“Lessons Learned from Engaging Family Caregivers in the Care of Acutely Ill Older Adults

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DISCLOSURE & ACKNOWLEDGEMENTS

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Purpose of this Presentation

DISCUSS

Family caregiver strain before, during, and after an acute illness or injury of an older adult

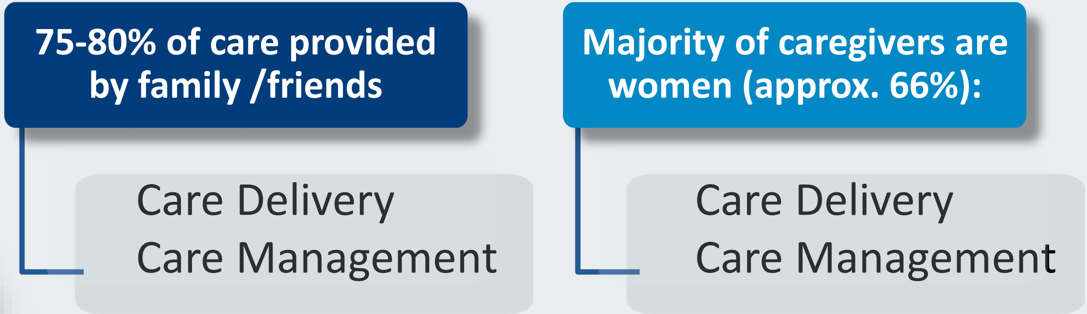
DESCRIBE

Key strategies to improve care with family as care partners

DISCUSS

Implications of engaging family care partners for those with dementia

FOCUS ON FAMILY



75-80% of care provided by family /friends

- Care Delivery
- Care Management

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

- Care Delivery
- Care Management

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

(Alzheimer's Association, 2021)

- 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

The chronic strain of family caregivers

Rewards of Being a Carer

- Reciprocity
- Learning and growing
- Emotional closeness
- Enactment of values

(McGillick & Murphy-White, 2016)

The Challenges Experienced by Carers

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)

Stigma Influences Person Living With Dementia and Family Carers

- Ignorance
- "War" metaphors for confronting this "epidemic,"
- The "Alzheimerization" of the dialogue to support euthanasia
- Defining "self" in relation to cognitive function ("I think therefore I am")

> ***"Getting dementia, you feel that you have suddenly become a lunatic."***

(Desai & Desai, 2016; Johannessen & Moller, 2011)

Family Experience in Acute Care

Worry, anxiety, and stress

(fear of falling!)

Increased burden during and after the hospital stay

Limited information and engagement with care decisions

- *Staff attitudes*
- *Staff time*

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

Key strategies to improve care with family as care partners

Why Focus on Family Carers 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)

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."

Family-centered Function-focused Care

GOALS: return to baseline function, less delirium, less behavioral symptoms of distress in hospitalized persons with dementia; increase care partner preparedness

Components

- Development of FamPath with family and patient
  - Family/patient education
  - Jointly developed goals and treatment plans in hospital
  - Post acute care follow-up by phone weekly for 8 weeks then monthly for 4 months
- Environment and Policy Assessment
- Education and Training for Nursing Staff
- Clinical Nurse Champions (1 day shift & 1 night shift)

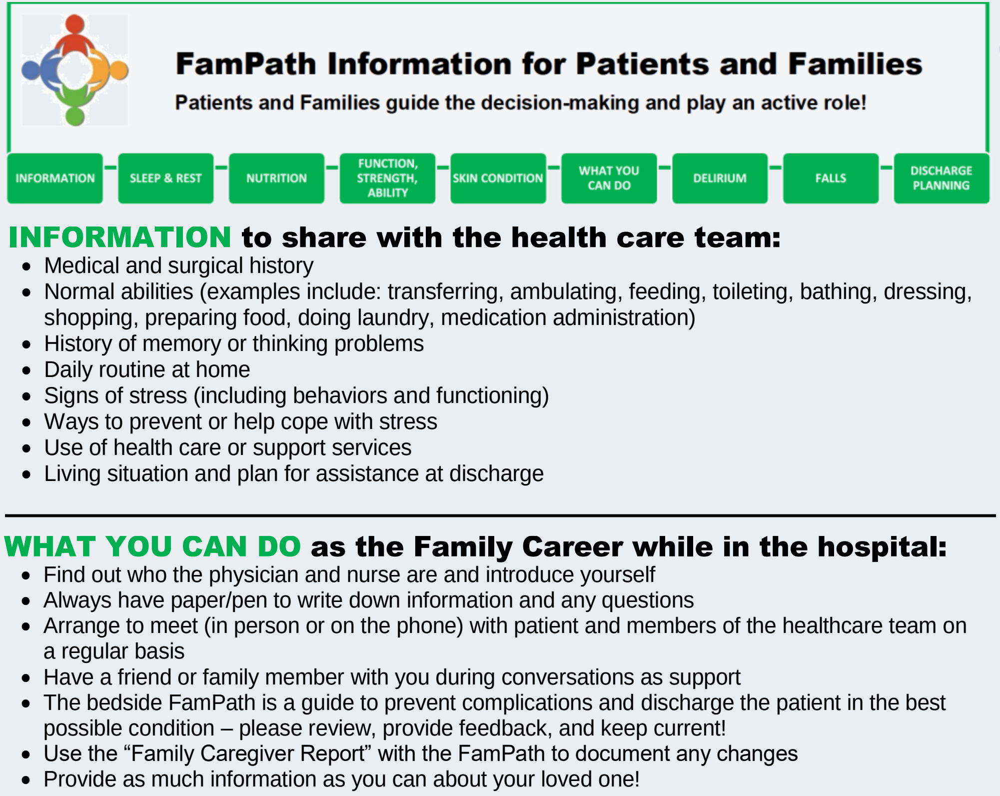
Implementing FamPath

Part 1

In-hospital engagement with patients and families

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

Partnering with Family Care Partners



FamPath Information for Patients and Families

Patients and Families guide the decision-making and play an active role!

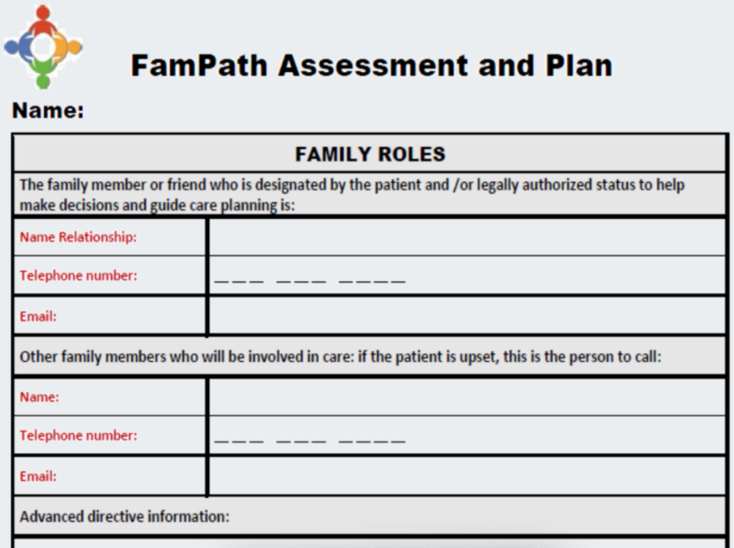
INFORMATION – SLEEP & REST – NUTRITION – FUNCTION, STRENGTH, ABILITY – SKIN CONDITION – WHAT YOU CAN DO – DELIRIUM – FALLS – DISCHARGE PLANNING

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 Career while in the hospital:

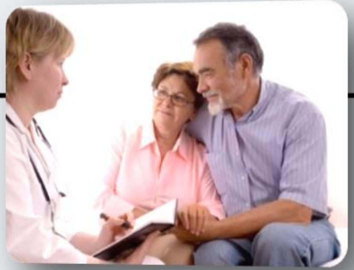
- Find out who the physician and nurse are and introduce yourself
- Always have paper/pen to write down information and any questions
- Arrange to meet (in person or on the phone) with patient and members of the healthcare team on a regular basis
- Have a friend or family member with you during conversations 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:	



Implementing FamPath

Part 2

Nurse Interventionist engagement: champions and staff

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

Discharge assessment and goal planning

- ➢ Evaluate progress toward goals and create function-focused home plan **(Daily plan!)**
- ➢ Education also addresses behavior, delirium detection/prevention…resources

Follow-up phone calls/coaching to care partner (weekly x 8 weeks, monthly x3)

- ➢ Use goals to guide the conversation; sleep, nutrition, function and falls; check in on caregiver

Fam- FFC Findings: Two Comparative Trials N=92, 86 Alz Assoc., UL1 TR000038

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 at all time points.

Family caregivers (FCGs) who participated in Fam-FFC reported better preparedness for caregiving, no effect on burden

ADAD 29 (3): 236-241; JAGS 62 (12):2398-2407; Neurodegen Dis Manag. 5 (3) 203-215

Results of Third (CRT) Study (N=455) R01 AG054425

NCT03046121 *Trials 19*: 496.

- Likelihood of **returning to baseline function** across time for Fam-FFC participants was twice that of the control group by the end of 6 months (OR = 2.39, p =.011, 95% CI 1.22-4.68). No delirium differences.
- New measures:
  - Fewer **behavioral symptoms** of distress at six-months (b = -1.114, SE = .555, p = .045)
  - **No difference** in the amount of moderate physical activity (MotionWatch) and depressive symptoms
- **Preparedness for caregiving** increased at two months (b=.893, SE=.450, d=.212 p = .02) in the intervention group, with **no group differences in strain and burden**.

Need to strengthen intervention: type of activity (physical) and care partner self care.

Bedside Goals

Goal attainment: measured at discharge

+2 = much more than expected, *+1* = more than expected, *0* = expected,*−1* = less than expected, *and −2* = much less than expected. *GA score:* –0.23 (*SD* = 0.731).

70% pts had at least one goal attained; 74% goals met

Types/frequency of attainment

- Mobility 74%
- Cognitive stimulation 74%
- Self-care: eating, hygiene 70%
- Toileting 63%
- Pain Management 100%
- Sleep 75%

JGN 47 (9), 13-20.

Goal Attainment and Discharge Outcomes

Multiple Linear Regression Model: Delirium Severity as the Outcome

						95% Confidence Level	
	B	*SE*	*B*	*t*	*p*	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

THEMES:
Care Partner Needs and Teaching during transitional care

Psychosocial Support

e.g., staying connected to others, managing behaviors

Managing Symptoms

Delirium Detection
Sleep hygiene

Physical Activity/ Cognitive Stimulation

E.g., helping activities, sit to stand, walks, leisure activities

Advocacy

Get involved in activities, walking, discontinuing an offending medication, getting and giving information

Caregiver Stress

e.g., referral to Aging Services and support programs
supportive listening

Care Partner Perspectives (N= 28; 14 African-American, 14 White)

Identity

- **Meaning** of the role: "who I am"
- **Everyday care:** attending to physical needs, ensuring safety, attention to emotional need and helping the care receiver enjoy life
- Use of **language:** "he's my father"….

Preferences

- **Spiritual** preferences
- "What matters" reflect **person/family values and unique situation**
- Want to consider **positive** outcomes !

Support of family engagement in the hospital

Environmental /Policies

- Intake: caregiver role and contact information (and back-up)
- Liberal visitation
- Inclusion of patient/family in rounds
- Use of white board for communication – include family
- Include family in assessment (AD8)
- Bedside education for patients and families
- Including family education as part of all clinical protocols

Implementation Considerations: Lessons So Far . . .

- Leadership “buy in” is important
- Hospitalists are key to promoting family engagement
- Staff training needs to be flexible
- Role of nursing assistants is critical yet under-recognized
- Feedback mechanism promotes staff engagement
- Rounds are important to support communication

TAKE HOME MESSAGES

- Family care partners can be valuable resources
- Language Matters; need more meaningful measures
- Transitional plan should address functional recovery
- Need to develop a plan for the family

Thank you

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