STAFF TRAINING PRACTICES TO IMPROVE PATIENT AND FAMILY ENGAGEMENT: 16 WAYS TO INCLUDE FAMILY CAREGIVERS AND PREVENT DISCHARGE DELAYS

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 AllianceSM, 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

To ensure family caregivers receive the instruction they need to care for a family member or friend after a hospital discharge, clinicians must have specific knowledge, skills, and competencies. Hospital leaders recognize that they need to provide this information through staff training, using consistent framing, content, and language. They also recognize that, because staff training alone will not create institutional cultural change, they must also provide learning resources for family caregivers themselves.

This holistic approach of promoting collaboration among staff, family caregivers, and patients leads to a better experience for all.

Hospitals teach interprofessional staff how to do the following:

- Include family caregivers as integral members of the team.
- Anticipate what family caregivers will need to know.
- Seek information from the patient and family caregiver on goals, values, fears, and preferences.
- Encourage family caregiver input in care planning and decision making throughout the hospital stay.
- Ask family caregivers about their biggest concerns.
- Offer family caregivers learning resources accessible in the hospital setting and after patient discharge to reinforce learning at home.

Promising practices that hospital leaders implement reflect that they must champion this fundamental shift to embed it throughout their organization. They understand that other aspects of this shift include enhancing electronic health records (EHRs) and using common language to identify family caregivers and set family caregiver expectations. This paper shares promising practices and considerations for staff training to more effectively include family caregivers in the care process.
Staff Training Practices to Improve Patient and Family Engagement

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, electronic health record 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.

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

- Staff training
  - Learning resources for family caregivers
  - Communication practices
  - 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
  - Addressing needs of specific populations
  - Benefits of the CARE Act

The Need

More than 20 million people in the United States perform complex medical/nursing tasks for their family members and friends. Many of these family caregivers do not receive instruction on how to perform the medical/nursing tasks they are expected to manage at home.

When family caregivers are asked what would make it easier for them to perform medical/nursing tasks at home after discharge, they report they want more and/or better instruction. More preparation would help them with the challenges of tasks such as caring for wounds, managing intense pain, and administering pills, suppositories, and injections. Their preferred instructional formats include additional exposure to the content during the hospital stay, practice with supervision, written instructions, visual instruction, videos, consistency in instructions, and a phone number to call with questions.
Missed Instructional Opportunities: A Vignette

The example below illustrates family caregiver knowledge gaps that staff training can address, subsequent consequences, and opportunities for system change. The promising practices shared in this paper can help prevent those gaps.

**Example:** Samuel has serious injuries from a car accident. His neighbor and friend, Maria, comes to the emergency department with him. The admissions registrar asks Samuel if he has named anyone as his agent in a durable power of attorney for health care. He says he has not. No one asks Samuel about Maria’s role, even though she spends most of her days with him as he recovers and prepares to go home. Staff members are friendly, but they do not identify Maria as a family caregiver. She watches as the nurses change Samuel’s wound dressings on his legs, but she feels it is not her place to ask questions. During the discharge process, a nurse asks Samuel who will help him when he goes home. Maria volunteers. She listens as the nurse explains the discharge instructions, and she starts to feel very anxious. Maria takes Samuel home, gets him settled, then rushes out to fill the prescriptions he received at discharge. When she gets back, she finds Samuel in intense pain. He has been moving around and his leg dressing has fallen off. The wound looks red and has some discharge that doesn’t look good to Maria. She calls the number the hospital provided for follow-up questions. Maria is so upset that she has trouble explaining her concerns to a nurse who is unfamiliar with Samuel. An hour later, Samuel’s pain is still not relieved, and Maria decides to take him back to the hospital because she feels unequipped to help him.

**Repercussions:** Samuel was readmitted. Maria felt that she failed him and is very upset that she didn’t know what to do.

**Opportunity:** The hospital could teach staff how to identify the family caregiver, who may be a friend or neighbor. Clinician training could include EHR documentation of gaps in the ability, willingness, availability, and instructional needs of family caregivers like Maria. Staff could be prepared to provide interactive guidance, instruction, and reinforcement throughout the hospital stay to ensure family caregivers are prepared to deliver safe follow-up care after discharge. Maria would be prepared to look for warning signs of complications, feel empowered to take action, and respond appropriately before Samuel develops a problem that results in readmission.

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### 16 Highlighted Practices

**Hospital Staff Training Practices to Support Family Caregivers**

Health care systems use new approaches to make changes in care processes, standardize specific changes that fulfill CARE Act requirements, and ensure sustained and reinforced training. Highlighted practices from our ongoing national CARE Act implementation scan include the activities listed below.

#### Training Content

1. **Establishing ownership and introduction strategies**
   
   Hospital leaders set the tone for the importance of the issue and communicate at the outset which group of hospital stakeholders is responsible for identifying family caregivers. Establishing ownership helps all involved understand their role and individual accountabilities in identifying family caregivers, documenting their contact information, and including them in care management throughout the hospital stay.

2. **Leading with the “why”**
   
   For those who participate in training sessions, understanding why such training is important enhances adoption of the content. With CARE Act implementation, this means recognizing that the mindset of integrating family caregivers into the care team makes good business sense and contributes to the goals of the patient care that clinicians work so hard to achieve. Whether delivered online or in the clinical unit, it is important to keep the training focus squarely on how family caregivers, at home after discharge, will build on the care that clinicians deliver in the hospital.
3 Promoting the transition from a patient-centered focus to a person- and family-centered philosophy

To facilitate person- and family-centered care, some health system leaders share the following with staff across the organization:

- The benefits of standardizing, expanding, and formalizing hospital identification of and interactions with family caregivers
- A clear way of asking who the family caregiver is
- Ideas about how to set the communication tone and welcome family caregivers as members of the care team

4 Introducing CARE Act tenets to staff across the health system

Health systems vary in how they introduce the CARE Act to staff, depending on the cultures of different geographic regions and specific hospitals. Some systems provide the information as a new initiative driven by their state’s legislation and as a common-sense way to enhance patient care, and others integrate it incrementally as part of existing processes and educational programs.

Everyone involved in care delivery—physicians, nurses, and other allied health professionals—must know who the primary caregiver is and to what extent that person should be involved in care planning.

5 Creating multiple opportunities to identify family caregivers

Hospital leaders recognize that people in at least two different roles should share responsibility to ensure identification takes place either upon admission or shortly thereafter. Identifying and documenting family caregivers should not be the responsibility of a single individual.

It makes sense to start training nurses and social workers first because they engage with families the most frequently and are the most involved with identifying family caregivers, teaching them clinical skills, and supporting them during the patient’s transition home.

It’s also helpful to train emergency department and admissions staff to, during routine intake questions, obtain and record in the EHR who the family caregiver is and how to contact that person. They can help families make distinctions among the terms next of kin, legal guardian, and family caregiver and determine whether those descriptors refer to one individual or to two or three different people. This helps prevent staff from providing information to someone who should not have access to it.

Having the emergency department and admissions staff enter the information upon patient admission enables unit nurses to access the name of the family caregiver in the EHR and quickly confirm it with the patient to ensure the information is accurate and current.

6 Providing standardized wording

Supplying simple, consistent language to staff across a health system facilitates identification of the primary family caregiver and any additional family caregivers. Examples of such wording include the following:

- “Who will help you manage when you get home?”
- “Who can receive updates about your health condition?”

7 Teaching nurses and staff in other roles how to use the teach-back method

- One skill that resonates strongly with nurses and other staff members is 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 to be certain the family member or friend understands and feels confident about performing the task at home after discharge.
  - Staff also offer opportunities for family members to perform a task and receive feedback and reinforcement as they practice.
Developing staff awareness of family caregiver differences

Family caregivers have differing needs and may require different approaches from staff:

- For example, men, millennials, and large families may have different learning needs and preferences about how they provide care.\(^5\)
- To serve family caregivers from multiple cultures, a system-wide course on diversity helps staff members understand cultural and ethnic variations in norms and assumptions, and appropriate approaches to collaborating with families. This understanding builds the foundational trust and cooperation needed to prepare family caregivers to provide effective postdischarge care at home.

Documenting family caregiver information in the EHR

Recording family caregiver information is supported through EHR enhancements that allow hospitals to do the following:

- Identify family caregivers during the admission process.
- Add hover boxes that provide standardized guidance about determining who the primary family caregiver is.
- Ensure family caregiver contact information is easily accessible to all clinicians so they can contact and prepare family caregivers as needed throughout the hospital stay.
- Incorporate an assessment of readiness and instruction plan for the primary family caregiver and document the family’s concerns and feedback.

Delivery Mechanisms

Reinforcing lessons through existing processes and programs

One of the most effective strategies for ensuring awareness of the CARE Act provisions and responsibilities of staff is to integrate the training into existing programs and ongoing efforts to engage patients, especially older adults. Examples of existing initiatives include Nurses Improving Care for Healthsystem Elders (NICHE) as well as palliative care and end-of-life care programs that address the needs of family caregivers. Including this education in existing continuing education programs or annual competencies may be effective.

Using existing and new internal education and training and dissemination channels

Identifying a champion in each unit or department to function as an internal team ambassador helps socialize the value of the education efforts. Partnering with clinical educators and nursing professional development teams leverages existing resources to ensure education occurs on a regular basis.

Examples of continuing education vehicles include nursing in-service and continuing education programs, EHR training, new-hire orientations, staff meetings, team huddles, introductory and booster modules for learning management systems, information technology (IT) tip sheets, clinical tip sheets, newsletter articles, emails, and posters.

Using external marketing channels

Examples of external marketing can include communicating the hospital’s focus on family caregivers to community organizations and partnering with these agencies to spread the information to the people they serve.
Building System-Wide Buy-In

Seeking external support and guidance before implementation

Some health system leaders collaborate with their state hospital association to obtain guidance on the upcoming culture change, then conduct trainings throughout the health system to teach staff in all roles the importance of family caregiver identification and engagement. They train their IT team to enhance their EHR, then train all EHR users involved in the discharge process. Health systems that have achieved the best adoption of new practices are those that sought feedback and support from a state hospital association or professional organization that proactively provides guidance on accountability for CARE Act implementation.

Developing comprehensive guidelines for family caregiver engagement

To help achieve scale, spread, and consistency throughout a hospital or health system, some hospitals develop formal processes for nurses and other staff that explicitly outline how to involve family caregivers.

Piloting

Implementing a successful new approach in one clinical unit often leads to requests from other units or clinicians for the same training. Some large health systems first deploy changes in one hospital, then throughout other hospitals in the system.

Leveraging team dynamics

The dynamics of interdisciplinary teams help achieve the spread of promising practices, as one member of the team shares successes with colleagues. Those involved in successful problem solving and innovations often spontaneously describe those practices to others. Hospital leaders who actively encourage clinical colleagues to share promising practices within and outside their own disciplines can help speed adoption of successes throughout the organization.

Quantifying the Benefits

Benefits of Staff Training

For Staff

- Instructing the right person in postdischarge care—By correctly identifying 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.
- Preventing discharge delays—Identifying family caregivers helps hospital staff avoid discharge delays. Staff can provide and reinforce instructions gradually throughout the hospital stay rather than deliver large quantities of information to distracted family caregivers during the flurry of discharge activity. They can also better coordinate discharge scheduling.
- Streamlining staff communication with family members—Family caregivers can relay information to other family members and friends, saving hospital staff the time and energy spent repeating the same information to multiple individuals. When families are uncertain about who is the most suitable person to serve as the primary family caregiver, offering time for them to come to consensus is helpful. Allowing extra time also helps when large families want to divide caregiving tasks among multiple individuals.
- Taking advantage of the knowledge family caregivers have about the person receiving care—Family caregivers can share relevant details about the hospitalized person’s goals, values, fears, preferences, and responses to treatment. They can also recognize subtle changes 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.
For Families

- **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.

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.

- **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.

- **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 discharge delays, readmissions, complications, staff satisfaction with CARE Act/family caregiver staff education, 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.**
Overcoming Perceived Barriers

Resolving Challenges in Implementing Staff Training

In a cohort of hospitals across the country, leaders identify obstacles to the change process and ways to overcome them. Initial reactions to the provisions of the CARE Act by hospital leaders and staff during site interviews include five primary concerns that ultimately diminish:

**Challenge: Difficulty accommodating training time**—When leaders seek critical feedback, the main concern they hear from staff is related to fitting additional training into busy schedules.

**Resolution:** Positive feedback after the training indicates that staff accommodate the training because they want and need the information so they can more deliberately include family caregivers in practices and workflows.

**Challenge: Lack of necessity**—Staff feel that they already do what the CARE Act requires.

**Resolution:** Focusing attention on the requirements of the CARE Act helps hospitals recognize the need to train staff on standardizing their identification of and interactions with family caregivers. Nursing and other staff in many hospitals report they already prepare family caregivers for the care they’ll provide at home. But once the staff hear poignant personal stories about the existing gap between the information family caregivers receive at hospital discharge and the knowledge they need to provide at home, nurses and other staff recognize gaps—and their initial concerns about making changes diminish. Information from the AARP *Home Alone* report creates additional awareness by staff of process gaps.7

**Challenge: Documentation**—Family caregiver education is not in one place in the EHR.

**Resolution:** Working with the EHR provider or internal IT team to reconfigure the display of family caregiver data, assessment of readiness, and instruction into a more easily accessible view enhances staff interactions with family caregivers and ensures professionals know where to find the information.

**Challenge: Liability**—Hospitals are concerned about inclusion of family caregivers creating Health Insurance Portability and Accountability Act (HIPAA) issues. Hospital staff worry about bearing responsibility for the health or well-being of family caregivers as well as negative patient outcomes at home.

**Resolution:** By more closely examining the provisions of HIPAA, hospitals clarify that, with patient permission, inclusion of family caregivers does not pose a legal risk.

**Challenge: Delay of discharge**—Operationally, discharge can be delayed when a family caregiver and staff are unable to coordinate schedules for instruction. People considered unsafe to discharge because the primary family caregiver is not ready or able to provide care at home may unnecessarily remain at the hospital for additional days.

**Resolution:** Staff begin the process of discharge planning at admission, are flexible in scheduling the timing of family caregiver instruction, and communicate early and clearly about the planned discharge time and date.
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.

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 homealonealliance@aarp.org.

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. 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.

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.

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)
- Communication Practices to Improve Patient and Family Engagement: 10 Ways to Identify and Engage Family Caregivers in Hospitals (PDF)
- Electronic Health Record (EHR) Practices to Improve Patient and Family Engagement: 9 Ways to Help Staff Access Data on Family Caregiver Discharge Preparation (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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2–6 Ibid.


8,9 Susan C. Reinhard et al., Home Alone Revisited.