

# ADDRESSING NEEDS OF SPECIFIC POPULATIONS TO IMPROVE PATIENT AND FAMILY ENGAGEMENT:

## 21 WAYS HOSPITALS TAILOR FAMILY CAREGIVER SUPPORT BY CULTURE AND CONDITION

### ABOUT THE SERIES

#### *Supporting Family Caregivers Providing Complex Care*

The Caregiver Advise, Record, Enable (CARE) Act is now law in more than 40 states and territories. Policy makers recognize that family caregivers need support to perform the medical/nursing tasks they face at home after a family member or friend is discharged from the hospital.

The landmark 2012 AARP and United Hospital Fund report *Home Alone: Family Caregivers Providing Complex Chronic Care*, funded by The John A. Hartford Foundation, drove rapid adoption of the CARE Act. The report also inspired the creation of the Home Alone Alliance<sup>SM</sup>, a partnership of public, private, and nonprofit US organizations coming together to change the way health care organizations and professionals interact with family caregivers.

Home Alone Alliance members are conducting a national CARE Act implementation scan to identify promising practices in hospitals and ways to overcome barriers. Some practices involve applying proven strategies to empower a new audience—family caregivers. Ten major themes emerged and provide a glimpse into the value and complexity of CARE Act implementation.

**The Supporting Family Caregivers Providing Complex Care series** includes 10 papers that highlight these themes. The series also features Promising Practice papers that provide specifics on a single practice in one health care system and Spotlight papers that describe innovative state efforts to promote change or a health care system that is implementing multiple practices simultaneously. See [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

These early snapshots from the field share insights about how hospitals are supporting family caregivers and open a dialogue among leaders involved in enhancing health care delivery. These early observations ultimately could inform practice recommendations.

### Overview

Health care system leaders recognize that specific populations of family caregivers each face distinct challenges as they provide increasingly complex care at home after a hospital discharge.

**Hospital staff provide guidance and instruction on medical/nursing tasks to meet needs that vary based on cultural background, age of the person receiving care, and whether the family caregiver is a family member, neighbor, or friend.**

**They also tailor family caregiver support to meet the wide variations in needs arising from vastly different health conditions, such as dementia, cancer, diabetes, stroke, and depression.**

Hospitals proactively address the needs of family caregivers caring for specific populations such as:

- People with specific health conditions, including chronic diseases;
- Individuals taking certain high-risk medications;
- Older adults with needs related to polypharmacy, dementia, and hospice;
- Culturally/racially/ethnically distinct communities, including those who may be underserved; and
- People receiving palliative care for chronic conditions.

Methods hospitals use to support family caregivers from diverse communities include:

- Culturally congruent translations of materials in multiple languages and formats;
- Staff training on diversity issues that need to be addressed in their service area;
- Assessment tools to address barriers and identify cultural, language, visual, and hearing preferences;
- Teach-back interventions;

- In-person, audio, and video remote interpreting and tools for the hearing impaired; and
- Partnerships with community-based organizations to coordinate support throughout the care continuum.

Some supports were partially in place before the CARE Act and hospitals make them consistent across the organization. Some are new innovations developed before and during the COVID-19 (severe acute respiratory syndrome coronavirus 2) pandemic.

## Identifying Themes from Hospital Visits

To learn how hospitals are supporting family caregivers after CARE Act implementation, we assembled a research team of Home Alone Alliance and AARP Public Policy Institute leaders, nurse researchers, and policy experts to design and conduct site visits at hospitals across the country. This work was funded in part by The John A. Hartford Foundation, the Ralph C. Wilson, Jr. Foundation, and AARP.

The research team has visited dozens of health systems and hospitals in Arkansas, California, Colorado, Illinois, Michigan, Nebraska, Nevada, New Jersey, New York, Virginia, and West Virginia. We typically meet with leaders and staff from at least two health systems per state and two to three hospitals per system. The team visits a variety of types of hospitals: nonprofit, for-profit, and government hospitals; academic health centers; midsize suburban systems; critical access hospitals in rural communities; and level I through level V trauma centers.

Participant informants include chief nursing officers, chief technology officers, service and unit managers, patient experience leaders, quality champions, administrators, educators, front-line nurses, physicians, electronic health record (EHR) leaders, and staff from areas such as clinical and social services, accountable care organizations, pharmacy, registration, and admissions. We consult individuals from family advisory councils, community-based organizations, AARP state offices, consumer advocacy organizations, professional groups, and state hospital associations. We conduct focus groups with family caregivers who have had a recent experience with a particular hospital or system. Interviews are recorded and then analyzed, identifying common themes and novel approaches.

The intention of the [Supporting Family Caregivers Providing Complex Care](#) series is to describe the experiences of those making changes that align with the CARE Act. These early

### Emerging Themes of the Supporting Family Caregivers Providing Complex Care Publication Series

#### ➔ Addressing needs of specific populations

- Learning resources for family caregivers
- Communication practices
- Staff training
- EHR supports to identify and include family caregivers
- Transition in care programs and postdischarge support
- Approaches to making practice and system changes
- Pharmacy innovations
- Screening practices
- Benefits of the CARE Act

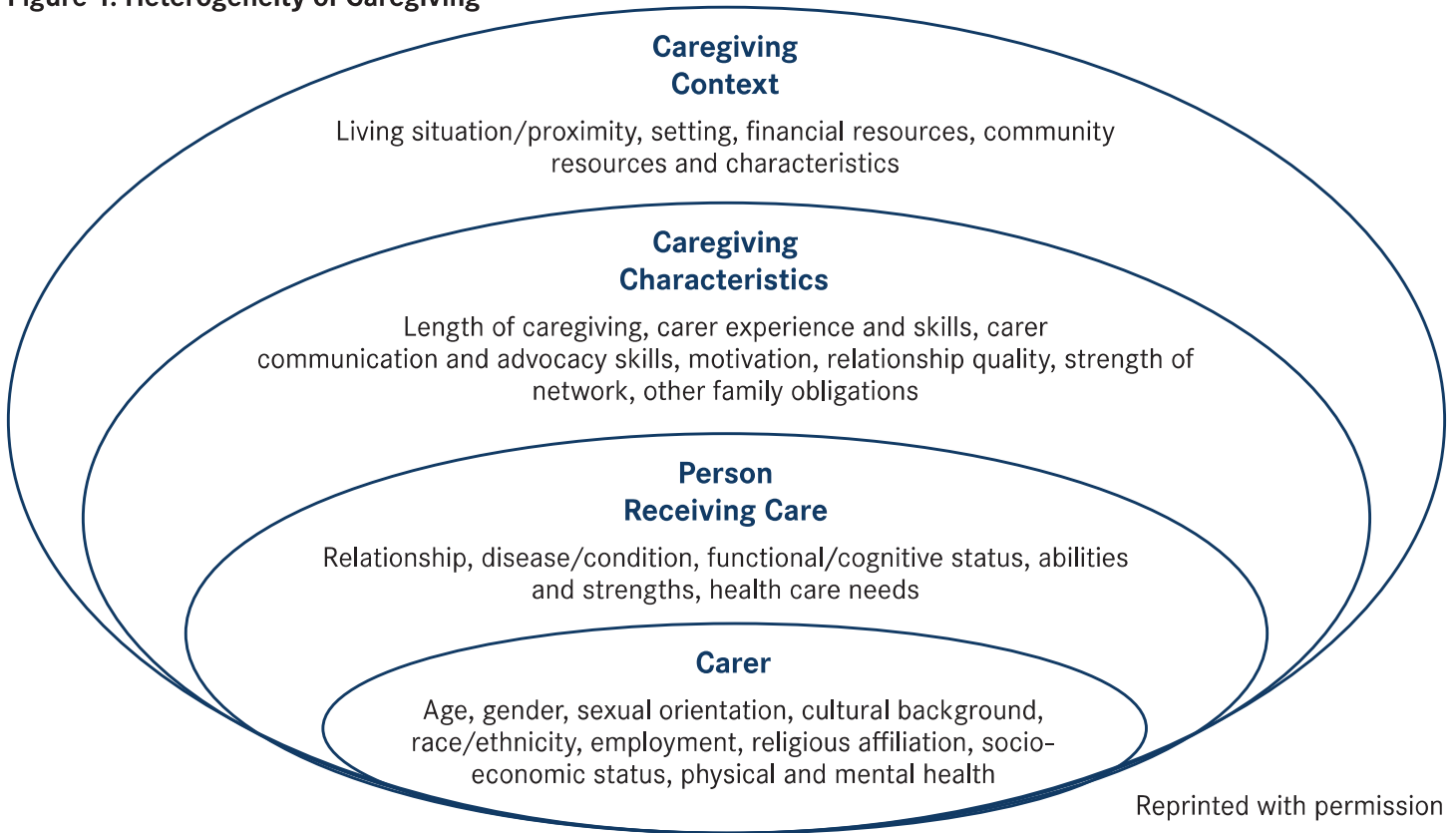
snapshots from the field describe the highlights of supports in place for family caregivers who provide complex care at home to a family member or friend after discharge from the hospital. The series opens a dialogue among health care leaders with a wide variety of perspectives. The papers share insights and could form the basis for future recommendations about supporting family caregivers.

## The Need

### Addressing Diverse Needs of Family Caregivers

Every caregiver functions in a situation comprised of numerous variable and intertwined socioeconomic and health factors and forces. Figure 1, Heterogeneity of Caregiving, organizes those elements with the family caregiver at the core. The figure originally appeared in *The Gerontologist*, a publication of the Gerontological Society of America, in an article titled Social Determinants of Health: Underreported Heterogeneity in Systematic Reviews of Caregiver Interventions by Heather M. Young, RN, PhD, FAAN, et al.<sup>1</sup>

**Common elements:** Elements that are common across a broad spectrum of family caregivers can be addressed when serving the general population of older adults.

**Figure 1: Heterogeneity of Caregiving**

Virtually all family caregivers need:

- Fundamental information about their role during the hospital stay and at home after discharge;
- Guidance and support to understand the importance of participating in care discussions and instruction on handling medical/nursing tasks; and
- Confidence in their ability to provide complex care at home safely and effectively.

**Context-specific elements:** Some elements are context specific. As hospital staff provide support, guidance, and resources, they must account for family caregiver differences and influences as displayed in Figure 1 and described below.

### Carer/Family Caregiver

A family caregiver is known as a carer in many countries, including Australia and much of Europe. Factors specific to an individual carer/family caregiver include, but are not limited to, age, gender, sexual orientation, cultural background, race/ethnicity, employment, religious affiliation, socio-economic status, and physical and mental health. The information in this section provides details on some of these factors.

### ● Age, gender, and sexual orientation

Caregiving is multigenerational for both men and women.

- Different age cohorts of family caregivers face distinct challenges for their life stage. Consider this data about millennial caregivers:
  - ◆ Twenty-five percent of caregivers are millennials, and 40 percent of millennials and younger caregivers are supporting someone with a behavioral health condition; these younger generations of family caregivers experience almost twice as much difficulty managing medications as older generations.<sup>2</sup>
  - ◆ Millennial caregivers, on average, have been providing care for a comparatively short period of 2.9 years in a moderate-to-high intensity care situation; half are the sole unpaid caregiver and fewer report having paid help compared with caregivers of older generations.<sup>3</sup>
- On average, Gen X caregivers have been caring for their care recipient for longer than younger generations.<sup>4</sup> Their recipient usually lives with them or within 20 minutes and most are the primary unpaid caregiver.<sup>5</sup> Most are in a moderate-to-high intensity care situation.<sup>6</sup>

- Men who are caregivers are less likely to receive instruction about performing medical/nursing tasks from health care providers.<sup>7</sup>
- More older family caregivers indicate they have no choice in taking on medical/nursing tasks like managing medications compared with younger generations of family caregivers.<sup>8</sup>
- Most LGBTQ family caregivers report their recipient lives with them in the caregiver's home or within 20 minutes.<sup>9</sup> More LGBTQ caregivers are in a high intensity caregiving situation than non-LGBTQ caregivers.<sup>10</sup> They are more often the primary caregiver for their care recipient.<sup>11</sup>
- **Cultural background, race/ethnicity, and language**

Expectations of involvement in caregiving differ between cultures.

  - [Multicultural family caregivers](#) are more likely to experience strain and worry about making a mistake, regardless of income.<sup>12</sup>
  - Linguistically and culturally appropriate resources are necessary because many hospitals serve communities comprised of multiple racial and ethnic groups. Family caregivers need resources and instruction on medical/nursing tasks—both written and verbal—in their own language through transcreation (ensuring the content is consistent with the cultural context of the specific community) instead of rote translation. Simple translation is often not culturally appropriate or tailored to local language variations, which can create more confusion or potentially adverse effects for both the family caregiver and the person receiving care.<sup>13</sup>

### Person Receiving Care

Factors specific to the person receiving care include, but are not limited to, relationship to the family caregiver, disease/condition, functional/cognitive status, abilities and strengths, and health care needs. The information in this section provides details on some of these factors.

- **Relationship, such as family member, neighbor, or friend**
  - A family caregiver may or may not be a family member. The care recipient may be a child, spouse, sibling, or older adult friend or parent. The type of caregiving support needed depends, in part, on the type and quality of the relationship between the person receiving care and the family caregiver, regardless of whether they are related. Needs especially vary depending on the role each person has in a relationship or in a family and the family dynamics.
  - Friends and neighbors may have more limitations in the responsibilities and time commitment they may be willing to assume. Gaps may indicate a need for social supports.
- **Disease/condition, functional/cognitive status, and risk factors of the person receiving care**
  - Individuals who require help from family caregivers have conditions as diverse as dementia, cancer, diabetes, and depression, and often more than one condition. Therefore, caregivers are dealing with different situational demands based on the health conditions of the care recipient.
  - Care recipients with dementia or other significant risk factors or safety concerns may require more vigilant attention from family caregivers.

### Caregiving Characteristics

Factors specific to the person receiving care include, but are not limited to, length of caring, family caregiver experience and skills, family caregiver communication and advocacy skills, motivation, relationship quality, strength of network, and other family obligations. The information in this section provides details on some of these factors.

- **Length of caring and family caregiver experience, skills, and expectations**

Family caregiver readiness differs depending on where the individual is in the trajectory of the caregiving journey. An inexperienced family caregiver may be in shock during an unexpected medical emergency and have difficulty processing new information. In contrast, a seasoned family caregiver may understand and feel confident about the fundamentals of managing postdischarge care but could be experiencing caregiving fatigue and physical or mental health problems of their own as a result of years of stressful hands-on caregiving.

- **Challenges, willingness, readiness, and knowledge gaps**

Family caregiver readiness depends on the stability of a family caregiver's physical, mental, and behavioral health, financial resources, living arrangements, employment, transportation, and food security. Readiness also depends on the effects of varying levels of literacy and health literacy and visual, hearing, and other impairments.

- **Family caregiver communication skills and preferences for learning materials**

- A family caregiver assessment can reveal which resources and communication formats will be most effective.
- Family caregivers report they want more and/or better instruction. More preparation would help them care for wounds, manage intense pain, and administer pills, suppositories, and injections.<sup>14</sup> Caregivers' preferences vary among practice with supervision, written instructions, visual instructions, videos, consistent instructions, and a phone number to call with questions.<sup>15</sup>
- Free how-to videos demonstrating medical/nursing tasks—created specifically for family caregivers—are available at [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone). Many of the videos are available in both English and Spanish. Printable resources guides are also available.

## Caregiving Context

Factors specific to the person receiving care include, but are not limited to, living situation/proximity, financial resources, and community resources and characteristics. The information in this section provides details on some of these factors.

- **Living situation/proximity and financial resources**

Every family has its own circumstances and each caregiver comes with a unique set of attributes, so listening to the individual concerns and priorities of each family caregiver is important.

- **Common barriers to providing follow-up care at home**

- Many family caregivers do not have the financial resources to cover the out-of-pocket costs of care, treatments, medications, equipment, and supplies, hindering their ability to be effective.
- Family caregivers often are not aware of community-based resources, some of which may be available at no or little cost. Those supports often vary by municipality, county, and state, making it even more challenging to navigate ways to get help.
- Long-distance family caregivers need specific types of support that can be especially dependent on their resources, ability to manage from afar, and willingness and ability to travel. Many long-distance family caregivers who want to travel to provide hands-on care may be unable to because of barriers related to the COVID-19 pandemic. Even local family caregivers cannot provide help if they are in quarantine or isolation or if hospital visitor restrictions are in place.

- **Community resources**

A single health care system can serve people in multiple states across rural, suburban, and urban areas with an array of educational and socioeconomic experiences. Family caregivers need hospital staff to have awareness of such differences and engage them accordingly. People living in a rural setting, for example, may be less accustomed to navigating the complex processes of large organizations compared with people living in urban areas. Rural areas may have few local resources available for postdischarge support of the person receiving care, which may affect the postdischarge care plan. Transportation options vary in different geographic areas, affecting discharge planning and timing. The availability and affordability of internet connectivity in rural communities can be challenging, limiting access to telehealth services.

## 21 Highlighted Practices

### How Hospitals Support Specific Populations of Family Caregivers

Health care systems use a variety of approaches to tailoring family caregiver guidance and instruction for different sets of circumstances. Highlighted practices from our ongoing national CARE Act implementation scan include the activities listed below. Hospital leaders use one or a combination of these practices.

Health care systems focus on:

#### People from culturally distinct communities

- 1 The phrase “family caregiver” does not have a direct Spanish translation. One hospital conducted focus groups to determine an appropriate word; they use *cuidadore*. AARP, on its Spanish-language website, uses “*los cuidadores familiares*” (roughly, family carers) because the term family caregiver indicates paid caregiver rather than (usually unpaid) family caregiver.
- 2 Health care systems train staff on the cultural norms of populations in their service area. One system that serves a large refugee population provides training modules for all employees to increase general awareness of the culture and historical trauma noting particular sensitivities, especially those that can directly affect care delivery. This helps staff communicate with family caregivers appropriately and use content that resonates with the cultural orientation of that community.
- 3 Hospitals create printed, audio, and video learning resources in multiple languages and provide extensive translation services for family caregivers, some of which can also add cultural context. They do not rely on other family members to do the translation as many health care terms are not familiar in vernacular language and require the skills of a medical translator to convey with accuracy and placing family in the position of translator can pose a conflict in regards to privacy. They also use the teach-back instructional method for educating family caregivers about medical/nursing tasks they will be performing at home. In this approach, as staff provide care, they explain to family caregivers what they are doing and why they are doing it in that particular way. They offer family caregivers opportunities to restate the same information in their own words, in their own language, to be certain the family member or friend understands and feels confident about performing the task at home after discharge. Family caregivers have the opportunity to perform a task and receive feedback and reinforcement as they practice.
- 4 One hospital created a Latino community council by partnering with 20 individuals from local community organizations that serve the large Latino community. Changes include installing bilingual welcome signage, offering multiple language options on the hospital’s website, and having bilingual staff members wear a button that says (in Spanish) “I speak Spanish.”
- 5 Another hospital serves an area where many residents are seasonal agricultural workers who collectively speak 14 different dialects of a language that is only spoken, not written. Hospital staff rely on a very limited number of local translators. They also partner with “*promotores de salud*” (lay community health workers who are part of a local indigenous or Spanish-speaking culture), who foster relationships with community members to build trust in the health care system and encourage them to acknowledge and accept the help they need. Promotores help individuals and families overcome the ingrained cultural norm that family caregiving is simply a difficult part of life that must be endured. Promotores also address the cultural assumption that only women will handle caregiving responsibilities.
- 6 Staff at one hospital noted that family caregivers who are Spanish speaking often are much more involved than English speakers in the patient’s care. The expectations that family caregivers have about their involvement are important considerations for hospital staff to understand as they engage and support family caregivers.

## How hospitals support caregivers of people with specific health conditions

Diagnoses such as dementia, cancer, heart disease, and brain injury require family caregivers to have specialized knowledge and skill to provide safe medical/nursing care at home after discharge. As a result, hospitals proactively focus on providing family caregiver guidance and instruction related to specific health conditions.

- 7 Hospital staff provide education on disease progression and support for family caregivers managing an array of medical/nursing tasks that can include administering medications such as pills, suppositories, and injections and handling equipment such as feeding tubes, catheters, blood glucose meters, and ventilators.
- 8 Interdisciplinary staff, including physicians, nurses, pharmacists, and physical therapists, provide information on prevention and management of condition-specific risks and medication side effects, such as those that can lead to instability and falls.

- 9 Some hospitals create their own printed and online learning resources for family caregivers who manage a particular condition, such as congestive heart failure.
- 10 People undergoing complex surgeries such as organ transplants need multiple skilled family caregivers to provide care at home. One hospital requires these family caregivers to commit to receiving detailed instruction over an extended period to prepare for safe discharge. The family caregiver and person receiving care must live in the vicinity of the hospital for at least three months because of the complicated nature of recovery and the complex devices used during the recovery process.

## How hospitals support caregivers managing multiple or complex medications

- 11 Hospitals teach family caregivers—especially those dealing with a high-risk situation—about the medications they will be managing after discharge.

### Practices that support family caregivers managing medications include:

- Helping family caregivers find medications at affordable prices;
- Encouraging family caregivers to practice giving medications that are challenging to administer in the hospital with supervision before discharge;
- Supplying medication in the hospital to take home or providing prescriptions to fill before discharge so the family caregiver does not need to leave the care recipient at home to pick up medications;
- Conducting medication reconciliations during multiple transitions to compare medications taken before and during the hospital stay with those to be taken at home after discharge—to account for differences, duplications, and gaps;
- Hiring dedicated pharmacists to educate family caregivers before discharge about medication risks, side effects, interactions, management, and barriers to compliance, especially when the care recipient takes a large number of medications;
- Enabling hospital pharmacists to coordinate with the family caregiver's local retail pharmacist;
- Making follow-up phone calls to the home after discharge from the hospital;
- Setting up primary care follow-up appointments that focus on discharge instructions and medication management;
- Adding to the EHR a list of medications older adults should potentially avoid; and
- Creating and sharing educational materials on frequently used medications.

## How hospitals support caregivers of people who are older

- 12 Many hospitals proactively help family caregivers address common aspects of caring for an older adult, such as dementia, delirium, polypharmacy, medication toxicity, frailty, palliative care, hospice, and end-of-life planning. Hospital staff recognize that family caregivers of a person with dementia may need more education, empathy, care, and attention because of the particular challenges of their responsibilities. Hospitals are expanding their understanding of who could be a family caregiver, recognizing that the person providing support at home could be a neighbor or a friend—especially for older adults. Ten percent of family caregivers of adults provide care to a friend or neighbor.<sup>26</sup>

One large health care system has a small family caregiver support team that receives internal referrals by phone or email for care recipients or community members who are 65 or older. Posters in the hospital advertise this family caregiver support and provide contact information to be used by professionals and family caregivers. To scale the internal referral process, the health system is developing a referral button in its EHR that triggers the involvement of the caregiver initiative team.

## How hospitals support caregivers of people receiving palliative care

- 13 Some hospitals have robust palliative care programs that provide focused symptom management for people with chronic or life-limiting conditions. Staff routinely work with these individuals and their family caregivers to help them create legal documents such as advance directives, health care proxies, do-not-resuscitate and do-not-intubate (DNR/DNI) forms, and provider orders for life-sustaining treatment (POLSTs). The documents provide a way to share the understanding of an individual's goals, values, fears, and preferences with family caregivers and clinicians, which facilitates decision-making at critical junctures.

- 14 Some integrated health systems provide palliative care across the care continuum, including rehabilitative, ambulatory, and home-based care. They conduct family care conferences to enable consistent support and smooth transitions—to ensure that at every step of care, family caregivers are prepared for how to handle care, what to look for, and when to call for help or more information.

- 15 One health system offers family caregiver classes in the community where nurses and physical therapists at teaching stations give live demonstrations and answer questions. Other health care systems partner with community-based organizations to achieve similar results.

- 16 Palliative care teams begin detailed discharge planning early. At one hospital, where about 80 percent of palliative care patients go home with hospice, staff prepare family caregivers to manage end-of-life care and refer them to hospice services.

## How hospitals support caregivers of people with vision and hearing impairments

- 17 Hospitals routinely facilitate communication for care recipients and family caregivers with vision or hearing impairments through the use of in-person, audio, and video remote interpreting.

## How hospitals support caregivers of people with differing learning styles and abilities

- 18 Because different learning styles and abilities can influence the effectiveness of teaching materials, hospitals assess the preferences and needs of family caregivers and provide information in various formats, including print, video, and audio. As they develop their resources, they consider that family caregivers with low incomes may have difficulty accessing online videos and those with low literacy can struggle to read instructions and develop materials accordingly.

## How hospitals address barriers to effective care after discharge

**19** Hospital staff conduct formal or informal family caregiving readiness assessments to screen for barriers related to willingness, ability, transportation, literacy, health literacy, finances, and social determinants of health such as living arrangements, employment, and food security. Recognizing barriers helps staff understand which community resources to recommend and where gaps in family caregiver support exist.

Hospitals then collaborate with community outreach organizations to put services in place that help family caregivers overcome an array of hurdles that prevent them from accessing and paying for needed care.

## Responses to COVID-19

**20** A collaborative of hospitals, a local philanthropic foundation, and more than two dozen social sector organizations revealed two divergent responses from older family caregivers resulting from COVID-19 hospital visitor restrictions. Some family caregivers did not seek any respite or health care for themselves; others quickly reached out to the local Area Agency on Aging, which experienced a significant increase in calls asking for referrals for help. The network responded by raising funds to deliver food and offer support to more than 1,000 isolated older family caregivers who did not qualify for state-funded meal programs.

This response was in addition to the organizations' work across the entire continuum of care to integrate the family caregiver into the care team, provide respite—especially to give older family caregivers opportunities to take care of their own health—and reduce readmissions for care recipients. Supports across the network include a family care support program embedded in a hospital transitional care team, a caregiver resource center located in a hospital, and assistance for families caring for someone with dementia.

**21** After recognizing the increased isolation experienced by Latino older adult family caregivers during the COVID-19 pandemic, one health care system used its outreach network to deliver Valentine's Day care packages of groceries, medications, incontinence supplies, and more. The hospital is turning what started as a project into a permanent program. Staff also focus more on helping these family caregivers manage their own health.

## The Effects of Unrecognized Cultural Norms: A Vignette

The example below illustrates how unaddressed cultural differences can affect safe postdischarge care. The promising practices shared in this paper can help hospital leaders address those differences.



**Example:** José is a widower with dementia and type 2 diabetes that he and his son, Alberto, struggle to control. Because their urban neighborhood stores often lack nutritious foods such as fresh fruit and vegetables, they have difficulty managing José's weight and diet. During José's hospitalization for an amputation, Alberto's visits are infrequent and short because the hospital is two bus rides from the apartment they share, and Alberto has three children and a job with long hours. As a result, Alberto rarely has an opportunity to talk with his father's nurses or doctors. José's primary language is Spanish, and his proficiency with English is limited, so the health information José can remember and report to Alberto is often incomplete. And because José does not want Alberto to worry, José purposely does not share some information.

[Like many Latino men, José had put off health care for years](#) because of cost, the lack of Spanish-speaking physicians and nurses, and fear of encountering culturally insensitive remarks and interventions such as diet plans that don't include foods he typically eats. Instead of seeing a primary care provider, José goes to the emergency department when symptoms become unbearable, and he uses [alcoholic beverages for pain relief](#) in the meantime. José was unaware that he had symptoms of diabetes.

Alberto had not noticed the signs of José's diabetes or dementia until both conditions had progressed. Alberto feels that he is simply taking care of an older family member—as expected by Latino families even when the situation is very difficult to manage. He is not aware that support services exist and that José is eligible for them. Even if offered an opportunity for no-cost mental health support, José and Alberto would not consider getting help because of perceived stigma around being seen as ill or mentally unstable.

After discharge, José's wound becomes infected and painful. Alberto is very concerned, but he is reluctant to ask for help from the hospital for fear of appearing

weak or unable to take care of his family. When Alberto finally decides he cannot put off calling any longer, he has challenges finding a time when he is with José at home so he can call and translate or wait for a callback.



**Repercussions:** José was readmitted to the hospital. Alberto's family felt mortified that they failed to take proper care of him, and they feared backlash from extended family members.

Alberto experienced even deeper anxiety and depression about his caregiving responsibilities and the limits he anticipates they will place on his life for years to come. He does not understand his many conflicting feelings, [such as the pressure he feels from his community to care for his father, his aversion to voicing complaints](#), and guilt.

José is no longer able to work in his construction job, creating additional financial and emotional stress for the whole family. Because Alberto sometimes needs to miss work to care for his father, he worries that he will encounter [family responsibilities discrimination](#) and lose his job, too.



**Opportunity:** Culturally informed clinicians could arrange bedside teach-back sessions in Spanish at a time when Alberto can attend to help José and his family learn how to manage his symptoms, wound, and medications. They could introduce Alberto to a case manager or promotore de salud (lay community health worker) who is a member of the family's cultural community and understands the relevant aspects of their culture and available community-based resources and can determine eligibility for services. José and Alberto could receive access to videos and other materials that incorporate their cultural norms and language in explanations about postdischarge care. They could also receive details on support groups for José's type of dementia and help Alberto become comfortable attending them.

Alberto could be prepared to arrange for additional postdischarge care for José, such as having a visiting nurse at the house. Alberto could hear that it is counterproductive to improving José's health and mobility when Alberto does everything he can for José throughout the day and that he should encourage José to do whatever he can for himself. Alberto could learn the early warning signs of complications, feel empowered to take action, and respond appropriately before a serious problem develops.

## Quantifying the Benefits

### Benefits of Integrating Family Caregiver Support

#### For Staff

- **Preventing discharge delays**—Instructing family caregivers helps hospital staff avoid discharge delays. Staff can provide and reinforce information gradually throughout the hospital stay rather than deliver large quantities of information to distracted family caregivers during the flurry of discharge activity. Staff can also better coordinate discharge scheduling when family caregivers understand the process and are prepared to arrive at the hospital at the time of discharge.
- **Streamlining staff communication with family members**—Primary family caregivers who receive complete instruction and preparation can relay information to other family members and friends, saving hospital staff the time and energy spent repeating the same information to multiple individuals.
- **Taking advantage of the knowledge family caregivers have about the person receiving care**—During live learning opportunities, family caregivers can share relevant details about the patient’s goals, values, fears, preferences, and responses to treatment. That information helps inform care plans. They can also bring to the staff’s attention subtle changes in the patient that signal a need for intervention and provide additional context that can affect decisions about care. Having information about unique circumstances such as social determinants of health, known medication side effects, delirium, dementia, and substance use can be vital in developing a successful care plan.
- **Instructing the right person in postdischarge care**—By instructing the person or people who will be helping at home, hospital staff can focus their efforts appropriately. It is vital to ask who will serve as the primary family caregiver because staff may not ever encounter that individual in the hospital room. It is also important to let families know they should inform the hospital staff if someone else becomes the primary family caregiver.

#### For Families

- **Detecting complications early to prevent problems that can lead to readmissions**—Qualitative data indicate that when staff thoroughly assess family caregivers and fully prepare them for what to anticipate, discharged patients may be less likely to have a complication at home that interferes with their recovery or requires a return trip to the hospital. When family caregivers understand how to identify a potential complication early, they can seek help before the problem requires treatment in the hospital setting.
- **Decreasing family caregiver emotional, practical, and financial strain**—Family caregivers who are adequately prepared to provide care at home can experience reduced strain and disruption of daily life during and after a family member’s hospital stay. They are better equipped to manage complex medical/nursing tasks and pain, which is a major issue that carries an emotional as well as practical and sometimes financial strain.<sup>27</sup>

When family caregivers understand what to do and expect and how to look for potential complications, they have increased confidence and attentiveness. Good preparation allows them to focus at home on providing emotional support to the care recipient and to address the impact of caregiving on their own health and well-being. Good preparation also gives care recipients confidence in the family caregivers.

- **Facilitating continuity of care**—A designated primary family caregiver with a good understanding of the care he or she will be providing at home can serve as the main point of contact to ensure continuity of care before, during, and after a hospital stay. The hospitalized individual may move to a skilled nursing or assisted-living facility or—more commonly—back home or to a family member’s home. Continuity of care during all transitions within and outside the hospital helps ensure medication reconciliation and accurate and complete communication of patient-specific details, including values and preferences. It can also prevent care and communication gaps, errors, and omissions.
- **Arranging appropriate support at home to foster a successful recovery**—By having early and ongoing conversations about care for the individual after discharge, staff and family caregivers can collaborate to arrange for adequate instruction, supplies, and equipment necessary to manage medical/nursing tasks

at home and any further help that may be required. Staff can provide referrals to community resources that support the plan for postdischarge care.

- **Supporting independent living**—Because a person’s ability to continue living independently can depend on the care he or she receives following hospital discharge, it is particularly important for staff to collaborate with family caregivers who will help people with special needs or older adults at home. It is also helpful for hospital staff to know if the person receiving care will have a temporary stay at another facility, such as a rehabilitation center, so they can provide information that will facilitate transitions to and from that setting.

## What Does Success Look Like?

During site visits with health care organizations that are implementing changes to include family caregivers in the

care process, we examined the impact of the enhancements. Although hospitals use scorecards and track many metrics, there was not universal identification of the direct link of family caregiver engagement with improvements in complication rates, emergency department visits, readmissions, follow-up inbound and outbound phone calls, and patient satisfaction.

An opportunity exists to set up a scorecard that monitors key metrics over time with a special emphasis on linking family caregiver interventions to specific outcomes. Health systems can consider tracking and trending data by unit and department to measure the impact of including family caregivers throughout the hospital stay.

**Ultimately, the best measure of success is the experience of the family caregivers and whether they feel included, heard, confident, and prepared to go home for the next phase of care.**

## Overcoming Perceived Barriers

### Resolving Challenges of Tailoring Family Caregiver Support for Specific Populations

While guidance and support should be provided to all family caregivers, tailoring information to meet the needs of specific populations can pose challenges. Below are four examples and how hospitals respond.



**Challenge:** There are not enough resources to provide the ideal level of support to every family caregiver.



**Resolution:** Hospitals increasingly innovate to provide instruction to support family caregivers. To put supports in place during the hospital stay and afterward, some health care systems develop close working relationships or partnerships with community-based organizations that focus on a specific populations or conditions commonly seen in their organization.



**Challenge:** For myriad reasons, family caregivers often cannot process information well in the hospital setting.



**Resolution:** At some hospitals, prescribers increasingly write orders for home health care so patients and family caregivers receive skilled nursing instruction at home shortly after discharge. Instruction can be more effective in a calm, familiar setting after the peak of a health care crisis. This path can be particularly helpful for patients with Medicare and/or Medicaid, who may qualify to receive skilled nursing support at home at no charge.



**Challenge:** It is difficult to convince people who have a life-limiting condition to create advance care planning documents.



**Resolution:** The palliative care team at one hospital conducts family care conferences for the 80 percent of their patients who go home with hospice. They also allow time for staff to talk with families about creating documents such as provider orders for life-sustaining treatment (POLST) and do-not-resuscitate/do-not-intubate (DNR/DNI) orders and advance directives to help the individual, family members, and care team have a common understanding of end-of-life wishes.



**Challenge:** There is a significant lack of awareness in the community and sometimes in hospitals about how to manage care for people with dementia.



**Resolution:** One health care system partners with multiple community organizations that focus on dementia. Social work staff developed and launched a seminar on aging that was open to the public. The traditional view of family is changing to include neighbors and friends—especially for older adults—so they also encourage attendance by friends and neighbors of those with dementia.

## Additional Information

### Implications of COVID-19

The COVID-19 (severe acute respiratory syndrome coronavirus 2) pandemic has revealed the profound importance of family presence on the health, well-being, and recovery of individuals during a hospitalization.

Health systems recognize that strict visitor policies hamper the ability of family caregivers to be part of the hospital experience and available to support their family member and participate in care. Health care leaders understand that limited face-to-face interaction between hospital staff and family caregivers hinders development of trust and communication about contextual details and decision support—creating challenges for staff members to maintain care quality and for family caregivers to obtain guidance and instruction on postdischarge care.

The absence of family caregivers underscores how much they contribute to day-to-day care in the hospital. Care recipients are left with little of the crucial emotional support family caregivers provide, resulting in loneliness and other negative effects on their mental and physical health. Front-line staff are left to manage the day-to-day bedside tasks family caregivers often handle, such as helping those with a high fall risk to the bathroom, assisting with ambulation to prevent the loss of muscle mass, and encouraging patients to eat and maintain hydration. Staff also do not have the benefit of family caregivers alerting them about increasing pain or changes in mental status, which is especially important when the care recipient has dementia or delirium.

The burdens of COVID-19 protocols and hospital staffing shortages make it even harder for front-line staff to fill the gaps left by family caregiver restrictions.

**To address issues related to COVID-19, some health systems do the following:**

- 1. Change visitation policies** to modify restrictions for essential family members and end-of-life visits;
- 2. Modify in-person encounters** to offer phone calls during rounds, foster intentional in-person connections during visits, increase home-visit safety, provide virtual support groups, and coordinate out
- 3. Adapt staffing models to redeploy** staff to the busiest areas, particularly to focus on connecting with family caregivers;

- 4. Use telephonic and video technologies** (with training and tech support) to enhance communication of instruction on postdischarge care; and
- 5. Deepen community partnerships** to mitigate strains families face, such as food insecurity and financial difficulty, that affect their ability to provide adequate, safe postdischarge care.

The timely launch of the [Supporting Family Caregivers Providing Complex Care](#) publication series highlights a wide variety of additional promising practices in family caregiver support just when they are most urgently needed.

### Inclusion of Diverse Caregivers in Program Design

A recent collaboration of the AARP Public Policy Institute, the University of California Davis Family Caregiving Institute, the Benjamin Rose Institute on Aging, and the Diverse Elders Coalition reveals the power of consulting with family caregivers from diverse backgrounds in understanding the meaning of research findings and in hearing their priorities for program and service design.

The family caregivers reiterated the importance of recognizing that while some caregiving experiences are common across groups, the meaning of caregiver experiences varies. It is shaped by both historical and cultural context and the intersection of numerous factors including age, gender identity, race/ethnicity, sexual orientation, immigrant status, and more.

Multicultural family caregivers experience significant socioeconomic inequality, racial discrimination, and intergenerational trauma.<sup>28</sup> With the diversification of older Americans, these inequities will only increase.<sup>29</sup> By 2030, almost 30 percent of older adults will identify as a person of color and/or an American Indian/Alaska Native; the number of older Americans who are lesbian, gay, bisexual, and transgender (LGBT) will double in size and include at least four million people.<sup>30</sup>

Recommendations from a series of three convenings to discuss in depth the topic of designing programs to support diverse caregivers can be found at <https://journals.healio.com/doi/10.3928/00989134-20210806-02>.

## Helpful Resources

### The CARE Act

The name of the law and its specific provisions vary by state, but CARE Act legislation generally requires that hospitals do the following to support family caregivers:

- Advise patients in the hospital of their opportunity to identify a family caregiver.
- Record the caregiver's name and contact information in the health record (with the patient's permission).
- Enable family caregivers by providing as much notice as possible about discharge timing, consulting with them about the discharge plan, discussing their role in carrying out that plan, and instructing them on the medical/nursing tasks they will handle at home.

See the [CARE Act map](#), which shows more than 40 states that have passed the legislation.

### Researcher Contact Information for Health System Leaders

The Home Alone Alliance and AARP Public Policy Institute leaders, nurse researchers, and policy experts continue to conduct the national scan of hospitals that have implemented the CARE Act and will share further results of that work. We welcome the opportunity to discuss findings with health system leaders to facilitate the culture change involved in fundamentally integrating family caregivers into existing hospital practices. To contact us, please email us, please email [homealonealliance@aarp.org](mailto:homealonealliance@aarp.org).

### Free Video Demonstrations of Medical/Nursing Tasks for Family Caregivers

Videos and printable resource guides created specifically for family caregivers show how to manage specific tasks related to wound care, mobility, managing medications, preparing special diets, and managing incontinence. These resources, many of which are available in both English and Spanish, are free of charge to all. Visit [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

### Education and Tools for Professionals, Clinicians, and Policy Makers

Health care leaders can find an array of resources and publications to help them integrate family caregivers into the care experience at [www.aarp.org/healthcareprofessionals](http://www.aarp.org/healthcareprofessionals).

To see details and data about the 20 million family caregivers in the United States who perform medical/ nursing tasks and worry about making a mistake, see [Home Alone Revisited: Family Caregivers Providing Complex Care](#), a 2019 special research report by the founding partners of the [Home Alone Alliance](#)<sup>SM</sup>, a collaborative of AARP, and funded by The John A. Hartford Foundation.<sup>31</sup>

The [Supporting Family Caregivers Providing Complex Care](#) series of publications is based in part on insights in *Home Alone Revisited* and [The CARE Act Implementation: Progress and Promise](#), a 2019 AARP Public Policy Institute Spotlight report.<sup>32, 33</sup>

The [American Journal of Nursing](#) (*AJN*) publishes award-winning evidence-based, peer-reviewed articles and videos that teach clinicians how to best support family caregivers. *AJN* also disseminates the work of the Home Alone Alliance to nurses through editorials, podcasts, and social media content. Home Alone Alliance articles approved for continuing education credit are funded by AARP, The John A. Hartford Foundation, the Retirement Research Foundation on Aging, and the Ralph C. Wilson, Jr. Foundation.

The [National League for Nursing](#) (NLN) offers simulation modules nurse educators can use at no cost to teach students about the individualized needs of family caregivers. The Advancing Care Excellence for Caregivers (ACE.C) program was developed with generous funding from The John A. Hartford Foundation and the AARP Foundation.

## Theme Papers in This Series

- [Staff Training Practices to Improve Patient and Family Engagement: 16 Ways to Include Family Caregivers and Prevent Discharge Delays](#) (PDF)
- [Learning Resources and Practices to Improve Patient and Family Engagement: 12 Ways to Facilitate Family Caregiver Education in Hospitals](#) (PDF)
- [Communication Practices to Improve Patient and Family Engagement: 10 Ways to Identify and Engage Family Caregivers in Hospitals](#) (PDF)
- [Screening Practices to Improve Patient and Family Engagement: 5 Ways Hospitals Prioritize Family Caregivers Who Need Extra Support](#) (PDF)
- [Benefits of the Caregiver Advise, Record, Enable \(CARE\) Act: 4 Perspectives on Enhancing Patient and Family Engagement in Hospitals](#) (PDF)

Additional publications in the *Supporting Family Caregivers Providing Complex Care* series are available at [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone). For more information about the CARE Act, visit the AARP Public Policy Institute website or <https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html>. To learn more about the Home Alone Alliance, visit [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

## Series Authors

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<sup>1</sup> Heather M. Young, et al., *Social Determinants of Health: Underreported Heterogeneity in Systematic Reviews of Caregiver Interventions in Gerontologist*, 2020, Vol. 60, No. S1, S14–S28 doi:10.1093/geront/gnz148.

<sup>2,3</sup> Susan C. Reinhard et al., *Home Alone Revisited: Family Caregivers Providing Complex Care* (Washington, DC: Home Alone Alliance, 2019), <https://www.aarp.org/ppi/issues/caregiving/>.

<sup>4–6</sup> National Alliance for Caregiving (NAC) and AARP, *Caregiving in the U.S. 2020* (Washington, DC: NAC and Washington, DC: AARP, May 2020), <https://www.caregiving.org/caregiving-in-the-us-2020/>.

<sup>7,8</sup> Susan C. Reinhard et al., *Home Alone Revisited*.

<sup>9–11</sup> National Alliance for Caregiving (NAC) and AARP, *Caregiving in the U.S. 2020*.

<sup>12–15</sup> Susan C. Reinhard et al., *Home Alone Revisited*.

<sup>16</sup> National Alliance for Caregiving (NAC) and AARP, *Caregiving in the U.S. 2020*.

<sup>17</sup> Susan C. Reinhard et al., *Home Alone Revisited*.

<sup>18–26</sup> National Alliance for Caregiving (NAC) and AARP, *Caregiving in the U.S. 2020*.

<sup>27</sup> Susan C. Reinhard et al., *Home Alone Revisited*.

<sup>28</sup> <https://www.diverseelders.org/2021/03/31/connecting-with-community/>.

<sup>29,30</sup> <https://www.diverseelders.org/what-we-do/current-campaigns/family-caregiving/>.

<sup>30,31</sup> Susan C. Reinhard et al., *Home Alone Revisited*.

<sup>32,33</sup> Susan C. Reinhard et al., *The CARE Act Implementation: Progress and Promise* (Washington, DC: AARP Public Policy Institute, 2019), [aarp.org/ppi/info-2017/from-home-alone-to-the-care-act.html](http://aarp.org/ppi/info-2017/from-home-alone-to-the-care-act.html).

*Supporting Family Caregivers Providing Complex Care*

Theme Paper #1009, November 2021

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