SUPPORTING FAMILY CAREGIVERS PROVIDING COMPLEX CARE November 2020

Theme

ELECTRONIC HEALTH RECORD (EHR) PRACTICES TO IMPROVE PATIENT AND FAMILY ENGAGEMENT:

9 WAYS TO HELP STAFF ACCESS DATA ON FAMILY CAREGIVER DISCHARGE PREPARATION

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℠, 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.

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

Exceptional health care is a shared goal for electronic health record (EHR) providers, hospital financial leaders, clinicians, patients, and families. Although these groups approach the goal from five different perspectives, hospital leaders point to one method to achieve it:

Standardize family caregiver data in EHRs

Health care systems increasingly expect family caregivers, who are often unprepared, to perform complex medical/nursing tasks at home after discharge of a family member or friend from the hospital. When hospital staff instruct family caregivers and involve them in shared decision making throughout the hospital stay, they form a team that can do the following:

- Significantly influence inpatient care plans.
- Avert discharge delays and postdischarge complications that can lead to costly readmissions.
- Ensure continuity of patient care.

To involve and guide family caregivers, clinicians across disciplines need easy access to contact information and assessment status for family caregivers in the EHR as well as common language to use for identifying family caregivers.

The benefits of standardized family caregiver data include the following:

- For EHR providers—Enriched value to health systems
- For hospital finance leaders—Improved success metrics, such as reduced preventable readmissions
- For clinicians—Streamlined care coordination
- For patients—Person- and family-centered care
- For family caregivers—Improved preparation for managing complex care at home after discharge

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

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

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 to 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 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, 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 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

The Importance of Documenting Family Caregiver Data in the EHR

Involving family caregivers during a hospital stay reflects a commitment to person- and family-centered care and improved outcomes for all care recipients, regardless of their age or diagnosis, and for the family members, neighbors, and friends who support them.

The EHR is a foundational system that is critical to standardizing communication with family caregivers and ensuring visibility of related information to all health system stakeholders. This can help care providers deliver coordinated care throughout a hospital stay and beyond. Health systems rely on the EHR to document and organize care and to facilitate communication among care team members across roles and shifts.

Health systems recognize both the strengths and the limitations of the EHR relative to the priority of staff communication with family caregivers. Hospital staff we talk with share strategies for optimizing the supports this resource can afford to the care team—which includes the family caregiver.

A number of patients have multiple family caregivers engaged in their care, and they all must be identified and documented in the EHR, with the permission of the patient. While one person should be designated as the primary family caregiver, all family caregivers who will provide care should receive instruction in the hospital.

Displaying Family Caregiver Data to Facilitate Communication and Care Coordination

EHR platforms should visually present information about family caregivers in a way that is usable for hospital staff.

Communication Breakdown: A Vignette

The example below illustrates the confusion, duplication of effort, and gaps that family caregivers often face because information about their preparation is not consistently available to clinicians. The promising practices shared in this paper can help prevent those issues. The example also describes repercussions and opportunities for change.

Example: Emily is an older woman who is hospitalized with complications of diabetes. She lives with her sister, Sara, who will help Emily at home after discharge from the hospital. Emily's son, Paul, lives nearby and is named as her agent in her durable power of attorney for health care. A social worker meets Sara and adds notes to a social work module of the EHR about Sara's abilities, willingness, availability, and instructional needs. A nurse sees information documenting Paul as Emily's family caregiver and adds notes to a nursing module about the instruction she gave him. The social worker and nurse do not see each other's comments because staff members can't access the notes of those in other functions. Yet both individuals are performing their duties according to expectations.

Paul receives some of the same information from both the social worker and the nurse. Based on the admitting notes, the nurse assumes that Paul will be the person providing care at home and tells him how to monitor blood glucose and inject insulin. A different social worker helps Paul enroll Emily in a senior meal program that offers special diets. Sara does not receive instruction about her sister's diet, monitoring, or medications.

Sara takes Emily home after discharge. Days later, Emily doesn't feel well. Sara tests Emily's blood glucose and gets a reading of 450, which is dangerously high. Sara takes Emily back to the emergency department.

Repercussions: Emily was readmitted. Sara experienced worry and frustration because she wanted to help her sister. Paul was unhappy about the disruption and miscommunications.

Opportunity: The problems could be avoided with enhanced EHR capabilities that foster better communication among staff members and help staff coordinate their communications with family caregivers who play different roles.

If all staff members understood what instruction their colleagues delivered to which family caregiver, both Sara and Paul would be better prepared. Throughout the hospital stay, Sara would receive the instruction and reinforcement she needs to help Emily and have a chance to ask questions. It would be a better experience for patients and families to have more support in the hospital and less disruption and stress after discharge. The likelihood of readmission would decrease.

At a minimum, staff members need new visualization tools to display relevant information about the status of family caregiver preparation for discharge in a concise and cohesive manner, bringing together information from many existing EHR fields. These tools would enable each care team member to readily understand staff roles in filling any gaps.

This dashboard or at-a-glance visual style of communication helps staff across all roles and shifts coordinate with one another and is critical to do the following:

- Ensure effective assessment of family caregiver readiness and appropriate instruction.
- Prevent duplication of efforts by multiple staff members.
- Avoid potentially conflicting information from multiple providers, which family caregivers are then faced with reconciling.

EHRs were initially designed to enable consistent billing practices. They must be reconfigured to enable consistent person- and family-centered care. This starts with identifying family caregivers upon admission, and family caregiver involvement must be connected to the discharge planning documents the family caregiver receives.

Increasing Staff Productivity

Incremental EHR enhancements can help sustainably resolve two significant issues that markedly decrease staff productivity:

- Staff, patient, and family confusion about the meaning of a number of terms (e.g., caregiver, family caregiver, next of kin, legal guardian, legally authorized representative, health care power of attorney, emergency contact), which can result in identifying the wrong person for postdischarge preparation.
- Delays or omissions in staff follow-up calls designed to help families address potential problems at home. Better-coordinated care could prevent postdischarge complications that trigger emergency department visits and readmissions.

9 Recommendations from the Field for Health Systems and EHR Vendors

Standardized EHR Enhancements

During our ongoing national CARE Act implementation scan, health systems told us that several features of EHR documentation should be embedded throughout existing hospital workflows and as a standard part of the EHR. These include the ability to document family caregiver identification, assessments of readiness, and preparation for postdischarge care.

The format of the information should allow all clinicians across disciplines and roles to view, enter, and update specific family caregiver information (rather than just check boxes) at any time.

EHR companies could make some enhancements incrementally. The following three changes may be manageable in the short term:

1. Enable hospital staff to easily access all family caregiver data at any point. EHR capabilities should include the following:
   - Identification of a primary family caregiver and any additional family caregivers in all admission-related workflows (e.g., preregistration, emergency admission, observation status, initial nursing assessment)
   - Visibility of data to all clinicians so they can contact and prepare family caregivers as needed throughout the hospital stay
   - Standard and optional prompts and select hard stops to support the cultural shift of including family caregivers at every step of the hospital stay
   - Enhancements to extend the accessibility of the data beyond the hospital environment into primary and specialty care, the community, and even home settings to enhance continuity of care from the perspectives of clinicians, patients, and family caregivers throughout the patient's lifespan

2. Document the family caregiver readiness assessment and instruction plan as well as the family caregiver's issues of concern.

3. Monitor staff member compliance with documenting in the EHR that the hospital asked the patient to name a primary family caregiver and additional family caregivers, entering whether the patient provided data or declined the opportunity, entering the name and contact information of each family caregiver, and asking patient permission for clinicians to share health information with each family caregiver.

   The enhanced EHR functionality should also include the following:
   - An indication that a family caregiver(s) consented to manage support at home
   - The ability to note that an individual declined to name a family caregiver (and the reason) or has no one to help at home. If there is no one to help, this should trigger a referral to social work or another department.
   - The ability for clinicians to change the primary family caregiver, add additional family caregivers, and retain a historical record of changes
   - Standardized wording and prompts for staff to clarify differences between the family caregiver and other family members and to separate family caregiver consent from general consent
   - The ability to scan a consent form into the EHR if a state requires a paper form
   - A popup that shows the name and contact information of the primary family caregiver each time a clinician confirms a treatment plan, to facilitate discussion about care plan changes and updates

Hospital leaders and front-line staff also shared their ideal: a dashboard of family caregiver data that includes the essential elements listed below. These could be included in a comprehensive electronic health record refinement.

A Single-Screen EHR Dashboard: The Gold Standard Ideal

4. Provide simple, prominently displayed language for staff to use consistently across hospital systems and nationally when documenting the primary family caregiver and any additional family caregivers in the EHR. Examples include the following:
   - "Who will help you manage when you get home?"
   - "Who can receive medical updates about your condition?"

5. Display caregiver status information:
   - Name, relationship, and contact information of each family caregiver
   - Consent for staff to communicate with each family caregiver
   - Documentation of the assessment of the skills that the family caregiver(s) is willing and able to use (assessment of family caregiver physical capability, emotional and practical preparedness, willingness, and availability)[1]
   - Documentation of information regarding instruction provided to the family caregiver(s) about medical/nursing tasks to be performed at home after discharge and who provided that instruction
   - Family caregiver skill gaps and instruction that includes demonstration, discussion, and an opportunity for the family caregiver(s) to perform the task and receive feedback (also known as teach-back)[2]

6. Document the name of each staff member who completes each task noted above, the date on which the communication took place, and the content of each interaction.

7. Include the discharge date and flags for gaps in staff and family awareness of discharge checklist items that may be incomplete and result in discharge delays.

8. Identify high-risk individuals whose family caregivers need deeper preparation to help reduce the even greater risk of emergency department visits and preventable readmissions.

9. Enable input from family caregivers about patient-specific situations, such as dementia, depression, substance abuse, and hearing loss, that significantly affect patient care in the hospital and after discharge.

Quantifying the Benefits

Benefits of Staff Access to Data on Family Caregiver Discharge Preparation

For Staff

- **Instructing the right person in postdischarge care—** By correctly identifying the person or people who will be helping at home, hospital staff across roles can focus their efforts appropriately. It is vital to document 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.
- **Preventing discharge delays—**Identifying the family caregivers helps hospital staff avoid discharge delays. Throughout the hospital stay, staff across roles can provide and reinforce family caregiver instruction according to documented assessed needs and fill noted gaps. They can also better coordinate discharge scheduling.
- **Taking advantage of the knowledge family caregivers have about the person receiving care—** Staff can document relevant details obtained from the family caregiver about the hospitalized person's goals, values, fears, preferences, and responses to treatment.

Gathering and sharing information from family caregivers 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.

For Families

- **Facilitating continuity of care—**Designated primary family caregivers with a good understanding of the care they 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, and prevents care and communication gaps, errors, and omissions.
- **Detecting complications early to prevent problems that can lead to readmissions—**Qualitative data indicate that discharged patients may be less likely to have a complication at home that interferes with their recovery or requires an emergency department visit or hospital readmission when staff across roles and shifts assess family caregivers and fully prepare them for the care they will be providing. 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.[3]

  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 improve their own health and well-being. And a confident family caregiver increases the confidence level and emotional comfort of the person receiving care.
- **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 determine what will be needed and arrange for adequate instructions, 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, readmissions, staff satisfaction with documentation workflow, and patient satisfaction with the discharge process.

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.

A Call to Action for EHR Vendors

We encourage EHR vendors to learn more about the role of family caregivers and their enormous influence on health outcomes, patient satisfaction, and preventable admissions, especially regarding the care of older adults and those with special needs.

An important opportunity exists for EHR vendors to create one view of "discharge readiness" that compiles all relevant information for easy access by all care team members.

EHR Vendors and Hospitals Can Leverage AARP Researchers

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 encourage EHR providers to consider recommendations from hospital users. AARP welcomes the opportunity to discuss the findings with hospitals and EHR vendors, to facilitate understanding of the many critical details involved when identifying, communicating with, and educating family caregivers. To contact us, please email homealonealliance@aarp.org.

Additional Information

Implications of COVID-19

The COVID-19 (severe acute respiratory syndrome coronavirus 2) pandemic has intensified the importance of identifying and engaging family caregivers. Strict visitor policies have hampered the ability of family caregivers to be part of the hospital experience and be available to support their family member and participate in care. Limited face-to-face interaction between hospital staff and family caregivers hinders 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.

Innovations are emerging to foster communication and support caregivers in new ways through technology. The timely launch of the *Supporting Family Caregivers Providing Complex Care* publication series highlights a wide variety of promising practices in family caregiver support just when they are most urgently needed.

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 individuals 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.

FREE VIDEO DEMONSTRATIONS OF MEDICAL/NURSING TASKS FOR FAMILY CAREGIVERS

How-to 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 handling incontinence. These resources, many of which are available in both English and Spanish, are free of charge to all. Visit aarp.org/nolongeralone.

RELATED PUBLICATIONS FOR PROFESSIONALS, CLINICIANS, AND POLICY MAKERS

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℠, a collaborative of AARP, and funded by The John A. Hartford Foundation.[4]

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.[5,6]

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 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.

ADDITIONAL THEME PAPERS IN THIS SERIES

- *Learning Resources and Practices to Improve Patient and Family Engagement: 12 Ways to Facilitate Family Caregiver Education in Hospitals* (PDF)
- *Staff Training Practices to Improve Patient and Family Engagement: 16 Ways to Include Family Caregivers and Prevent Discharge Delays* (PDF)
- *Communication Practices to Improve Patient and Family Engagement: 10 Ways to Identify and Engage Family Caregivers in Hospitals* (PDF)

Publications in the *Supporting Family Caregivers Providing Complex Care* series are available at www.aarp.org/nolongeralone. For more information about the CARE Act, visit the AARP Public Policy Institute website or https://states.aarp.org/tag/the-care-act. To learn more about the Home Alone Alliance, visit www.aarp.org/nolongeralone.

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

[2] Ibid.

[3] 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/.

[4,5] Ibid.

[6] Susan C. Reinhard et al., *The CARE Act Implementation.*

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