

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

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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
- 84% 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

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- 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

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 (±19.4)

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

R² = .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	
Falls (without injury)*				
Post-disch	10	10	20	.88 (.35)
2 month	27	29	56	1.46 (.23)
6 month	25	32	57	.77 (.38)
Falls (with injury)*				
Post-disch	2	6	8	2.28 (.13)
2 month	14	13	27	0.5 (.83)
6 month	15	14	28	1.78 (.18)
Emergency room visits*				
Post-disch	15	11	26	1.01 (.32)
2 month	40	43	83	.82 (.37)
6 month	34	41	75	.94 (.33)
Hospitalizations*				
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

Type of Goals	n (%)	Goal Attainment n (%)					70% had at least one goal attained
		much less than expected	less than expected	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	

Number of Goals (N=433)
by attainment level

16 (4) 98 (23) 276 (64) 29 (7) 14 (2)



Goal Attainment and Discharge Outcomes

Multiple Linear Regression Model: Delirium Severity as the Outcome

	B	S.E.	B	t	p	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

	B	S.E.	Wald	df	p	Exp (B)
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

	B	S.E.	Wald	df	p	Exp (B)
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 (± 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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