_____
Email:	_____
Advanced directive information:	

## Fam- FFC Findings: Two comparative trials (N=92, 86)

Patients exposed to Fam-FFC demonstrated more return to baseline ADL performance at two months post-discharge, less 30-day hospital readmissions, and less delirium.

Family caregivers (FCGs) who participated in Fam-FFC reported better preparedness for caregiving and less anxiety from admission to two months post-discharge.



*Boltz et al. (2015a). Neurodegenerative Disease Management 5 (3) 203-215; (2015b) Alzheimer Disease & Associated Disorders 29 (3): 236-241; (2014). Journal of the American Geriatrics Society 62 (12):2398-2407.*

## What are mechanisms for Fam-FFC?

### Including:

- the nature of family caregiver engagement
- family perspectives of enablers of functional recovery
- family caregiver characteristics associated with return to baseline function, controlling for patient characteristics



## Type of FCG Engagement

	Never (%)	Once (%)	Several times (%)	Daily and/or frequently (%)	FCG Perception: Frequency* Mean (SD)	Family Perception: Importance* Mean (SD)
Decision-making	4%	22%	74%	—	2.6 (.90)	3.7 (.48)
Advocacy	8%	2%	80%	10%	3.8 (.56)	3.9 (.42)
Companionship	—	2%	46%	52%	3.3 (1.10)	3.8 (.36)
Direct Care	26%	38%	36%	—	2.0 (2.1)	1.8 (.76)

\* 0= never | 1= rarely /not important | 2= occasionally/somewhat important | 3= frequently/important | 4= very frequently/important

## Enablers of Function: FCG Views

### Staff communication skills

- *He felt more comfortable with some nurses....the ones who told him he could do it, ....come on come on.....they joked with him..*
- *The patient has to feel secure.*
- *It was good that the nurses really listened to my concerns. I could not take her home in bad condition....*

### Staff accessibility

- *They needed to be there when she needed them especially for the bathroom.*

### Environmental factors (bedside communication tools, bed safety) and policies (inclusion of patient/family in rounds)

- *Keeping that bed down low*
- *Leaving us a note on the board.....*
- *Talking to us about how she was doing...*

## Factors Associated with return to baseline function

Outcome: Return to baseline function (change admission to two months post-discharge) Mean: 7.0 ( $\pm 19.4$ )

	B	SE B	$\beta$	t	p
Admission function $r = -.66, p < .0001$	-.48	.07	-.64	-7.25	<b>.001</b>
Delirium $r = .30, p = .04$	7.32	4.04	.16	1.81	.077
FCG level of education $r = .32, p = .03$	2.82	1.08	.23	2.62	<b>.012</b>
FCG anxiety $r = .40, p < .0001$	-.24	.40	-.05	-.6	.557
Advocacy role $r = .42, p = .002$	12.37	3.13	.35	3.95	<b>.001</b>

$R^2 = .65 (p < .001)$



## Findings suggested that FCGs can be a valuable resource in promoting functional recovery of hospitalized older adults.

Higher FCG education and advocacy role is associated with patient return to baseline function.

- Need to examine uptake of Fam-FFC across health literacy levels and adapt as needed
- Need for orientation of staff, patients, and families to acknowledge the role of FCGs as patient advocate for function-focused care.



## Current RO1: 3 cohorts of diverse hospitals

ClinicalTrials.gov identifier: NCT03046121

- Intervention
  - Examining cultural appropriateness
  - Strengthened staff education to support family advocacy
- Measurement
  - Examined goal attainment
  - Additional outcomes: physical activity (MotionWatch)
  - Added care partner literacy as a co-variate and BPSD/mood as outcomes
- Enrollment complete (N=461); data collection complete on 318



## Preliminary Outcomes

Less 30-day hospital readmission rates in the intervention group

	N=159	N=162	N=321	
<b>Falls (without injury)*</b>				
Post-disch	10	10	20	.88 (.35)
2 month	27	29	56	1.46 (.23)
6 month	25	32	57	.77 (.38)
<b>Falls (with injury)*</b>				
Post-disch	2	6	8	2.28 (.13)
2 month	14	13	27	0.5 (.83)
6 month	15	14	28	1.78 (.18)
<b>Emergency room visits*</b>				
Post-disch	15	11	26	1.01 (.32)
2 month	40	43	83	.82 (.37)
6 month	34	41	75	.94 (.33)
<b>Hospitalizations*</b>				
Post-discharge (30 day)	19	9	28	4.48 (.04)
2 month	39	35	74	1.85 (.18)
6 month	32	27	59	.13 (.71)



## Types of Goals and Attainment

<u>Type of Goals</u>	Goal Attainment						
	<u>n (%)</u>	much less than expected	less than expected	<u>n (%)</u> expected	more than expected		much more than expected
Mobility	252 (58)	3 (1)	62 (25)	155 (62)	21 (8)	11 (4)	
Cognitive stimulation	81 (19)	3 (4)	18 (22)	57 (70)	3 (4)	0	
Self-care: hygiene	35 (8)	4 (11)	4 (11)	24 (69)	3 (9)	0	
Self-care: eating	35 (8)	4 (11)	8 (23)	20 (57)	1 (3)	2 (6)	
Toileting	19 (4)	2 (11)	5 (26)	11 (58)	0	1 (5)	
Pain managed	7 (2)	0	0	6 (86)	1 (14)	0	
Sleep	4 (1)	0	1 (25)	3 (75)	0	0	
<b>Number of Goals (N=433) by attainment level</b>		16 (4)	98 (23)	276 (64)	29 (7)	14 (2)	<b>70% had at least one goal attained</b>



## Goal Attainment and Discharge Outcomes

Multiple Linear Regression Model: Delirium Severity as the Outcome

	<i>B</i>	<i>SE</i>	<i>B</i>	<i>t</i>	<i>p</i>	95% Confidence Level	
						lower	upper
Pre-admission Function	-.008	.008	.085	1.042	.300	-.023	.007
Admission cognition	.156	.029	.438	5.351	.000	-.214	-.098
Goal attainment	-.839	.375	.175	2.239	.027	-1.581	-.097

Logistic Regression Model: Return to Baseline Function as the Outcome

	<i>B</i>	<i>S.E.</i>	<i>Wald</i>	<i>df</i>	<i>p</i>	<i>Exp (B)</i>
Admission function	.009	.008	1.59	1	.219	1.009
Admission depression	.014	.029	.23	1	.629	1.014
Admission cognition	.069	.033	4.52	1	.034	1.072
Goal attainment	.826	.404	4.17	1	.041	2.285

Logistic Regression Model: 30-day hospital readmission as the Outcome

	<i>B</i>	<i>S.E.</i>	<i>Wald</i>	<i>df</i>	<i>p</i>	<i>Exp (B)</i>
Co-morbidity (Charlson)	.069	.096	3.52	1	.044	1.079
Goal attainment	.776	.395	2.77	1	.045	2.362



## Discussion/Conclusions: Goal Attainment



- \*Attainment of goals developed in partnership with family caregivers may have a positive influence upon delirium and physical function at discharge, and recidivism.
- \* There is a pressing call/need for dementia-adapted rehabilitation, beginning upon admission
- \*Findings warrant future examination of the contribution of patient, caregiver, and organizational factors upon the process of goal development, negotiation, implementation, and outcomes, as well as the maintenance of benefits in the post-acute period

## Cultural Appropriateness of the Intervention: Caregiver Views

Explored after intervention completed (after post- acute follow-up)

### Methods

- Ecological Model (EM) originally developed by Bernal and colleagues as a framework to assess the cultural appropriateness of the Fam-FCC intervention, and to refine Fam-FCC for future studies
- Caregiver Perspective.
- Sample: 28 Caregiver semi-structured interviews

## Cultural Appropriateness of the Intervention: Caregiver Views

The EM posits that there are eight dimensions to consider when assessing the cultural appropriateness of an intervention.

- **language:** Did the family receive the intervention information in terminology, vernacular in which they felt comfortable?
- **persons:** In how many of the 28 dyads did the nurse champion reflect the preferences of the family?
- **metaphors:** Use of cultural terms equivalent to those used by participants
- **content:** Were the values, customs, and traditions shared by the ethnic or minority group apparent in the intervention?
- **concepts:** Were caregiving concepts congruent with cultural norms?
- **goals:** Were intervention goals congruent with family cultural norms and goals
- **methods:** Delivery of the intervention is culturally appropriate.
- **context:** Does the intervention consider the family's socio-community context?



## Cultural Appropriateness of an Intervention to Cultural Appropriateness of the Intervention: Caregiver Views

- Qualitative Content Analysis
  - Familiarization/transcript review
  - Coding for themes by 2 researchers
- Descriptive Statistics for Family Caregivers (N=28)
  - Age: mean: 64.7 ( $\pm$  11.8) 38-83
  - Lives with patient: n=22 (79%)
  - Females: n=22 (79%)
  - Black or African American: n=14 (50%); White: n= 14 (50%); Non-Hispanic: n=27 (96%)
  - Married: n=14 (50%) Some college and above: n= 15 (54 %)
  - Kinship: daughter: n=12 (43), son: n=6 (21%), spouse/partner: n= 10 (36%)



## Cultural Appropriateness of the Intervention: Caregiver Views

### *Caregiver Identity*

- Do not identify as caregivers, did not express need for additional assistance
  - Prefer to be considered just family members
- Expressed joy and privilege
  - Their responsibility as a spouse, child, family member

### *Gender preferences of medical and nursing staff*

- No gender preferences
- Wanted “care”
- Some preference for a nurse with the physical ability to assist with patients who have mobility limitation



## Cultural Appropriateness of the Intervention: Caregiver Views

### *Spirituality*

- Not typically asked about or discussed (by medical staff)
- Deemed as important by the CG/Or not important at all
- Spirituality helps get the CG through CG-related stress
- Requests for community activities that “engage the spiritual mind”

### *Limitations*

- Potential social desirability associated with interview questions
- Caregivers limited to those caring for patients with mild to moderate dementia, not severe.
- Inclusion of participants from only three hospitals in Pennsylvania and lack of inclusion of other racial and ethnic groups.



## Cultural Appropriateness of the Intervention: Caregiver Views

### Implications for Practice

- Additional research is needed on care partner identity and the relationship to help-seeking.
- Individualized family-centered care may benefit from supports for family spiritual preferences.
  - How about the non-religious?

## Operational approaches aligned with family-centered care



- Assessing family role(s) upon admission
- Liberal visiting hours
- Facilities (overnight accommodations, showers, nutrition stations)
- Patient and Family Advisory Programs
- Bedside rounds that include patients and families
- Partnering with family in evaluation and research



## Working with persons living with dementia and families: lessons so far....



- Leadership “buy in” is important
- Hospitalists are key to promoting function
- Role of nursing assistants is critical yet under-recognized
- Feedback mechanism promotes staff engagement
- Rounds are important to support:
  - Family engagement
  - Follow-through

## Working with persons with dementia and families: Lessons so far....



- Information on preferred communication needed to support on-going intervention and data collection
  - Back-up contacts
- Concept of “caregiving” may not be concordant with care partners’ views
- Issues that we have not/should have considered :
  - Spirituality as a source of strength /resource
  - Food insecurity
  - Inclusion of care partner network

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