

# Family Caregivers' Definition and Perception of the Nursing Home Placement Process

---

Sarah M. Koplow PhD, RN  
Assistant Professor, College of Nursing  
Geriatrics Training Institute  
Friday February 26, 2016

# Acknowledgements

- This research study was funded by:
- UIC Chancellor's Education Award Fund, 2011
- Illinois Area Health Education Centers Network,  
Health Professions Student/Fellowship Grant, 2011
- Midwest Nursing Research Society Dissertation Research Grant,  
2012
- Sigma Theta Tau International, Alpha Lambda Chapter, Research  
Award, 2012
- UIC College of Nursing, Seth and Denise Rosen Research Award,  
2012

# Acknowledgements

- This research has been previously published:
  - Koplow, S. M., Gallo, A. M, Knafel, K. A, Vincent, C., Paun, O., & Gruss, V. (2015). Family caregivers define and manage the nursing home placement process. *Journal of Family Nursing*, 38(2), 469-493. doi: 10.1177/1074840715571365
  - Koplow, S.M., Gallo, A.M, Knafel, K.M, Vincent, C., Paun, O., & Gruss, V. (2015). A Case Study Approach to Nursing Home Placement: Smooth and Difficult Cases and Implications for Nursing. *Journal of Gerontological Nursing*, 41(7), 58-65. doi: 10.3928/00989134-20150413-08
- I would like to acknowledge my sincere appreciation for the support of my co-authors and dissertation committee members.
- I would like to thank all of the caregivers who participate in this study and the helpful partners and nursing home staff who assisted in recruitment.

# Background

- Caregiving for older adults in the United States is a complex system involving informal and formal services.
- Family caregivers provide many time- and labor-intensive tasks to any older family member
- Maintenance and responsibility for ongoing caregiving is associated with negative consequences for the caregiver
- The decision to place a family member in a nursing home has long been considered a difficult and emotional process.

# Purpose

- The purpose of this qualitative, descriptive study was to understand the ongoing caregivers experiences of the primary family caregiver during the first few months following nursing home placement of an older family member utilizing the Family Management Style Framework (FMSF).

# Conceptual Framework: Family Management Style Framework (FMSF)

- Developed more than 20 years ago to conceptualize how family members incorporate the management of a child's chronic condition into everyday family life (Knafl & Deatrck, 2003; Knafl, Deatrck, & Gallo, 2008, Knafl, Deatrck, & Havill, 2012)
- Three components & related dimensions provide a more complete understanding of family processes and strategies to manage complex conditions
  - Definition of the Situation
  - Management Behaviors
  - Perceived Consequences

# Adapted FMSF

- Definition of the Situation Surrounding Care and Placement
- Management of Care and Placement
- Perceived Consequences of Care and Placement

# Methods – Design and Setting

- Qualitative, descriptive, two-time point study  
Initial placement & 3 months post-placement
- Interviews of 10 primary family caregivers caregivers
  - Recruited from four nursing homes in the Midwest
  - Small, nested in-context sample



# Data-analysis: Across-Case Analysis

- The FMSF was interwoven into all aspects of the study, from the interview guides, to coding, and data analysis.
- Across-Case Analysis highlights the similarities and differences in experiences across cases (across the family caregiver) and over time (from initial to 3 month post placement interviews).
- The data are organized across the 3 major components of the FMSF.

# Data analysis: Within-Case Analysis

- Within-Case Analysis provides an understanding of each individual case to capture the family context of the unique caregiving situation
- Purposeful selection of two cases
  - Smooth transition
  - Difficult transition

# Results - Sample

- 10 primary family caregivers
- Age range from 52 – 85 years, with a mean age of 70 years
- All caregivers identified themselves as non-Hispanic Caucasian
- Eight of the caregivers were woman, with the most prevalent relationship being wife (caregiver) and husband (older family member)
- Familial relationships
  - Spouse
  - Adult-Children

# Definition of the Situation Surrounding Placement

- Describes how the caregiver defines the illnesses, vulnerabilities, and capabilities of their older family member and how these characteristics influence their ability to accomplish caregiving responsibilities

## Across-Case Analysis: Definition of the Situation Surrounding Care and Placement

“He followed me everywhere. I had no alone time and that started to really bug me and I did not want to be resentful but there were times when I did become resentful. ...if I was in the bathroom too long, that he thought was too long, he'd be there knocking on the door and, you know, if I was okay and he always had to know where I was if he wasn't in the room with me and he always wanted to help but if he did help it would end up in a disaster...”

## Across-Case Analysis: Definition of the Situation Surrounding Care and Placement

“...but I do feel like I've had to grieve a portion of my mom now that I can – I'm trying to articulate it. She's just – I mean she's not the same mom that we had before just because of the memory issues and she might not even remember what I was talking about, you know, so a little bit. A small portion, you know, some of us feel like we've had to grieve that portion...”

## Across-Case Analysis: Definition of the Situation Surrounding Care and Placement

“He’s there alone. He’s with all these other people but the bottom line to it is he’s there alone and even though he can’t get out on his own and he’d be in harm’s way, he was an outdoorsman, he was a sailor. He still thinks about escaping all the time. He needs that. Otherwise I come in there and he’s sitting at a table with a bunch of people and they’re all vegetables”

# Across-Case Analysis: Management of Care and Placement

- Encompasses the goals and philosophy that guide the caregivers' overall approach to their role and responsibilities during the nursing home placement process.



## Across-Case Analysis: Management of Care and Placement

“I think it’s an obligation for sure. My dad was always there for me through thick and thin my entire life. I mean completely. So I owe it to him. The other part of it is that, you know, it brightens up his whole day... if there’s multiple definitions to obligation, it’s a loving obligation, not a painful obligation”.

## Across-Case Analysis: Management of Care and Placement

“...my responsibility as I saw it was to be there for him as much as I could and I really made a bargain with myself that as long as he was there, I was going to go every day even though some advised me against it. So I was there every day”

## Across-Case Analysis: Perceived consequences of Care and Placement

- Reflects how the caregiver views the impact of caregiving and the nursing home placement on their relationship with their older family member, their continued role expectations post-placement, and their predictions regarding the trajectory of functioning of their older family member.

# Across-Case Analysis: Perceived Consequences of Care and Placement

“Well, really I mean relating to him as a wife as I said earlier rather than as a caregiver. In a lot of ways having [him] at [the nursing home] is – the separation is – I think what I’m trying to say is I recognize the fact that I’m probably going through a grieving process at this point because our life has changed so dramatically and certainly it’s not as final as death but it represents a different kind of finality in terms of our relationship, so ...”

# Across-Case Analysis: Perceived Consequences of Care and Placement

- “Well, what I’ve seen with the disease so far is it’s not linear, so it isn’t likely to just go along slowly like this. Something will happen. Maybe not a catastrophic event but it will be a trigger and all of a sudden we’ll see a falloff in some way. I think it’s for us to just be there. I think right now it’s to set him up in the right place, which we’re at where he can be taken care of in full. Make the effort to bring him out, be with him, connect with him, have other people see him which we did recently and had him over and a bunch of friends came, and I think it’s just to make this as comfortable for him as humanly possible through this journey. That will be it.”

# Discussion

- The adapted FMSF used in this study provided a unique appreciation of the impact of nursing home placement and changing caregiver roles.
- This study highlights the unique differences between different types of caregiving dyads (e.g. spouses and adult children)
- This study also provides considerations of the benefits of nursing home placement.

# Strengths & Limitations

- Strengths:
  - Variability in the types of caregiving dyads
  - Strong theoretical underpinnings
  - Advances the FMSF for various types of caregiving situations
- Limitations:
  - Slow and challenging recruitment
  - Diversity in the sample
  - Not all participants remained in the nursing home by the three month post-placement interview
  - Memory recall of the caregivers

Thank you!

- Questions or comments?
- References available upon request