

Dyadic Interventions: From Early-Stage to End-of-Life

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#DementiaCareSummit

Definitions / Background

Dyad

Two individuals who maintain a significant relationship
(husband and wife, gay/lesbian couple, siblings, adult child and parent...)

Dyadic intervention

A program or service that focuses on
and/or intervenes at the level of a family dyad

Person- and family-centered care (PFCC)

Providing care in a way that includes the person living with dementia, family caregiver,
and family as equal partners in planning, developing, and monitoring care

- Dyad not necessarily = compatible, close (emotionally or geographically), like-minded, or share similar values
- For our purposes here, the dyad consists of both the person living with dementia AND his/her family caregiver (inclusive definition of family)

Interventions for Persons With Dementia and Family Caregivers: Varying Levels of “Dyadicness”

Some interventions were originally designed to be dyadic to varying degrees 1,4,5,6,9:

- Based on conceptual models that embraced dyadic measures, processes, and outcomes
- Asking same or parallel questions of both participants who compare responses, perceptions, and preferences
- Designing a plan of future care together that reflects both participants’ values and preferences for care

Other programs gradually adopted dyadic approaches and protocols 2, 3, 7:

- Evidence that a dyadic approach could have a positive impact on person, caregiver outcomes, but know little about impact on service providers
- Many participants voiced a strong desire and preference for including their care partner and families in discussions about care planning
- Increasingly, funders have seen the benefit of including both care partners in programming, reimbursement, and research studies, and in identifying evidence-based practices

1. Ensure that person- and family-centered interventions with a strong evidence base are available to all families at all stages:

- Dyadic = PFC = focusing on and engaging both care partners (and family)
- Funding more inclusive programming (siblings, aunt/uncles, younger persons)
- Standard process to designate evidence-based programs

What We Know About Interventions Designed to Engage Persons With Dementia and Family Caregivers: Early-Stage

Persons with dementia:

- Answer questions with a high degree of reliability and validity
- Contribute and participate actively in interventions
- Have strong and stable opinions about their values and preferences for care

AND....

Care partners don’t always:

- Have the same ideas about getting diagnosed and disclosing the diagnosis
- Know each other’s values and preferences for care
- Talk about care issues and plan for the future
- Communicate effectively

2. Encourage families to discuss care values and preferences early on and throughout the disease process:

- Develop early-stage programs that focus on the diagnostic process and its aftermath
- Conduct research to understand the experience of younger-onset families and develop programs that address their needs

What We Know About Interventions Designed to Engage Persons With Dementia and Family Caregivers: Middle-Stage and End-of-Life

More dyadic interventions exist for families in the middle-stage of dementia:

- Managing behavioral and psychological symptoms of dementia (BPSDs)
- Managing caregiver stress
- Developing a plan of care (care consultation)
- Conducted in-home or over the phone
- Caregiver skill building

Few dyadic interventions exist for families in the early stages, but even fewer address the needs of families in the late and end-of-life stages of dementia:

- Reviewing and updating the plan of care that was developed during the early stages
- Helping both care partners adapt to relocation to assisted living or skilled care
- Persons with dementia can engage and benefit from targeted programming

3. Identify key care values and preferences that are critical to late stage and end-of-life concerns and experiences:

- Research and evidence-based programming for later-stage families is minimal, critical, and needs to be conducted with attention to practice applications
- Encourage family members and professionals to engage with late-stage and end-of-life persons and their caregivers
- Adjust plan of care accordingly and as needed as disease progresses

Recommendations & Action Steps

1. Ensure that person- and family-centered interventions with a strong evidence base are available to all families at all stages

- Fund research that examines the experiences of families during the time leading up to and just after diagnosis through early stage
- Adopt more inclusive definitions of family and age of care partners in research and public policies, and determine the numbers of individuals in these diverse kin groups and their service needs (FMLA siblings, grandparents, aunt/uncle, LGBT, younger onset)
- Conduct a review of telehealth options, and of programs for distance caregiving
- Agree upon a standardized evidence-based designation for dyadic interventions

Recommendations & Action Steps

2. Encourage families to discuss care values and preferences early on and throughout the disease process

- Fund the development of evidence-based psychoeducational programs that facilitate conversations with care partners and other family members to build a realistic plan of care for current and future needs
- Conduct longitudinal research (5+ years) that examines long-term use of care plans, services, and support and the effect on families and service providers

“[I] liked everything about the session. It was the first opportunity [we] had to talk with a counselor about my problem.”

~Husband with dementia who is cared for by his wife

Recommendations & Action Steps

3. Identify key care values and preferences that are critical to late stage and end-of-life concerns and experiences

- Need for research that determines best practices for engaging and eliciting care preferences from persons in the late and end-of-life stages
- Conduct research with families facing or who have faced end-of-life
- Develop targeted training programs for professionals who support families at the final stages of dementia

Thank you!

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