

# Convoys of Care: Developing Collaborative Care Partnerships in Assisted Living

Wave One Report

April 2016

Funded by the National Institute on Aging



# Acknowledgements

The research team would like to thank all of those who participated and so generously and graciously gave their time and shared their insights and experiences. We are so very grateful. Thank you.

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# Study Purpose

The purpose of the study is to learn about residents' care arrangements in assisted living. We are interested in learning about resident self-care and about care given by family and friends, assisted living staff, and other care workers. *Our overall goal is to learn how to support caregivers in ways that build collaborative care partnerships and improve resident and caregiver quality of life and also facilitate residents' ability to age in place.*

We are interested in residents' "convoys of care." Convoys of care are the evolving collection of individuals (i.e. networks) who provide care, including residents themselves.<sup>1</sup> Care activities involve:



# Study Design and Settings

Our 5-year study involves collecting information in eight different assisted living communities or personal care homes in and around Atlanta, Georgia. Over the course of the project, we will study 50 residents and their entire care convoys, following their care activities and experiences over a two year period. The study is divided into two waves. Wave 1 began in 2013 and ended in 2015. Wave 2 begins in 2016 and ends in 2018. This report describes Wave 1.

In Wave 1 of this study, we selected four homes that differed in ways we thought would affect resident care, including location, licensing category, capacity, and resident characteristics. Study homes were located in three counties in and around Atlanta.

One home was licensed by the State of Georgia as an assisted living community and three were licensed as personal care homes.



Licensing capacity ranged from approximately 10 to 90 beds with average resident census ranging between 8 and 74 across homes. Two homes had designated areas for residents with cognitive impairment. Two homes were family-owned and operated, one was corporately owned, and another was foundation owned and operated.

<sup>1</sup> Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies*, 27: 15-29. doi: 10.1016/j.jaging2012.10.002 NIHMS:415156NIHMS:415156

# Study Methods

Eighteen researchers, including faculty, staff, and graduate students from the Gerontology Institute at Georgia State University spent two years in each of the four homes. We collected data in a variety of ways:

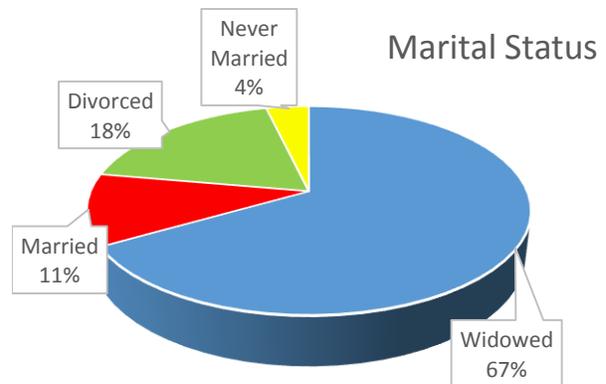
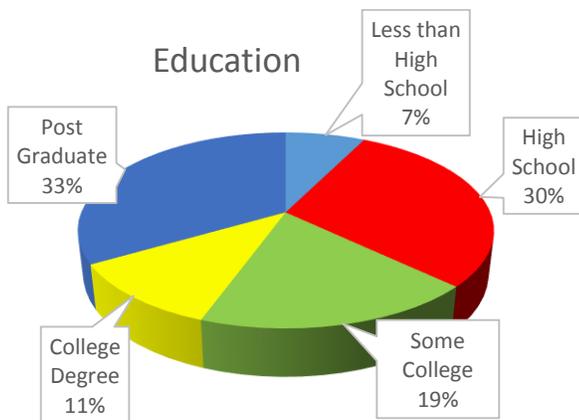
- 809 visits with a total of 2,224 observation hours, including informal conversations with those who live, work, and visit in the homes
- 142 qualitative interviews with residents, executive directors, direct care workers, health professionals, residents' family and friends, and volunteers

## Participant Characteristics

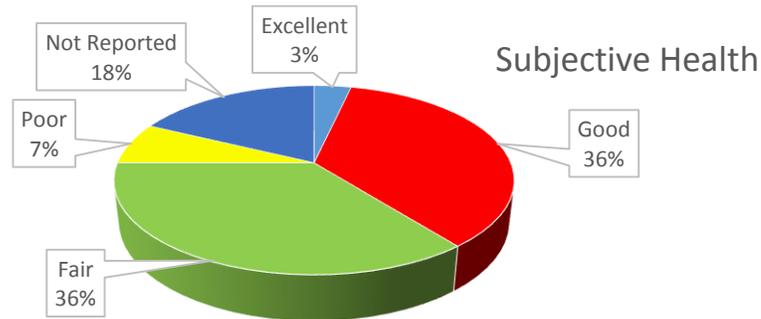
In Wave 1, researchers interviewed and closely followed 28 residents and 114 members of their care networks for two years. Care network members included their family and friends, assisted living administrative and direct care staff, and external care workers. Below, we share some of our participants' social and demographic characteristics by participant type.

### Focal Residents

- 17 were women and 11 were men; 18 identified as White and 10 as African American.
- Ages ranged from 58 to 96 years with an average of 84 years.
- Most had at least some college and most were widowed.

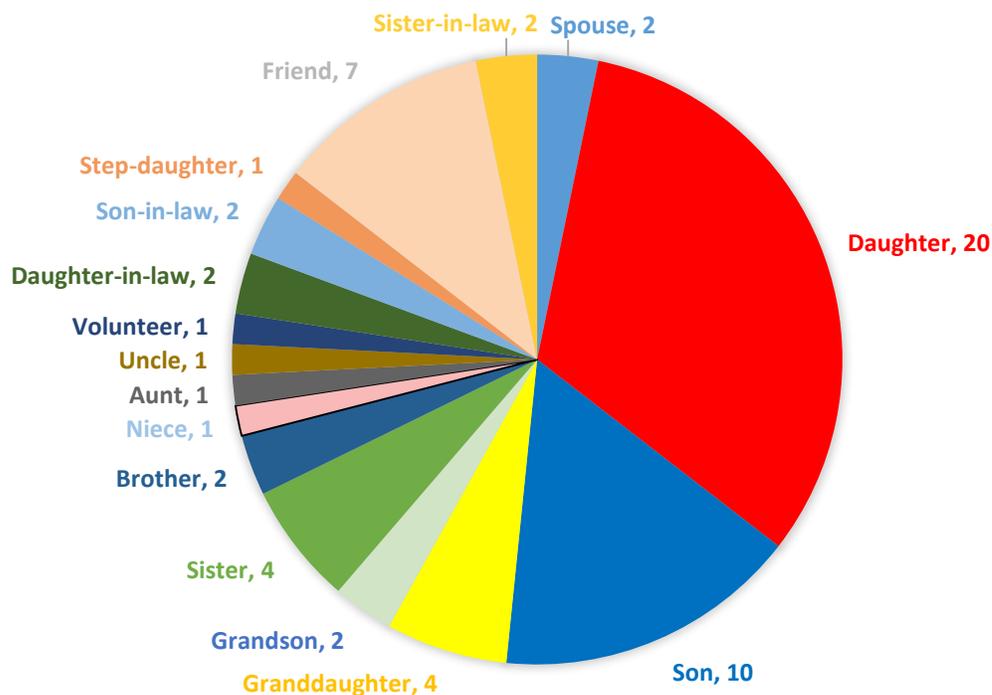


- Most residents (16/28) needed help with at least 3 ADLs; most (24/28) needed help with at least 3 IADLs; and most (21/28) needed help with medication.
- 39% had Alzheimer’s or a related dementia; 50% used a walker and 39% used a wheelchair.
- Most residents felt their health was good or fair.



### Informal Caregivers: Residents’ Family and Friends

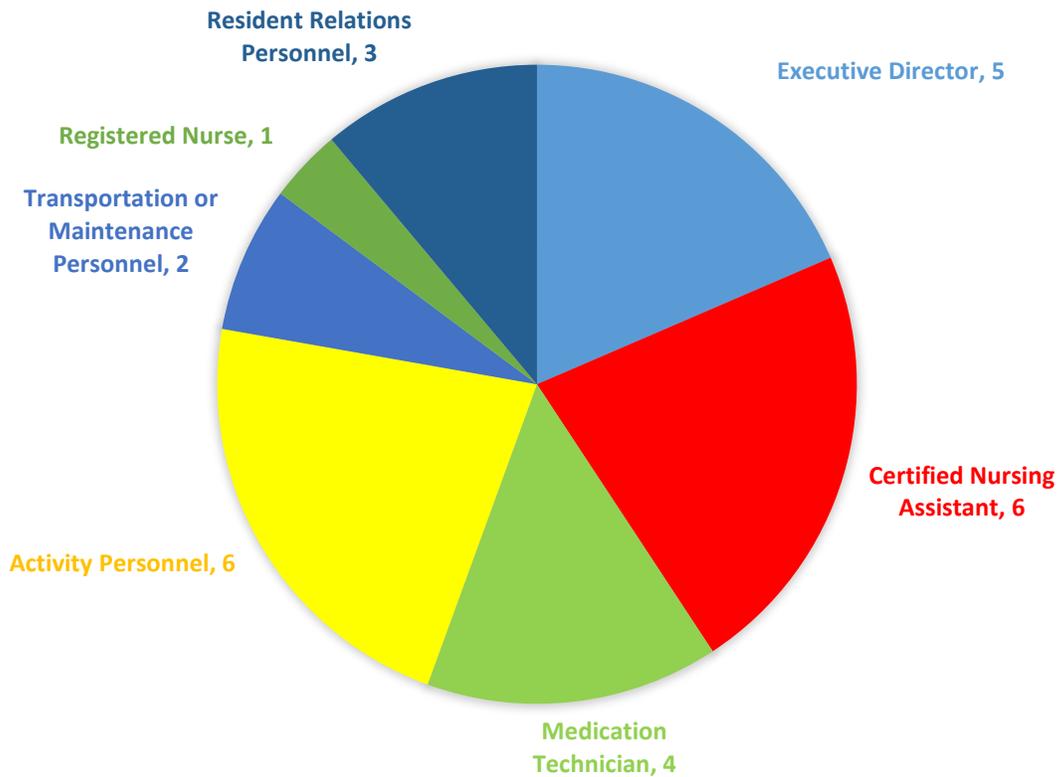
Of the 114 network member participants, 65 were informal caregivers. Children were among the most common informal caregivers, but residents’ relationships to network members varied widely.



- Most informal caregivers (46/65) were women and most (54/65) identified as White.
- The majority had at least some college.
- Slightly less than half were retired or unemployed.
- The majority (43/65) were married.

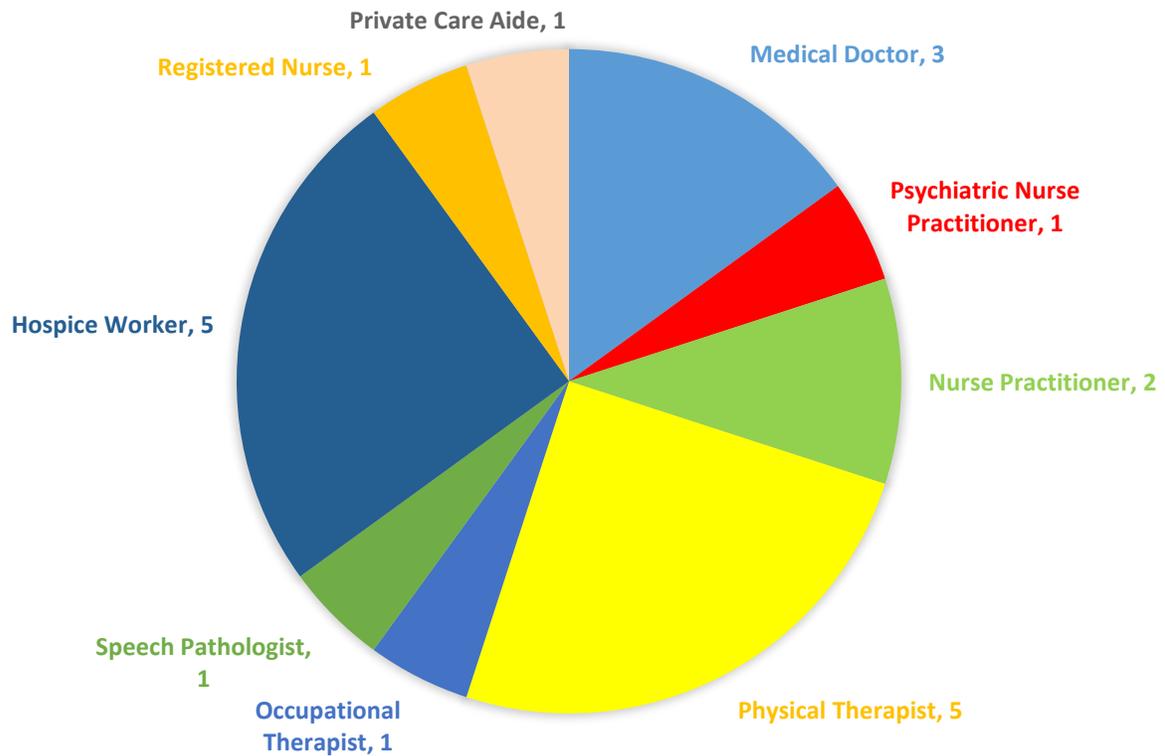
## Formal Caregivers: Paid Care Workers

**Assisted Living Directors and Staff.** Our study also involved 29 assisted living personnel covering a wide range of care and support activities for residents.



- All 5 Executive Directors were women between the ages of 38 and 59 years; their number of years working in the industry ranged from 5 to 25 with an average of 14; most had some college education.
- Among the 24 Assisted Living Staff: 21 were women; 13 identified as African American; their ages ranged between 24 and 72 years with an average of nearly 46; most (21/24) had at least some college with 5 having postgraduate education; 17/24 had additional long-term care training.

**External Care Workers.** In addition to care workers employed by the 4 homes, study participants included 20 care professionals from the external community who provided care within assisted living. These caregivers had a wide range of professional experiences, expertise, and job titles.



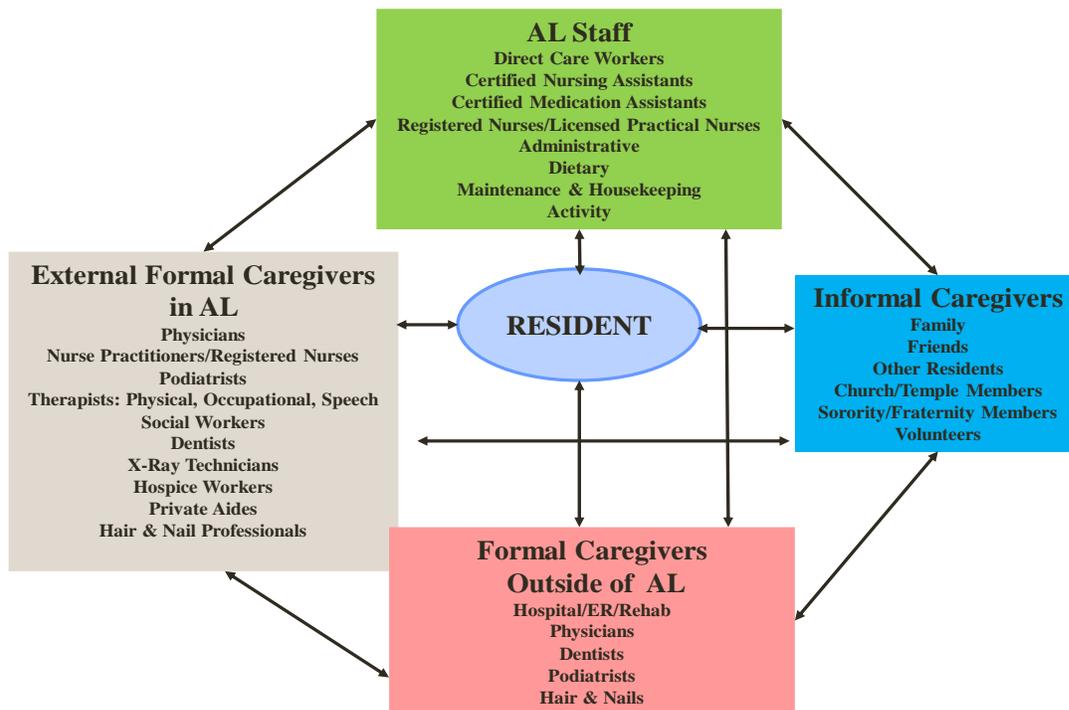
- 15 of these 20 care professionals were women.
- Ages ranged from 24 to 63 years with an average of 46.
- 12 identified as White, 7 as African American, and 1 as of Asian descent.
- All had at least some college education; 4 held a college degree and 14 had some postgraduate education.

# Key Findings

## Care Convoys: Who is involved in resident care in assisted living?

Residents' care convoys contained a variety of caregivers. Convoy makeup ranged from simple to complex and could change over time. The figure below illustrates some of the many types of individuals, including residents, who contributed to care. In addition to AL staff, convoys included residents' family members and friends and numerous types of formal care professionals from the outside community who provided services to residents in and outside of the AL setting. Together, these multiple care partners performed an array of care tasks to manage residents' instrumental, socio-emotional, and health care needs.

Care Convoy Members



## What do care convoy members do?

Care convoy members shared in the provision of needed care, which, like the make-up of convoys, could change over time. Care included: monitoring/management; ADL/IADL care; medication management/assistance; skilled health care; health promotion; and socio-emotional care. Although each type of care could be carried out by multiple types of caregivers, certain care tasks typically were the responsibility of particular individuals.

## Family and Friends in Care Convoys

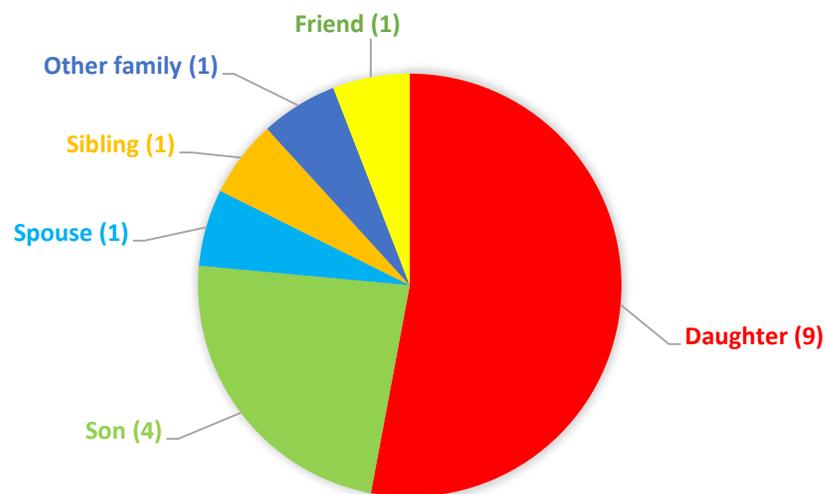
One focus of our study is on the care that residents' family members and friends contribute. As expected, residents' informal care networks were highly variable, yet shared commonalities in their make-up and how they operated. Almost all resident convoys included family members. The majority of family caregivers were children, yet 4 focal residents had no children. Others had children who were not involved in care, either because of estrangement, geographic distance, or competing demands.

**In general informal caregivers provided socio-emotional care, handled most IADL tasks, and played a key role in overall care coordination.**

“Yeah, I’m the primary person. Really, I kind of do everything. Dad calls me his ‘quarterback.’ I guess that’s sort of accurate. I deal with all things related to dad. My husband is very supportive, and he definitely helps out in terms of transporting dad, and going occasionally to medical appointments with him if I just can’t get there or take off work. . . My daughters have [helped] occasionally.”  
*Daughter*

### *One Primary Caregiver*

Over half (17/28) of the residents had one primary informal caregiver.

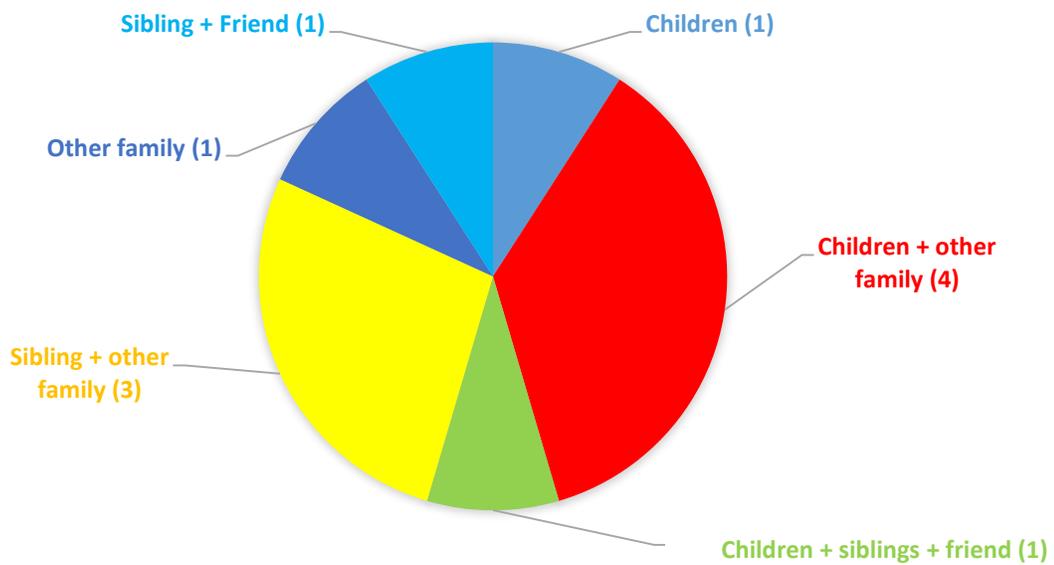


- For 13 (46%) residents, the primary person was a child: 9 daughters, 4 sons.
- Other primary family caregivers were a spouse, sibling, and niece.

- One primary caregiver was a non-family member, a former volunteer in the home.
- Most primary caregivers lived locally, but in one case a niece lived out of state and hired a paid caregiver to coordinate and carry out some IADL tasks.
- Primary caregivers generally had others they could call on for periodic support or respite.

### *Shared Caregiving*

- For 11 of the 28 residents, care responsibilities were shared among multiple persons, mostly family members, with no one person taking charge.



- Most shared convoys contained all family members, 1 exclusively children.
- For 2 residents, a friend shared responsibilities with family members.

## Resident Self-Care in Assisted Living

“It is great that God lets me do it 'cause there are people who can do and don't. I say, ‘Thank you Lord that you are enabling me to continue to do for myself.’ I don't know how long it's gonna last, but I'm glad that I can do it now.”

*Resident, Age 85*

Most residents, including those with cognitive and physical impairment, are involved in self-care, including the full range of care activities (ADLs, IADLs, medication management, socio-emotional care, monitoring and advocacy, and health care) to the extent they are able, willing, and supported by others. Involvement can take different forms:

- Performing tasks – doing certain activities oneself, including those that maintain or promote function and prevent decline
- Assisting with tasks – collaborating and helping others to complete care activities
- Instructing others – working with others, teaching others to perform care tasks effectively or in the ways one prefers
- Directing and managing care – establishing priorities and organizing care activities directly by making arrangements or indirectly through delegation
- Monitoring and tracking health – keeping tabs on health status/conditions, including indicators (e.g. pain and mobility levels, weight, blood pressure, etc.)
- Communicating/Advocating – keeping others apprised of physical and socio-emotional health and related care needs, including changing needs and preferences if needs are not being met
- Complying – following the requests/directions of caregivers

### Why is self-care important?

Self-care promotes resident independence and autonomy. For most, but not all residents, retaining control over and carrying out care tasks to the extent possible affects well-being, quality of life, and quality of care and can influence aging in place in assisted living.

## What factors influence self-care?

- The main resident factors influencing self-care include physical and cognitive function, mental health, communication skills, personality and past experiences, education and knowledge, personal preferences, attitudes, values, goals, and expectations. Financial and other types of resources (e.g. insurance, support and encouragement from others) also play a role in resident self-care.
- Key informal and formal caregiver factors include: understanding of and expectations for resident self-care; and attitudes, willingness, and ability to support or encourage resident involvement in care.
- Perceptions of and willingness to accept risk influence both residents and caregiver roles. Some facilities had “negotiated risk agreements” signed by residents and family members acknowledging and accepting that certain self-care activities may be risky.
- At the facility level, staffing levels and overall resident profile also influenced how much time care workers had to support resident self-care, which could take more time than performing the task for the resident.

## Health Care in Assisted Living

“In 2001 everybody might have been over 90, but they were pretty healthy. Today, they’re 90 plus . . . and they have health issues, you know, that are, some of them are fairly significant.”

*Executive Director*

As with most states, Georgia regulations do not allow assisted living staff to provide skilled nursing care. Yet, residents are older and frailer and have more complex health care needs than in the past, making health care a critical component of resident care.

Health care for residents in the four study homes involved chronic, acute, and end-of-life care and included, in addition to direct care, health monitoring, management, promotion, and advocacy. Each resident had an individualized, often evolving, portfolio of health care arrangements characterized by the type, frequency, and amount of care provided, who was involved, and when and where health care activities took place.

### What is the role of facility staff in health care?

- Facility staff, especially the direct care workers who see residents daily and respond to their day-to-day needs and health crises, were pivotal.

“They really have an important role and more than the family, they are there 24/7. They know what their baseline is...” *Resident’s MD*

- Medication management, blood pressure, weight, and glucose monitoring was mostly performed by specially certified care staff in each facility. In 3 homes, these activities were supervised by skilling nursing staff (RNs/LPNs).
- Each home had a “point person”, typically the resident care coordinator, who communicated with care providers, residents, and families about residents’ health conditions and status.

“We [physicians] want to know minor changes . . . It starts with small changes and if you can pick it up at that time you can avoid major hospitalization, major decline in mental and physical activity.” *Resident’s MD*

- In most homes staff were involved in arranging appointments and transportation for medical appointments when residents lacked other resources. Greater responsibility falls to facility staff when family are less involved.
- All homes offered activity programming intended to promote physical, emotional, cognitive and social well-being.
- Administrative and dietary staff worked with residents and families to accommodate dietary restrictions.

### What types of external health care professionals provided care on-site?

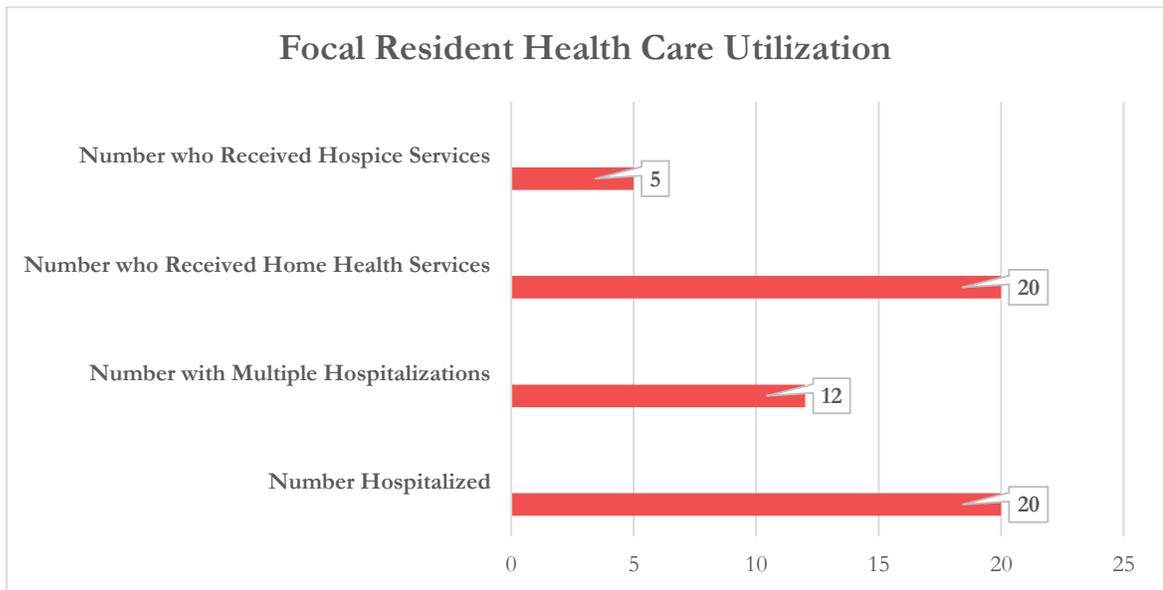
- Physicians, nurse practitioners, dentists, podiatrists, x-ray technicians, psychotherapists, and a full complement of home health and hospice workers were among the external care providers who brought their services to the homes.

“Some people we truly are now their primary care provider . . .A lot of them fall into the category of having advanced dementia and family has found it extremely difficult to take them out to appointments, both because of their cognitive ability as well as mobility issues.” *Nurse Practitioner*

- Over half of our focal residents received nearly all health care in-house, which eliminated the need to transport residents for chronic and most, though not all, acute and end-of-life care.

### What health care is received outside of assisted living?

- Some residents received almost all health care off-site, including from primary care physicians, multiple specialists, dentists, and podiatrists.
- Compared to in-house care, health care received externally required more effort in terms of making appointments and accompanying and transporting residents.
- Over the 2 years, 20 of our 28 residents were hospitalized, including 12 multiple times. Four residents spent time in rehabilitation facilities, 20 received one or more type of home health care, and 5 received hospice services.



### How are residents involved in their health care?

- Residents' own roles in their health care varied by resident and over time, largely depending on their ability to understand and communicate their health concerns.
- Certain residents had primary control of their care (e.g. made appointments, communicated with providers) with support from others as needed; a few performed health care tasks.

### How do informal caregivers support residents' health care?

- Along with AL staff and residents, informal caregivers monitor residents' health conditions.
- Most residents relied on family and friends to manage their health care, including making appointments, providing and arranging for transportation, and accompanying residents to physician offices and clinics.

- Family members participated in decision making regarding residents' health care and, together with AL staff, responded to health crises.

### What factors influence resident health care?

The availability, quality, and effectiveness of residents' health care depended on a combination of influences, including from the wider society and community, from the facility, and from residents and their family and friends.

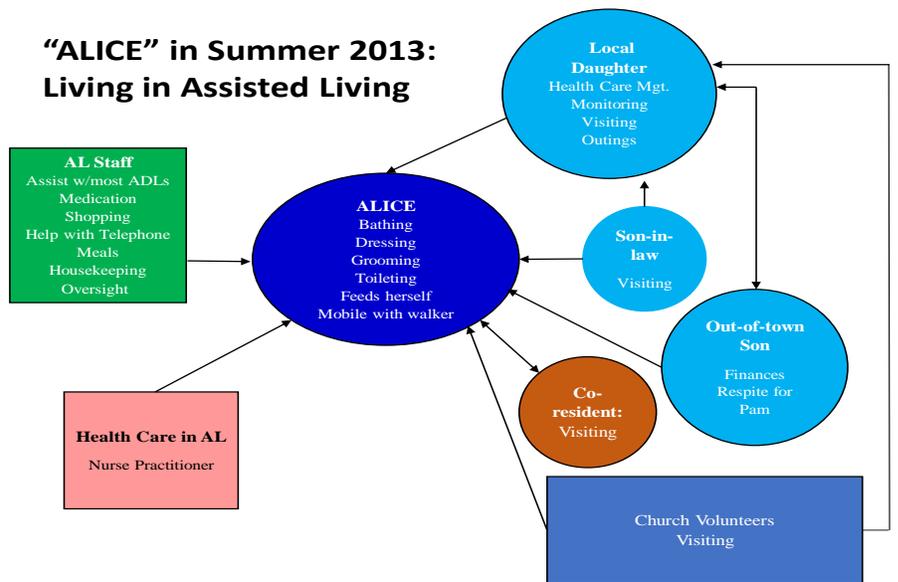
- Medicare reimbursement for skilled care provided in assisted living and state regulations, including what staff can and cannot do and with what training requirements, shape health care possibilities.
- Community factors include the availability and quality of external health care resources.
- Facility factors are critical and include: well-trained and consistent care staff; adequate staffing levels, size, ownership, fee structure, location, including proximity to health care resources, communication practices, and overall care strategies.
- Principal resident factors include functional status, involvement of informal caregivers, the desire and ability to participate, attitudes towards care and compliance, resourcefulness, expectations, care goals and knowledge.
- Informal caregiver factors include: availability, willingness, and ability to provide support, attitudes and beliefs about assistance, levels of engagement, knowledge, and expectations.
- Health care provider factors include: availability, responsiveness, and openness to communicating with convey members. Their attitudes and ability to collaborate with others lead to better outcomes.

“I really see myself as part of a larger team that is helping to take care of a particular person. So they have family, they have long time friends, they have staff of the assisted living community and then they also have other providers in the greater community . . . it is important to collaborate with them; many of the facilities will call me or send me a fax if they are noticing a change in somebody's condition . . . A lot of time because we work closely together we have been able to intercede and prevent a hospitalization.”

*Nurse Practitioner*

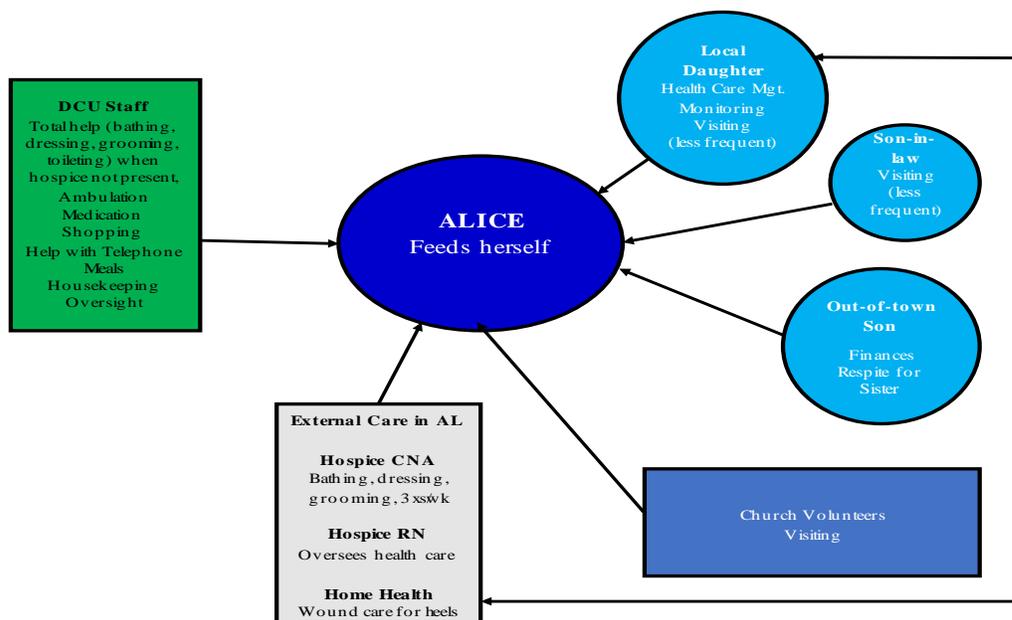
# Convoy Changes Over Time

Although we identified general care patterns involving residents and informal and formal caregivers, care convoys were dynamic. Most residents experienced health changes that affected their own care roles as well as the amount, type, and source of assistance over time. Convoy members also had changes in residence, family status, employment, and health. "Alice" for example shows some typical changes.



- In summer of 2013, Alice could manage all ADLs with some assistance from staff; other convoy members provided health care and IADL and socio-emotional support.
- By winter of 2014, Alice could only feed herself and hospice and home health workers had joined her convoy.

## "ALICE" in Winter 2014: Move to Memory Care Unit, Terminal Diagnosis



# Recommendations

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Our research indicates the importance of key elements of strong care convoys that support residents and their caregivers and contribute to positive outcomes.

## Care Plans & Consensus

- Establishing (and maintaining) clear, well understood, agreed upon, and up-to-date care plans and goals is crucial for quality care and positive care experiences among residents and those caring for them.

## Communication

- Ongoing, direct, and clear communication among convoy members is essential and leads to good care and partnerships.
- Insofar as possible, it is necessary to listen to, understand, and be respectful of the viewpoints of all care convoy members.

## Collaboration

- Collaboration among convoy members should be encouraged and fostered in an ongoing way.
- Strategies to promote collaboration could include creating opportunities for residents, staff, and families to interact and develop positive relationships (e.g. social events, care meetings).

## Responsiveness

- Convoys are complex and dynamic; attending and responding to resident and care convoy changes are crucial and communication and collaboration strategies may need to vary by resident and over time.
- It is essential to identify, communicate, and discuss changes with residents, family, care staff, and other relevant care providers.

## Leadership

- Absence of convoy leadership and consensus can have negative outcomes for resident care and residents' ability to age in place.
- Convoys without clear leadership should be identified and, insofar as possible, facilities should attempt to provide guidance to residents and, if available, family and friends. This approach could involve identifying alternative resources (e.g. social worker, etc.).

## Resident Self-Care

- Resident self-care helps maintain and promote independence and autonomy and requires support, encouragement, and occasionally time and patience on the part of other convoy members.
- Educating residents, family, and staff about the importance of self-care and how to support it, including among those with cognitive and physical impairments, is highly recommended.

## Contributions of Family & Friends

- The contributions of families and friends influence residents' quality of care and life and ability to age in place.
- Facilities play an essential role in promoting and supporting informal caregivers and their involvement in residents' lives and care activities.

## Centrality of Assisted Living Staff

- Assisted living staff are central to the effectiveness of care convoys.
- Staff play a critical role in monitoring changes to resident health, care needs, and abilities and preferences.
- Supporting and recognizing the important role staff play in care convoys can promote satisfaction and care quality.

## Coresident Contributions

- Coresident relationships can play an important part in the care process.
- Fostering positive, supportive co-resident relationships can lead to additional monitoring, advocacy, and instrumental and socioemotional support.

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