No Place Like Home: Advancing the Safety of Care in the Home

Report of an Expert Panel Convened by the Institute for Healthcare Improvement

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The Institute for Healthcare Improvement (IHI) and the National Patient Safety Foundation (NPSF) began working together as one organization in May 2017. The newly formed entity is committed to using its combined knowledge and resources to focus and energize the patient safety agenda in order to build systems of safety across the continuum of care. To learn more about our trainings, resources, and practical applications, visit ihi.org/PatientSafety

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Executive Summary

There truly is no place like home, and care in the home holds many potential benefits, including support for person-centered care. Care recipients generally prefer to be at home, where they may have more autonomy than in inpatient settings. Care in the home is not without its challenges, however, and these challenges may affect both care recipients and everyone who supports them. Existing data suggest that preventable harm to care recipients is an important issue in the home setting. In addition, both home care workers and family caregivers may be physically or emotionally harmed as they provide care.

The safety of care provided in the home has not yet received nearly as much attention as patient safety in hospitals and other clinical settings, despite the fact that the home has become the site of care for many people. In 2016, more than 2 million personal care attendants provided care in the home, according to the US Department of Labor, and this number is expected to grow by 40 percent in the next decade.[1] Care in the home comprises a number of different services, including personal care, home health care, hospice, palliative care, and, through some specialized programs, primary care and hospital-level services. These services are provided by a variety of home care workers with a range of training and expertise. In addition, many aspects of care are provided by family caregivers.

The Institute for Healthcare Improvement (IHI) convened an expert panel in November 2017 to consider the specific challenges to safety in the home setting and to offer recommendations for improvement. This report describes the panel's feedback and generally focuses on safety related to two primary aspects of care in the home: personal care and home health care (see box on page 14 for the definitions used in this report). It considers the physical and emotional safety of the care recipient, the family caregiver, and the home care worker, while recognizing the interconnected nature of the safety of all these individuals. The goal of this work is optimizing safe, person-centered care for the unique environment of the home.

The panel found that a number of factors make safe care in the home especially challenging:

1) The provision of care outside the controlled environment of the health care system
2) Issues with communication and care coordination among the care team, the care recipient, and the family caregiver
3) The need to balance autonomy and risk
4) The closeness of the link between the care recipient and those providing care
5) The limited health literacy of the care recipient and the family caregiver
6) Variable availability of data
7) Social and physical isolation
8) The variety of needs and populations

Safety interventions used in other settings cannot simply be applied to meet the specific challenges of safety in the home setting. Understanding the type and scope of the risks specific to care in the home is essential to identifying effective strategies for mitigating risks and optimizing well-being for people who receive care in their homes. These risks include the following potential harms:

1) Adverse events related to medication and other forms of treatment
2) Injuries due to physical hazards in the home (e.g., falls)
3) Injuries related to equipment and technology
4) Pressure injuries
5) Infections
6) Conditions related to poor nutrition
7) Adverse effects on family caregivers

8) Adverse effects on home care workers
9) Potential neglect and abuse of care recipients

These harms and their underlying causes are interrelated. For example, medications may lead to dizziness or unsteady gait, raising the risk of falling — a risk also heightened in a poorly designed physical environment (e.g., a home with scatter rugs and no grab bars).

To date, we do not yet have a full understanding of the nature and prevalence of risks in the home and optimal ways to improve safety in that setting, but we do have a strong foundation for advancing safety. Over the past several decades, home health care and hospice and palliative care are two of the many fields that have contributed to this foundation, and any strategies to advance the safety of care in the home going forward must recognize and build on that foundation.

The panel identified five guiding principles to advance the safety of care in the home, as well as recommendations and specific strategies and tools to put these principles into action (see box below).

Five Guiding Principles for Advancing Home Care Safety

Principle 1: Self-determination and person-centered care are fundamental to all aspects of care in the home setting.

- o Recommendation 1.1: Improve communication with care recipients and family caregivers.
- o Recommendation 1.2: Provide meaningful, relevant education for care recipients and family caregivers.
- o Recommendation 1.3: Develop tools to improve person-centeredness in systems of care.

Principle 2: Every organization providing care in the home must create and maintain a safety culture.

- o Recommendation 2.1: Create a vision for a safety culture in the home health and personal care fields.
- o Recommendation 2.2: Ensure the emotional and physical safety of family caregivers and home care workers.

Principle 3: A robust learning and improvement system is necessary to achieve and sustain gains in safety.

- o Recommendation 3.1: Build a measurement and reporting infrastructure.
- o Recommendation 3.2: Share data on safety in the home.
- o Recommendation 3.3: Teach safety and improvement skills across the home health and personal care fields and evaluate competency in these skills.
- o Recommendation 3.4: Create an intensive improvement collaborative for early adopter organizations.
- o Recommendation 3.5: Create a learning system for identifying and sharing best practices related to care in the home.

Principle 4: Effective team-based care and care coordination are critical to safety in the home setting.

- o   Recommendation 4.1: Create a common, longitudinal care plan based on the goals of the care recipient or a care recipient/family caregiver dyad.
- o   Recommendation 4.2: Develop and test new models of team-based care.
- o   Recommendation 4.3: Ensure the visibility and use of community-based and underutilized resources.
- o   Recommendation 4.4: Utilize technology to support team-based, coordinated care.

Principle 5: Policies and funding models must incentivize the provision of high-quality, coordinated care in the home and avoid perpetuating care fragmentation related to payment.

- o   Recommendation 5.1: Align payment models with the goals of whole-person, community-based, coordinated care.
- o   Recommendation 5.2: Reduce the regulatory burden.

Increasing the reliability of the care system would be an important contribution to advancing the safety of care in the home. As outlined in the IHI White Paper, *A Framework for Safe, Reliable, and Effective Care*, increasing the reliability of the care system in ways that will move the needle on safety in the home requires work in two foundational domains: the culture and the learning system.[2]

Imagine what care at home would look like if best practices were widely adopted. Family caregivers would be confident in the care they provide and would have access to support; those who provide care, both family caregivers and home care workers, would be safe, healthy, capable, and resilient; the home care workforce would care for the whole person rather than providing only the specific services for which they are reimbursed; harm would be minimized; care would be coordinated; and care recipients would receive safe, high-quality, coordinated care in the comfort of their own home.

IHI recommends that every individual and organizational leader across the health care system who is associated with care in the home — including clinicians, delivery organizations, policymakers, and payers — come to a better understanding of both the potential harms in this setting and effective mitigation strategies and take the necessary actions to improve the safety of care recipients, family caregivers, and home care workers. This report describes these harms and mitigation strategies. We hope that home care workers and leaders will read it carefully and share it widely. This report will also be of interest to care recipients and family caregivers, because it can provide them with an understanding of the safety issues that may arise in the home and help them in decision making and advocating to reduce the risk of harm.

Safety in the home deserves the same level of attention to harm prevention, creation of a safety culture, use of standard practices, and dedication of resources as we have given to other care settings. This report is intended to convey a pressing call to action.

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The Current State of Safety in the Home and a Future Vision: A Case Study

The Current State

Maria Lopez is an 89-year-old widow who lives alone and has mild cognitive impairment. Her daughter lives two blocks away and tries to visit on weekends. However, she travels frequently for work and is not always able to visit. Mrs. Lopez has a modest income, but her income is not low enough for her to be eligible for Medicaid. She qualifies only for limited home services.

Mrs. Lopez's advanced arthritis and heart failure make mobility difficult, and she also has diabetes, which now requires daily insulin. She takes 12 medications each day, which the home health agency puts out in a weekly reminder box. Owing to her poor vision, Mrs. Lopez receives prefilled syringes from her local community pharmacy.

She receives home-delivered meals five days a week from her local council on aging, but she rarely eats them because the food is unfamiliar to her (the dog enjoys them, however). Her family is unaware that she is not eating well.

Mrs. Lopez misses her friends, most of whom have died or moved back to Puerto Rico. She spends a lot of time alone, and she feels lonely.

Her primary care physician at the local community health center (CHC) is new to Mrs. Lopez; her previous physician recently retired. At a routine visit, her blood pressure medication is increased and she is given a referral to a neurologist to assess the worsening cognitive impairment. The neurologist, noting her affect, adds an antidepressant medication and sends a note about the change to her primary care physician, who does not receive it for several weeks.

One day Mrs. Lopez experiences dizziness getting up out of her chair, falls, and hits her head. Her daughter arrives shortly afterward and, finding her mother on the floor, calls 911. In the ambulance, Mrs. Lopez's blood sugar is found to be 45. The emergency department (ED) physician suggests that the family obtain more help at home or consider a nursing home. Mrs. Lopez begs her daughter to take her home. The home care program adds two more hours per week of in-home care.

A month later, Mrs. Lopez falls again, this time sustaining a hip fracture. After hospitalization, she is transferred to a skilled nursing and rehabilitation facility for three weeks. Every day she asks her family to take her home.

A Future Vision

Maria Lopez's income is not low enough to make her eligible for Medicaid, but she is eligible for a payment program for people approaching Medicaid eligibility (similar to the Washington State waiver, the Massachusetts state home care program, and programs found in other states). Her community has volunteer time banks through which volunteers provide companionship for homebound individuals, addressing their loneliness, and assist them with instrumental activities of daily living.

Culturally sensitive meals are delivered to Mrs. Lopez five days a week (as with some Meals on Wheels programs today). Technology is used in several ways: to ensure proper medication administration through talking medication reminders and to convey her pharmacist's instructions for the family, as well as through telemedicine, which enables her physician to watch Mrs. Lopez self-administer insulin, and a unified pharmacy record that includes all of her medications, regardless of where her prescriptions were filled.

Mrs. Lopez was taking a total of 12 medications daily, but she now takes seven, after her primary care provider at the CHC asked the pharmacist to review and stop any unnecessary medications.

She misses her friends, most of whom have died or moved back to Puerto Rico, but does not often feel lonely because she is visited regularly by volunteers coordinated by age-friendly, livable community programs. These programs receive some municipal and local aid as well as state and federal funding.

One day Mrs. Lopez experiences dizziness getting up out of her chair. She falls and hits her head, and her daughter arrives shortly afterward. Finding her mother on the floor, the daughter calls 911. In the ambulance, Mrs. Lopez's blood sugar is found to be 45. The ED visit triggers a comprehensive evaluation and risk assessment by the local community-based service organization. The assessor recommends an integrated home care program, such as Medicaid/Medicare's Program of All-inclusive Care for the Elderly (PACE) program.

Her electronic health record is cloud-based, secure, and accessible to the entire care team, including Mrs. Lopez herself, who can access the information in Spanish. The system can flag potential drug interactions and polypharmacy (continued prescription of one or more drugs that are not, or no longer, needed) and allows her care team to see the changes in her medication made after the ED visit, including a reduction in her daily insulin dose. Community health workers from the public health department conduct a fall risk assessment and develop a care plan with Mrs. Lopez and her daughter. This information is accessible to the CHC and specialists. Mrs. Lopez does not fall again.

The Imperative to Improve Home Care Safety

Since the release of the Institute of Medicine's seminal report on medical errors in 1999, *To Err Is Human: Building a Safer Health System,* patient safety in hospitals and other clinical settings has received a great deal of attention.[3] Various types of medical errors have been identified and their prevalence estimated. Targeted interventions have been created to prevent these errors, and some, such as catheter-related bloodstream infections, have been reduced.[4–6] The same attention has not yet been focused, however, on the safety of care provided in the home.

Today the home has become an important site of care for many people. Care in the home comprises different services provided by a variety of individuals with a range of training and expertise:

- Personal care services include assistance with bathing, eating, and shopping, and some nonskilled basic health care, as well as help with other tasks. These services are provided by personal care attendants (PCAs) or home care aides, who can be hired privately or through an agency. Training requirements for PCAs are limited and licensure is not required.
- Home health care, which includes skilled nursing and medical or clinical services in the home, such as skilled wound care, is provided by certified home health aides, visiting nurses (registered nurses and licensed practical nurses), licensed social workers, physical therapists, occupational therapists, and other professionals.
- Multidisciplinary teams deliver hospice care, or end-of-life care, which includes social worker services, spiritual care, bereavement counseling, and volunteer services.
- Multidisciplinary teams also provide palliative care services to alleviate suffering for people at any stage of disease.
- Mental or behavioral health services may be provided by a licensed social worker, behavioral health specialist, mental health clinical nurse specialist, therapist, or psychologist.

- Primary care services are sometimes provided in the home through specific programs. Complex hospital-level medical or surgical services are sometimes provided in the home by a skilled care team (e.g., through the perioperative surgical home model).
- Coordinated hospital-level services are sometimes provided in the home through formalized programs, such as Hospital at Home. (See Appendix A for more information on this exemplar program.)
- Emergency medical services (EMS), which are critical to transitions to more acute care services, sometimes also provide coordinated care in the home through specific collaborative programs. (See Appendix A for more information on exemplar EMS programs.)

In addition, although not often present in the home, physicians and pharmacists play critical roles in the safety of care provided in the home. By directing and ordering care and serving as a resource for medication management, respectively, physicians and pharmacists have a substantial impact on home care safety.

Essential to all aspects of care in the home are family caregivers. These family members, friends, neighbors, or volunteers coordinate services, provide the bulk of personal care services, and support many aspects of home health, hospice, and palliative care services. They are an integral part of the care team and the care recipient/family caregiver dyad.

The home health and personal care fields emerged in the early 1980s when Medicaid began paying for services through waivers at the state level. The average hospital length of stay subsequently declined from 6.5 days in the mid-1980s to 4.5 days in 2012.[7–8] With the trend toward shortened hospital stays, accompanied by a relative reduction in nursing home beds, states expanded Medicaid home- and community-based services waiver programs to provide continuing services for recent hospital patients. These programs cover personal care for eligible individuals, with eligibility requirements varying by state. In addition, Medicaid-managed long-term services and private insurers have begun covering an increasing volume and type of personal care services.

Across the country, workers from home health agencies provide home health care services to more than 3 million Medicare beneficiaries.[9] As mentioned earlier, the US Department of Labor reports that more than 2 million personal care attendants provided care in the home in 2016, and that number is likely to grow by 40 percent by 2026.[10]

More and more people are seeking hospice services, or end-of-life care, and a majority of this care is provided at home.[11] More than 1 million Medicare beneficiaries were enrolled in hospice for at least one day in 2015, collectively receiving more than 96 million days of hospice care that year.[11] In addition, a substantial amount of care is provided by family caregivers. Approximately 43 million people provide unpaid care to an adult or child each year.[12] It is worth noting, however, that changing family and social dynamics have left many care recipients with no family or other social support.

Many of us, including most care recipients and those who care for them, would agree that there's no place like home. Compared with inpatient settings, many benefits accrue from home care, which:

- Preserves autonomy: Care recipients generally prefer to be at home and may have more autonomy at home than in other care settings.[13]
- Is patient-centered: Home care workers can more readily identify and respond to the preferences of the care recipient, especially regarding the balance of autonomy and harm.
- Maintains family and social ties: Remaining in the home may allow care recipients to better maintain connections with family and friends.

- Avoids complications: Care at home may reduce the risk of complications associated with hospital and nursing home environments, such as infections, sleep disruption, and confusion.
- Enables home care workers to assess social determinants of health: Home care workers can better understand and address social determinants of health in the care recipient's home. For example, they can more easily manage poor nutrition because they can readily see the condition and amount of food available.
- Lowers costs for society: Providing care in an appropriate, yet less intense, setting may lower overall costs for federal programs, such as Medicare and Medicaid, which are funded with taxpayer dollars.[14]

Although there are many benefits of care in the home, it is not without its challenges — for both care recipients and everyone who supports and cares for them. Existing data suggest that preventable harm is an important issue in the home setting. Studies in the United States and Canada have found that between 4 percent and 13 percent of home care recipients experience an adverse event, the majority of which are falls, infections, mental health or behavioral problems, or adverse drug events.[15–17]

Both home care workers and family caregivers may experience physical and emotional harm as they provide care. Indeed, the health and safety of both care recipients and caregivers are strongly interconnected. Family caregivers often find caring for a family member at home to be frightening and overwhelming. They may also feel confused about how to navigate home care services and anxious about making a mistake that could harm the person in their care. Other possible physical or emotional harms to family caregivers include exposure to verbal abuse or violence, compassion fatigue, and burnout.

Like family caregivers, home care workers can experience emotional harm — though in different ways — from verbal abuse, physical and professional isolation from colleagues, and anxiety due to difficult interactions with care recipients or family members.[18] And like other health care professionals, home care workers are at risk for burnout, especially given the long shifts, the unpredictable environment of the home setting, and the isolation associated with working alone.[19]

The physical harms to which home care workers and family caregivers are vulnerable include needlesticks and other injuries from sharps (sharp medical devices),[20–24] back pain and injuries,[25–26] violence,[25] and environmental hazards, such as exposure to the respiratory irritant chemicals used for infection control.[27] Additionally, some safety hazards found in home settings are not present in institutional settings, such as the presence of smokers (care recipients and/or family caregivers) on or near oxygen tanks, the reuse of needles for injections, and failure to safely discard used needles. All of these hazards can pose serious threats to caregivers and care recipients alike.[21, 28]

Care recipients and family caregivers need a reliable system of care and easy access to timely resources. Family caregivers need effective training so that they can feel confident that they are supporting the care recipient's health and not causing harm. Care recipients who do not have family caregivers need additional support and education to manage services and care for themselves.

Similarly, home care workers need adequate training, ongoing monitoring, and ready access to supervising professionals to provide guidance when needed. They require highly functional teams with effective communication within which to work. In addition, home care workers need greater awareness of and protection from the hazards within the home that can cause physical or emotional harm.

More attention to safety is needed in an environment where an increasing amount of care is now provided — the home. While a considerable amount of work has been completed in this area,

especially in the home health and hospice and palliative care fields, safe care in the home setting has generally received less attention nationally than safety in hospitals, nursing homes, and ambulatory settings. We have yet to completely elucidate the nature and prevalence of risks in the home and create optimal ways to improve safety in this setting. Given the increasing proportion of care provided in the home, improving safety in this setting deserves urgent attention and immediate action.

Safe Care in the Home: Definition of Terms

The variety of definitions used in the literature and in practice for terms related to care in the home can make those terms unclear. What does the word "home" actually mean? Does it include assisted living facilities and group home settings? What exactly is "home care"? Some groups use that term to refer to personal care services only. Others define "home care" to include both personal care and home health care. In discussing such variations in the terminology, the expert panel identified the establishment of common definitions as an important early step in the journey to optimizing safety in the home.

To ensure clarity in the terminology used to discuss safety in the home setting, the expert panel recommended the following definitions. These definitions are not intended to replace those developed by established groups, such as the World Health Organization or accrediting agencies. Instead, they are offered here in the hope that clearly defined terms will contribute to a productive conversation about safety in the home.

Two definitions, in particular, are fundamental. First, "home" is defined here as the place where a care recipient lives. The expert panel's narrow definition of home excludes care provided in nursing homes, skilled nursing facilities, assisted living residences, and residential care settings, because these settings have more paid staff and infrastructure than a private home. Second, "care in the home" is defined as encompassing both personal care and home health care.

- **Adverse event:** Any injury caused by medical care. Identifying an injury as an *adverse event* does not imply error, negligence, or poor-quality care, but simply indicates that some aspect of diagnosis or therapy, not an underlying disease process, had an undesirable clinical outcome.[29]
- **Adverse drug event:** An *adverse event* involving medication use.[29]
- **Care recipient:** An individual who is receiving care at home (term used in this report instead of "patient").
- **Care recipient/family caregiver dyad:** A term emphasizing the interrelated nature of the safety of the *care recipient* and the *family caregiver*.
- **Care recipient safety:** The *care recipient*'s freedom from accidental or preventable harm occurring in the home (e.g., a medication error in the home) or during the provision of home care (e.g., an injury in a car accident caused by a *personal care attendant* driving while impaired).
- **Care in the home:** Both *personal care services* and *home health care* provided in a home setting.
- **Error:** An act of either commission (doing something wrong) or omission (failing to do the right thing) that leads to an undesirable outcome or poses a significant threat of such an outcome.[29]

- **Family caregiver:** The person who cares for the *care recipient* in the home yet is not a worker employed within the health care or home health care system. This person — who can be a family member, friend, or community-based volunteer — is an integral part of the care team and the *care recipient/family caregiver dyad* and often provides backup care for all types of care provided in the home. In rare circumstances, *family caregivers* may be paid to provide care.
- **Harm:** Impairment of the structure or function of the body and/or any deleterious effect arising from such impairment. *Harm* includes disease, injury, suffering, disability, and death[30] and is now recognized to include both physical and emotional harm.[31]
- **Home:** The place where the *care recipient* lives (excluding group homes, nursing homes, skilled nursing facilities, assisted living residences, and other residential care settings).
- **Home care worker:** An umbrella term for all who provide care in the home (with the exception of *family caregivers*), including *personal care attendants,* certified *home health aides,* visiting nurses (registered nurses and licensed practical nurses), licensed social workers, physical therapists, and occupational therapists.
- **Home health aide:** A certified *home care worker* who provides health-related services, such as medication management, and works under federal training requirements.
- **Home health care:** Skilled nursing and medical or clinical services provided in the home, such as skilled medication management and skilled wound care. Federal regulations identify six components of *home health care:* skilled nursing, *home health aides,* medical social services, occupational therapy, physical therapy, and speech-language pathology.[32]
- **Hospice care:** End-of-life-care provided to terminally ill people and their families. Hospice services include medical and nursing care, social worker services, spiritual care, bereavement counseling, and volunteer services. This report uses the term specifically to refer to care delivered by a hospice program.
- **Hospital at Home®:** A program in which a care team that includes professionals with specific training provide hospital-level care in the home with the goal of avoiding hospitalization or rehospitalization.
- **Palliative care:** Multidisciplinary services to alleviate suffering for people at any stage of disease. This report specifically defines *palliative care* as services delivered through the benefits provided by a health plan or other insurer, an accountable care organization, a state home care program, or another entity.
- **Personal care attendant (PCA):** Sometimes referred to as a "personal care aide," a PCA is a *home care worker* who is hired either through a home care agency or directly by a *care recipient* and whose primary responsibility is providing *personal care services,* such as assistance with the activities of daily living, homemaking, meal preparation, and transport to medical appointments. Training requirements are limited and licensure is not required, although some PCAs have the certification required by nursing homes, such as that required to work as a certified nursing assistant.
- **Personal care services:** Care that includes assistance with the activities of daily living (eating, bathing, dressing, toileting, transferring, and continence) and may also include help with the instrumental activities of daily living (e.g., shopping, homemaking, meal preparation, and transportation) and help with basic health care (e.g., nonskilled medication management). *Personal care services* are sometimes referred to as "long-term services and supports."
- **Pressure injury:** An ischemic injury to the skin and underlying tissues stemming from the sheer force or friction of pressure on the body (also referred to as a "pressure ulcer").[33]
- **Primary care at home:** Home-based primary care services provided by physicians, nurse practitioners, and interdisciplinary care teams and operating under specific regulations.

The Focus of This Report

This report details the feedback from the expert panel that IHI convened in November 2017 to consider the specific challenges to safety in the home setting and offer recommendations for improvement.

To inform the two-day expert panel meeting, IHI enlisted a research organization to complete a landscape analysis of the topic that included a literature review and feedback from semistructured interviews conducted with subject matter experts: care recipients, family caregivers, health care professionals, researchers, payers, and representatives from professional organizations, government, and accreditation agencies. The results of this analysis are described in the IHI report, *Patient Safety in the Home: Assessment of Issues, Challenges, and Opportunities*.[34]

The panel (and by extension this report) focused on the largest drivers of safety concerns, but the conversation it began must expand eventually to include equally significant safety issues that affect fewer people. For example, this report does not consider safety hazards that put people at risk outside the home or clinical care setting, such as falling in the hospital parking lot before gaining access to the facility, or being assaulted on the street outside the neighborhood pharmacy. Although the report mentions some initiatives that provide a specific type of care in the home — such as Hospital at Home — specialized programs are not its focus. (See Appendix A to learn more about Hospital at Home and other exemplar programs.)

As noted earlier, the major focus of this report is safety related to two primary components of care in the home: home health care and personal care. It considers the physical and emotional safety of the care recipient, the family caregiver, and the home care worker, while recognizing the interconnected nature of the safety of all these individuals.

The panel's discussion was shaped by the ultimate goal of optimizing safe, person-centered care for the unique environment of the home and creating a highly reliable system for delivering such care. On the panel's recommendations, the specific goals of this report include:

- Prioritizing key safety issues
- Identifying the effective tools and innovative strategies being used today
- Determining areas of focus and developing strategic recommendations that will have the greatest impact on safety in the home

The Financing and Regulation of Care in the Home

Care in the home as currently provided is deeply shaped by its financing and the regulations by which it is governed. Programs and services that provide care in the home are paid for and regulated through different mechanisms, and one result is that care recipients may experience inconsistent care coordination and gaps in services.

Financing

Home health care and personal care are paid for in a variety of ways by several different sources:

Home health care financing. The current payment options for home health care include Medicare, Medicaid, the US Department of Veterans Affairs (VA), commercial insurance, and self-pay. Many Americans have a misconception that governmental agencies fully cover services

related to care in the home. However, coverage under governmental programs is available only for short-term, medically necessary care; it is not available for long-term, ongoing services.

Medicare is the federal health insurance program for people who are age 65 or older and those younger than 65 with a disability. Medicare covers health services in the home for eligible beneficiaries who require a skilled service and have been certified as homebound by a physician.

Medicaid — a collaborative program between federal and state governments that covers health care for low-income people of any age and children with special needs — pays for certain qualifying home health services, although eligibility and benefits vary by state.

In recent years, the Centers for Medicare & Medicaid Services (CMS) has launched several programs and demonstration projects aimed at containing the costs associated with home health care and improving care quality. Value-based payment programs move away from fee-for-service reimbursement and include incentives for care quality and safety. The move toward managed care in Medicare Advantage plans and dual-eligible plans has increased the incentives for care coordination and the potential for improved safety — through reduction of avoidable hospital readmissions, for example. The impact of managed care on the safety of home care is currently unknown.

In the past, Medicaid-managed care programs, such as [CareSource](#), which was launched in Ohio, have worked with community-based resources to support care in the home. Accountable care organizations covering Medicaid recipients are now tasked with providing or finding this support. If additional resources are provided through this payment model, it may be effective in increasing safety in the home.

One important program launched by CMS is the Program of All-Inclusive Care for the Elderly (PACE), which is available in 38 states. PACE provides primary care and home health services to individuals who are eligible for both Medicare and Medicaid benefits and are clinically eligible for nursing home admission in their state. (See Appendix A for more information about PACE.) Payment for PACE is capitated and allows for more flexibility in selecting services, as the program is not limited to only those services reimbursable under Medicare and Medicaid fee-for-service plans.

The Department of Veterans Affairs provides home health care services for eligible military personnel, such as through the Veterans Affairs Home-Based Primary Care initiative. The program is available to homebound veterans, as well as to those who are isolated or whose caregiver is overburdened by their care. Although it provides some home health services, the program's primary goal is providing ongoing care in the home to veterans with functional impairment who have significant difficulty with travel to the VA's outpatient clinics. The VA also offers the Veterans Independence Program which allows veterans in VA medical centers in 34 states, the District of Columbia, and Puerto Rico to access and self-direct home- and community-based services.

In addition, many accountable care organizations and integrated health systems have home health care programs in place.

Commercial insurance plans generally provide coverage for home health services that is similar to that provided by Medicare, with payment for skilled, short-term, medically necessary care. Separately, long-term care insurance is another option for covering services. Care recipients may have the option to purchase long-term care insurance to supplement their medical coverage and help finance potential long-term care expenses. Depending on the policy, home health care services may also be covered. Long-term care policies reimburse insured individuals for a set amount per day, up to a predetermined limit. However, the premiums are generally expensive and the specific benefits vary by policy.[35]

Finally, some states have programs to pay family caregivers to provide care in the home. Beyond the benefits of such programs, families must provide care or pay for care out-of-pocket. However, these services are costly and self-pay may be financially challenging for many individuals and families.

For example, as the family member of a person needing care at home stated in an interview conducted for the IHI report, *Patient Safety in the Home: Assessment of Issues, Challenges, and Opportunities*: "In 2013, when my mom had a major fall, [suffering a] severely broken arm, she was in our home recovering. We realized immediately, we desperately needed in-home care. We had an organization calmly sit in our kitchen and tell us that would be $500 a day out of our pocket, $500 a day for the care that she needed. We ended up having to put her in a rehab facility, which in the end cost Medicare far more than if we had had the support to keep her in our home."[34]

Personal care financing. Medicare generally does not cover personal care.[36] Medicaid may cover some personal care services, which are referred to as home- and community-based services (HCBS) when provided outside of nursing homes. HCBS are available to eligible individuals, but eligibility and benefits vary by state, and many states maintain HCBS waiting lists. The VA offers foster care or family care and other personal care services to eligible veterans. In some instances, the VA reimburses family members for providing personal care services.

Self-pay for personal care services is common. Care recipients or family members can hire personal care attendants either through agencies or privately. Finally, family caregivers provide a large proportion of personal care services. Each year approximately 43 million adults in the US provide unpaid care to an adult or a child.[12]

Today many middle-class care recipients and families cannot afford home care, including both personal care and home health care services. More financially secure individuals and families may be able to cover out-of-pocket costs, and very low-income people may be eligible for Medicaid coverage. Socioeconomic status and ability to pay affect the care recipient's choices and must be recognized as important factors in access to appropriate, cost-effective care. In essence, the lack of access to affordable care is in itself a safety issue. In addition, current payment models that cover only specific services (e.g., fee-for-service payment) incentivize an approach that is narrow and siloed rather than focused on the needs of the whole person — or the total cost of care.

In essence, the lack of access to affordable care is in itself a safety issue.

Regulation

Regulation of care in the home varies based on the services provided. In the United States, no single entity oversees all care in the home. In home health care, however, there are regulations governing licensure, workplace conditions, and participation in federal and state payment programs. In contrast, the field of personal care services is largely unregulated.

State licensure. Each state sets minimum standards for the licensure of home health agencies. The standards, which vary by state, may include, for example, a required orientation class, evidence of current commercial general liability insurance, and a description of the agency's organizational structure.[37] Some states require licensure, others require a certificate of need, and the remainder require both.[38]

Workplace regulations. Home care agencies that employ home care workers must comply with federal standards and regulations that are enforced by the Occupational Safety and Health Administration (OSHA). Some of the relevant OSHA regulations include:

- A blood-borne pathogens standard, which requires that employees be trained about hazards and record-keeping of needlesticks, sharps injuries, and blood exposure[39]
- A hazard communication standard, which requires businesses to inform employees about known workplace hazards (chemicals, toxins, and blood-borne pathogens, for example) and train employees in the safe handling of these hazards[40]
- OSHA Form 300 Log Book, which requires home care agencies to maintain records on needlestick and sharps injuries[41]

In addition to these federal regulations, state regulations are in place that govern employee training. These regulations vary widely by state.

It is important to note that privately hired, independent personal care attendants who are not affiliated with a home care agency are not required to comply with these standards and regulations.

Participation regulations. In the US, federal regulations govern the participation of home health and hospice agencies as well as primary care providers in Medicare and Medicaid programs and in demonstration projects, such as Hospital at Home. These standards are overseen by the CMS central office, CMS regional offices, and state survey agencies. In January 2018, new rules went into effect dictating the conditions of participation and designed to improve the quality and safety of home health care.[32]

Accreditation. Besides federal and state governments, home health care is also governed by accrediting bodies. For 2018, The Joint Commission issued five National Patient Safety Goals for Home Care:[42]

- Correct patient identification
- Safe use of medications
- Infection prevention
- Falls prevention
- Identification of patient safety risks

The Home Health Certification Program, through which The Joint Commission certifies home health agencies, hospice providers, personal care agencies, and others, is based on these goals.

The Accreditation Commission for Health Care (ACHC) has also established standards for home health and hospice services provided in the home. These include:

- HH5-2C: A comprehensive assessment of the care recipient's environment and identification of safety and health hazards, including the adequacy of the living arrangements, the safety of the home, and emergency preparedness
- HH6-1A: The Quality Assessment and Performance Improvement (QAPI) program focuses on indicators related to the use of emergent care services, hospital admissions and readmissions, and the prevention and reduction of medical errors
- HH6-5A: Performance activities that identify issues that directly or potentially threaten the health and safety of care recipients
- HH7-1A: Education for both the care recipient and the caregiver on infection prevention and control issues
- HH7-2B.01: The established policies and procedures addressing safety in the home for care recipients, including measures to monitor the care recipient's medication compliance, the safety of the care recipient's medical equipment, and basic home safety measures[43]

Challenges Unique to Safe Care in the Home Setting

Providing safe care in the home setting is challenging for several reasons that differ from the safety issues in hospitals, nursing homes, or ambulatory settings. Care in the home is very complex because it brings up issues of physical space, socioeconomic differences, isolation, and the balance of respect for autonomy and prevention of harm.

Care in the home is provided outside the controlled environment of the health care system. One of the most important differences between care provided within the health care system and care provided at home is the environment in which care is delivered. While health care system settings are strictly regulated for safety, including environmental factors such as sanitation, equipment, and infection control, the home is not. The physical layout of the home may present constraints that are not present in the hospital setting, such as several sets of stairs. And unlike hospital staff, some individuals who provide care in the home may have limited training.

The home environment also highlights the multidimensionality of safety. Safety encompasses more than mitigating the risk of physical harm. It also requires attention to potential emotional, social, and financial risks. Feedback from people receiving care in the home and family members illustrates the importance of a holistic approach.[34] In the home setting, the consequences of harm across the range of parameters — physical, emotional, social, functional, and financial — are very apparent, and maintaining a whole-person perspective is especially important. In addition, experienced safety and quality professionals, practices, and measures may not be available in the home setting for accelerating focus and improvement in safety, as they are in most hospitals.

For anyone receiving care in the home, safety should be a priority, not an add-on or afterthought. Safety needs to be taken into account not only at every individual care encounter, but also in the design of the technology to be used in the home, in the creation of communication tools, in the training of care recipients, family caregivers, and care workers, and in monitoring and other aspects of care.

Important safety-related questions to consider include:

- In which circumstances is the home the best setting for providing the safest and the most effective and efficient care?

- What is the optimal way to balance delivering more care at home, to avoid more intensive treatment settings, while preserving the sanctuary of the home and the autonomy of the care recipient?

- Are family caregivers available and capable of providing the level of care needed?

Communication and care coordination can be more difficult in the home setting. Although ineffective communication and poor care coordination are common safety issues across the health care system, the physical separation of the home setting makes effective communication and optimal care coordination an even greater challenge. Care provided in the home comes from many sources and may take place in geographically diverse locations. Also, care in the home involves a large number of handoffs — among the different professionals providing care (located within and outside the home) and between the care team and the care recipient/family caregiver dyad. Each handoff represents an opportunity for effective communication and care coordination — or for lapses that introduce the risk of harm. Best practices for communication in the hospital, such as SBAR (Situation, Background, Assessment, Recommendation) and standardized handoffs, are often not applied in the home, not even in adapted form.

Many home health agencies are highly adept at sharing information across the care team and connecting care recipients and family caregivers with community resources. However, in other

cases, information vital to optimal care in the home setting is not well disseminated. In addition, care recipients and family caregivers often do not receive upfront training about the tasks that they will be undertaking and timely information about resources to address subsequent questions and concerns.

Different care workers in the home have varying areas of expertise and different priorities. Some may focus only on their own tasks, in part because of the incentives in many payment models, which reimburse for specific services for specific diagnoses, rather than for whole-person care. As one family member noted, "A nurse can come in from one agency. A physiotherapist might be in from another agency. A personal support worker could be there all the time from a different agency. And none of them talk to one another."[34]

Gaps in care coordination are especially evident at care transitions. Poor communication and inadequate transfer of information, lack of education for care recipients and family caregivers, and lack of understanding of the home environment and the implications for care increase the risk of harm when the care recipient's site of care or source of care changes. In addition, needed supplies, such as dressings and colostomy bags, may not be readily available when care recipients transition to their homes. Too often, care recipients or family caregivers must fill the vacuum in care coordination and find themselves reporting test results and clinical recommendations to various members of the care team.

In addition, clinicians, such as emergency department staff and primary care physicians, are often unaware of community-based resources and networks that could be leveraged to assist with care in the home setting. Even clinicians who are aware of community support organizations may not consider whether the care recipient needs assistance in interfacing with these resources. For example, as one expert panel member noted, a frail older person living alone may need "more than an 800 number on a slip of paper" to coordinate transportation.

Finally, existing resources that could be leveraged to improve care coordination and efficiency are underutilized. For example, the emergency medical services (EMS) personnel who respond to calls for assistance in people's homes are critical to transitions to more acute care services. In some areas of the country, innovative programs have been implemented that enlist EMS personnel to provide and coordinate care. One study found that an integrated program utilizing EMS personnel to provide care for people who frequently use the ED for conditions that could be treated in the primary care setting reduced ED usage and increased quality of life.[44] (For more information on exemplar EMS programs, see Appendix A.)

Safe care in the home requires balancing autonomy and risk. The home should be a place controlled by the care recipient and not, as in other care settings, by the provider of care. In the home setting, the care recipient is more likely to be autonomous and better able to make choices. Self-determination includes people's right to make their own decisions and put themselves at risk if other factors are more important. Care workers' desire to mitigate potential risks and care recipients' desire for autonomy may come into conflict. For instance, a throw rug may be an object of personal importance, not simply a tripping hazard. Reducing the risk of falls must be balanced with respect for the agency and rights of the person receiving care.

Home care workers must clearly explain the risks and benefits of activities intended to prevent harm, giving care recipients who are capable of making their own decisions the opportunity to make informed choices. Understanding the values and preferences of the care recipient is essential to preventing unintentional harm related to the presence of a care worker in the home. Failure to respect self-determination may stem in part from the historical paternalism of our health system, but also from the concerns of those who provide care in the home about protecting themselves legally if harms occur.

In addition, it may be challenging to balance the safety concerns of family caregivers with those of the care recipient. For example, family members may want complete control over their loved one's actions and care, but the care recipient may desire greater autonomy. The importance of balancing autonomy and harm and what matters most to the individual receiving care must be discussed with family caregivers as well.

The care recipient and the people providing care are often closely linked. A home with safety hazards endangers both the person receiving care and the people providing it. Hazards such as sharps, clutter, unsanitary conditions, and verbal or physical abuse by family members or care recipients can affect the safety of everyone in the home.

In addition, family caregivers without adequate support or training may develop health problems themselves, such as back pain from lifting the care recipient. It is important to view the care recipient and family caregiver as a single unit of care because the two function as a dyad. As one family member described it, "Family caregivers and the person they're caring for are intertwined like a double helix. We're completely intertwined, so what happens to me happens to [spouse], and what happens to [spouse] happens to me."[34] Mitigating risk must take into account both the care recipient and the person providing care.

The health literacy of those in the home is often limited. Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[45] Research has demonstrated that most adults have difficulty understanding information about health care.[46–48] Depending on how health-literate they are, many care recipients and family caregivers may be confused about how to use medications safely or adhere to a care plan.[46-47] Failure to acknowledge and adapt messages for audiences with low health literacy skills can reduce the effectiveness of communication and training.

Available data measuring safety in the home are highly variable. One of the most glaring deficiencies related to care in the home is the failure to use a common system for measuring safety in this setting. True advancement in safety in the home setting will require standard measures that can be used by all who provide care and that remain relevant across a variety of home settings. The use of standard measures would allow for systematic data collection, which is critical to understanding the magnitude of safety issues in the home. At present, there are no national or state requirements for reporting safety issues in the home, and only pockets of data are available for care provided in the home. Home health agencies have developed common measures of safety, and data related to home care workers are captured in the Outcome and Assessment Information Set (OASIS). Home health agencies must report on OASIS data as a condition of participation in Medicare.

However, these data may not be easily accessible to others working in the health care system, such as emergency department staff evaluating a person who has received care at home. In addition, many care recipients do not have home care workers collecting their data, and data on care provided by family caregivers is often not captured systematically. Thus, much of what occurs in the home is not visible across the health care system. Collection of such data remains a key challenge to improvement.

There is a need for research in many aspects of safety in the home, including:[34]

• Standardizing operational definitions and taxonomy

• Developing and testing home-based safety measures

• Understanding family caregivers' and home care workers' characteristics, abilities, and needs

- Assessing technology for effectiveness and safety, including consistency with human factors principles

- Developing and testing standard, comprehensive, person-centered processes that assess the care, the family caregiver, and the environment

- Identifying and testing models of care delivery and financing

- Assessing the safety, health, and well-being of home care workers and implementing preventive interventions to benefit both the home care worker and the care recipient

The home setting is often socially and physically isolated. The home may be a more isolated environment than other care settings. Home care workers often work alone, with little access to peers and direct supervisors for immediate support. Similarly, care recipients and family caregivers may struggle with isolation and find that their ability to engage in social activities is restricted. Feeling that others do not fully understand their situation, they may withdraw socially. Family caregivers who are unable to leave their care recipient may become isolated if they cannot find respite care. In addition, some care recipients and family caregivers may experience more physical distance from those providing care within the health care system.

Home settings encompass a variety of needs and populations. Although a majority of care recipients in the home are older adults (who will make up an increasing proportion of home care recipients with the aging of the US population), it is important to recognize the variety of people receiving care in their homes. Care recipients include adults, adolescents, and children as well as people with short-term and long-term care needs, including:

- Frail older adults

- Older adults with multiple comorbid conditions

- Adults and children with cognitive impairment or dementia

- Adults and children with chronic illness, or physical, mental, behavioral, or intellectual disabilities

- Adults and children receiving palliative or end-of-life care

- Adults and children who are otherwise healthy and receiving acute postsurgical services, such as rehabilitation after joint replacement surgery

- Adults and children living in rural communities and those living in inner cities

- Low-income adults or families

These populations have very different needs. For example, older adults may have diminished cognitive function and be increasingly dependent on their family caregiver. People with disabilities who are young and cognitively healthy may need to assert their independence. The vast variety of needs among the various populations receiving care in the home makes appropriate standardization of practices and safety a challenge. In addition, culture and language differences between the care recipient and home care workers can introduce bias, racism, and language barriers into the provision of care.

Because of the specific challenges to providing safe care in the home, safety interventions used in other settings cannot simply be applied to the home. Understanding the type and scope of the risks specific to care in the home is essential to identifying effective strategies for mitigating those risks and optimizing the well-being of people who receive care in their homes.

Key Types of Harm in the Home Setting

Although there are many types of potential harms in the home setting, the expert panel focused on those that affect the greatest number of people. The November 2017 panel discussion emphasized the interrelated nature of these harms and their underlying causes. For example, medications may raise the risk of falling by inducing dizziness or unsteady gait. That risk is increased in a home that has not been adapted for safety in care — for example, scatter rugs have not been removed, or grab bars have not been installed. Acknowledging the impact and interplay of these harms can help inform effective prevention strategies.

Types of Harm in the Home

- Adverse events related to medication and other forms of treatment

- Injuries due to physical hazards in the home

- Injuries related to equipment and technology

- Pressure injuries

- Infections

- Conditions related to poor nutrition

- Adverse effects on family caregivers

- Adverse effects on home care workers

- Potential abuse and neglect of care recipients

Adverse events related to medication and other forms of treatment. Medication errors and other problems with medication use represent a significant source of harm for people receiving care in the home. It is estimated that about 40 percent of recipients of home health care experience a medication error or other drug therapy problem.[49] In addition, the risks associated with medication use in the home affect care recipients across all subgroups. Inappropriate polypharmacy and the use of inappropriate medications have been identified as two of the primary underlying causes of medication-related harm in the home.[50–51] Other issues include improper dosing; confusion about medication orders and names; poor medication adherence due to economic, access, or social factors; unsafe storage; and improper disposal.[34] Drug misuse and abuse, accidental ingestion by children, drug diversion, and poorly labeled packaging are other potential problems. (See Appendix B for the expert panel's suggested tactics for advancing medication safety.)

Adverse events related to other forms of treatment are also important types of harms that occur in the home setting. Dialysis, wound care, central line changing and maintenance, and other treatments in the home introduce the risk of infection, poor healing, and other injuries.

Injuries due to physical hazards in the home. Both the person receiving care and those providing it are at risk for injury due to physical hazards present in the home, such as clutter, tripping hazards, expired food items, faulty equipment, and potential needlesticks and sharps injuries. Falls — a growing safety risk in the home, especially for older people — are now the leading cause of accidental injury and death among older adults.[52–53] Approximately 30 percent

of adults age 65 and older fall each year, resulting in about 29 million falls.[53] About one in four of these falls require medical treatment or restricted activity for at least one day. Direct costs related to fatal and nonfatal falls in 2015 were $637.5 million and $31.3 billion, respectively.[54] In addition, older adults who experience a fall may restrict their activity because they are fearful of falling again, but restricted activity can contribute to subsequent physical deconditioning.[55]

There are many reasons why people fall, including issues with gait and balance, clutter in the home, medication side effects, poor nutrition, dehydration or other acute illness, cognitive impairment, poor vision, and the effects of existing health conditions. Falls can also be caused by physical limitations due to poor conditioning or progression of disease, particularly at the end of life. In addition, substance use — for example, alcohol or misused prescription drugs, such as opioids or benzodiazepines — can be a factor.

Fall prevention begins with recognition of risk, yet research has shown that fall risk assessments are not routinely conducted.[56] Fall prevention can be challenging in that the risk may not be fully appreciated until after a fall has occurred. In addition, to assert their independence, care recipients may avoid the use of assistive devices and resist or refuse other adaptations to the home environment (such as reducing clutter).

The detrimental effects of clutter extend beyond raising the risk of falls. As one clinician recounted in an interview, "I had a patient who had sores due to extreme swelling in her feet. When I finally entered the home to provide her care I found out that her house was so dirty and cluttered she did not even have a place to lay down to put her feet up... There was two to four feet of garbage everywhere in her apartment."[34]

Although outside the scope of this report, other physical hazards may arise from neighborhood crime, which can impact both the care recipient/family caregiver dyad and the home care worker. For instance, the presence in the home of medications that are commonly "diverted," such as prescription opioids, may increase the risk of theft and associated violence.

Injuries related to equipment and technology. Technology, such as wearable sensing devices, telemedicine, Internet-based education programs, and automatic medication dispensing systems, can extend the time that patients are able to reside safely at home and help them maintain a sense of security in the home. However, health care–related equipment present in the home can also heighten the risk of harm for the care recipient, family caregivers, and home care workers if it is used improperly, if it adds to clutter or becomes a tripping hazard, and if it introduces alarm fatigue.

Safety challenges related to technology include insufficient training of the care recipient and family caregivers in technology use, lack of confidence in ability to use the technology, off-label uses of technology, sometimes high out-of-pocket costs, lack of technical support, lack of user-centered design, poor assessment of home readiness, and lack of data about errors and equipment malfunctions.

As one researcher commented, "Any device that's being deployed in a hospital these days, you'll see them at home as well: infusion pumps, ventilators, and different kinds of assistance devices... but you don't have someone who can necessarily fix them if they break, or figure out if there's a problem. There's a potential of a safety issue if a device malfunctions. It may not be recognized."[34]

The proper use of equipment requires training, servicing, and upkeep, which can overburden the care recipient or family caregivers. Inappropriate, broken, or poorly fitting equipment, such as mobility aids, can also introduce risk. In addition, an insufficient stock of supplies in the home due to inadequate communication, planning, or inventory management, or other supply issues, can introduce barriers to safe care.

The use in the home of complex devices such as ventilators, infusion devices, and dialysis machines introduces risks that generally do not arise in more closely monitored settings. For example, care recipients or family caregivers must be trained to understand and appropriately respond to alarms, to maintain a hygienic or sterile environment, and to identify and replace malfunctioning equipment. Some care recipients and family caregivers may become very comfortable, even expert, in the use and maintenance of devices used in the home, but others may find these tasks overwhelming.

The trend toward providing care in the home via telemedicine, remote monitoring, home hospital programs, or home dialysis raises safety issues in the home to a new level. Continued research is needed to determine the best type of care that is warranted.

Pressure injuries. Pressure injuries, or pressure ulcers, are ischemic injuries to the skin and underlying tissues caused by the pressure of sheer force or friction on the body.[33] Because a primary risk factor for pressure injuries is prolonged pressure,[33] they are a serious concern for care recipients with restricted mobility. The reported incidence ranges from 0 to 17 percent of home health agency clients, compared with 0.4 to 38 percent of patients in hospitals, according to the National Pressure Ulcer Advisory Panel.[57] Research suggests that prevention strategies in the inpatient setting need to be adapted for use in the home, such as repositioning and adequate nutrition.[58] Economic and social resources should also be taken into account — for example, the care recipient's financial resources and the availability of support inside the home.[59]

Infections. The lack of a controlled environment in the home introduces challenges related to infection prevention. As a member of a health-related association stated in an interview, "Being trained in the hospital is being trained in a safe environment. Oftentimes, the questions that patients have about a certain procedure don't become apparent until they're in the home. 'Is the dog allowed to jump on the bed when I do this wound care?' It's the uncontrolled environment that makes training in the home really important."[34]

> *"Oftentimes, the questions that patients have about a certain procedure don't become apparent until they're in the home. 'Is the dog allowed to jump on the bed when I do this wound care?'"*

Care recipients and family caregivers are often called upon to prevent or treat infections, but they may be inadequately trained for these tasks or may not know when to seek help. They may be unaware of the importance of handwashing and personal hygiene to infection prevention and may not know how to recognize infections early in their course. Care recipients and family caregivers also may not know how to avoid harms related to infection control prevention — such as avoiding the use of products that contain bleach and other strong chemicals that are respiratory irritants and can trigger chronic obstructive pulmonary disease and asthma events in both care recipients and caregivers.

Conditions related to poor nutrition. Compromised nutrition is both a health and a safety issue. In the inpatient setting, the acute nutritional needs of patients can be addressed by ordering a customized dietary plan. In the home setting, by contrast, lack of access to safe, adequate food may increase the risk of harm. Barriers to adequate nutritional resources include limited financial resources, difficulty with food preparation, lack of transportation to purchase food, or a residence located in a "food desert" (i.e., a community with little access to fresh meats, dairy, and produce).

While poor nutrition is not an exclusive function of a home setting, a poor nutritional state or lack of fluid intake can lead to dehydration, electrolyte imbalance, poor healing for pressure ulcers, and the potential for falls and other injuries.

Other potential nutrition-related concerns in the home setting may stem from safety issues related to tube feedings, the use of infusion devices, and the care of gastrostomies and jejunostomies. Safety issues can also arise when the food supply in the home is unsafe because of expired use-by dates, spoilage, or poor storage practices. A key issue in nutrition safety is inadequate communication about nutrition and the status of the food supply in the home at handoffs and transitions from other care settings to the home.

The presence of care workers in the home opens a window onto the type and amount of food available for the care recipient and provides an opportunity to focus on improved nutrition as an important driver of health.

Adverse effects on family caregivers. Care provided in the home has become increasingly complex, and family caregivers are often asked to take on complicated aspects of care, such as:

- Supporting activities of daily living, which may include heavy physical work such as lifting or transferring the care recipient

- Medication management

- Wound care

- Scheduling and coordinating services

- Training other family members to provide care

- Addressing mental, behavioral, or cognitive conditions, including physical and emotional manifestations of distress

Perhaps most notably, half of all family caregivers perform skilled care and three-fourths manage medications, including those administered via intravenous lines, injections, and infusions.[60] This level of care may prove to be physically and mentally overwhelming for some family caregivers.

A noteworthy sign of progress is legislation that has now been either introduced or already passed in several states called the Caregiver Advise Record and Enable (CARE) Act, which requires that hospitals provide support to the family caregiver by recording his or her name in the medical record, telling the caregiver when the care recipient will be discharged, and providing instruction on any medical tasks the caregiver will need to perform at home.[61] The legislation seeks to address a gap in communication and education that has too often left family caregivers without the information they need to provide care safely and confidently at home.

Family caregivers are at risk for caregiver burnout and compassion fatigue due to the stress of caring for a loved one. Caregiver burnout manifests in physical symptoms such as weight loss or gain and sleep disturbances.[62] Compassion fatigue is suspected when a caregiver comes to feel hopeless, indifferent, pessimistic, and generally uninterested in other people's issues.[63] Limitations of time, energy, and financial means may prevent family caregivers from attending to their own health, and such neglect can cause them to develop significant health conditions themselves. The mortality rate of family caregivers who experience mental or emotional strain from caregiving is 63 percent higher than it is for a matched control group.[64] A family member explained in an interview, "I am now a senior myself, but I shoulder the entire household responsibility, from cooking, cleaning, and shopping to mowing the lawn and shoveling the snow. I am overworked and worn out."[8]

Family caregivers may feel overwhelmed or saddened by the circumstances that have made care a necessity, and burnout or inadequate support may make them "second victims" of adverse events that occur during their time as caregivers. One clinician described such a situation: "This man — a tough guy — was crying his eyes out. He was saying, 'I can't imagine that I'm the one who hurt my

own mother. How can this happen? How can they make me do this to her?'"[34] This emotional burden is also particularly difficult for parents caring for their children with chronic conditions.

Family caregivers may feel isolated and overwhelmed, especially if inadequately trained and psychologically unprepared for their caregiving tasks. An index has been developed to assess family caregivers' experience of burden from caring for a care recipient based on the number of hours of care provided and the number of activities of daily living and instrumental activities of daily living performed.[12] Research has shown that about 40 percent of family caregivers experience a high level of burden and that the same percentage report a high level of stress.[12]

Specific programs to assess the needs of family caregivers in the home are being piloted in a number of states. A family caregiver support program in Washington State has been shown to reduce depression, relieve the stress burden, and decrease the possibility that the caregiver will place the care recipient in a nursing home.[65]

Adverse effects on home care workers. Home care workers are also at risk for emotional and physical harm, although these often differ from those affecting family caregivers. Factors that may lead to safety issues for this workforce include low pay, lack of benefits, limited training, and language or cultural differences. In addition, home care workers may be harmed by physical hazards in the home or by verbal and physical abuse by patients and family. A key challenge in advancing safety in the home is balancing the well-being and preferences of the care recipient with the safety of the home care worker. For example, the risk of harm to the home care worker may sometimes be unacceptably high — such as when a care recipient smokes while on oxygen.

Health care workers in general have a relatively high injury rate, and that risk extends to home care workers. For example, home health aides employed by agencies have a reported incidence rate of 15.3 nonfatal illnesses and injuries per 100 workers, compared with 3.9 per 100 workers employed in the health care private sector, such as physician's offices.[1, 66] As one home health aide stated, "I have a client that is on oxygen and she smokes while she has it on... she doesn't want to stop. She has had social workers, nurses, everybody you can think of going in there to tell her to stop. I actually see sparks on her nose."[67]

Like family caregivers, home care workers may feel isolated and overwhelmed in their work. In addition, home care workers are sometimes not given adequate tools or supervision to complete their work effectively and efficiently. For example, some home care agencies continue to use paper-based recording systems, which make it difficult to communicate across the care team and to collect and assess data related to care in the home.

Potential neglect and abuse of care recipients. Care in the home may sometimes lead to — or make evident — the neglect, abuse, or financial exploitation of care recipients, including those who are especially susceptible, such as older adults, people with physical or intellectual disabilities, and children. It is estimated that, overall, one in ten elderly people are victims of abuse.[68]

The Existing Foundation for Care in the Home

Advancing safety in the home is an issue with a strong foundation. Home health care and hospice and palliative care are two of the many fields that have built this foundation over the past several decades.

Considerable work has been done to develop a reporting structure, a safety culture, and safe practices in home health care. In particular, this field has amassed a substantial body of research and data on safety through OASIS, a database that was launched in 1999 and is used for research and policy-setting.[69] Upon hospital admission, discharge, transfer, and change in condition, all Medicare patients receiving home health care are assessed by professional registered nurses using this standardized tool. When physical, occupational, or speech therapists are involved, they coordinate with the registered nurse to complete the OASIS assessment. This tool forms a universal body of information about patients that tracks changes and progress over time, and the resulting database is a public resource that can be used for research and public reporting.

Components of the OASIS tool that are considered key to the quality and safety of care in the home are combined with responses to the Home Health Care Consumer Assessment of Healthcare Provider and Systems survey and then shared transparently with the public through the Medicare Home Health Compare website. Other examples of the focus on home health care safety are reflected in the national Home Health Quality Improvement campaign. Sponsored by CMS, this campaign by the nonprofit organization Quality Insights is a collaborative effort to develop resources and education for home-based care professionals.

In addition, numerous private groups and coalitions work across the country on safety in the home setting. One example is the Stop Sepsis at Home project. The Home Care Association of New York led a statewide, multistakeholder effort funded by the New York Health Foundation to develop a novel in-home screening tool for sepsis, complete with a full program of educational opportunities to support implementation. This effort demonstrates the impact of home health care leadership on safety.

Separately, the hospice and palliative care fields offer a holistic model of coordinated, interdisciplinary care in the home in a person- and family-centered manner. Hospice provides end-of-life care and support services to people with a terminal illness and their families. Hospice programs effectively coordinate skilled nursing, social worker services, spiritual care, bereavement counseling, and volunteer services and demonstrate best practices for delivering whole-person and family-focused care. Palliative care comprises multidisciplinary services to alleviate suffering for people at any stage of disease. Included in the Affordable Care Act was a provision for the establishment of the Hospice Quality Reporting Program for hospice providers. Data on hospice quality and safety are routinely collected and shared via the Medicare website Hospice Compare.

Previous work in the home health and hospice and palliative care fields provides a foundation on which to build. Going forward, efforts must be made to spread these achievements across all forms of care provided in the home.

Guiding Principles

In discussions during and after the expert panel meeting in November 2017, several overarching principles emerged that are foundational to improving the safety of care in the home regardless of the population, type of home environment, or clinical situation. The expert panel firmly believes that these principles should guide every interaction, every discussion, every decision, every care plan, and all aspects of training and education.

1) Self-determination and person-centered care are fundamental to all aspects of care in the home setting.

Respect for the sacredness of the home is essential to maintaining dignity. People receiving care at home may not see themselves as "patients." For example, people with physical disabilities who receive care at home are not ill. With this in mind, home care workers must avoid "medicalizing" the home environment.

Care provided in the home must balance the need to respect the care recipient's right of self-determination and autonomy with mitigation of the risk of harm. Family caregivers and home care workers must acknowledge that it is impossible to mitigate all risks in the home setting and that self-determination and the care recipient's values must be respected in any attempts to improve safety. All aspects of care, and especially care plans, must incorporate the values of the care recipient and family caregivers. In addition, some safety experts suggest that incorporating the concept of dignity into safety work can help prevent unintended consequences.[70] Respecting and upholding self-determination is an important component of person-centered care.

Person-centered care in the home must be focused on the care recipient and family members and is especially critical in the home setting — safety in the home cannot advance without it. Person-centered care is one aspect of people-centered care, which "is broader than patient- and person-centred care" and is defined by the World Health Organization as:

> "…an approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people rather than individual diseases, and respects social preferences. People-centred care also requires that patients have the education and support they need to make decisions and participate in their own care and that carers are able to attain maximal function within a supportive working environment. People-centred care …encompass[es] not only clinical encounters, but also includes attention to the health of people in their communities and their crucial role in shaping health policy and health service."[71]

It is important, however, to recognize the inherent tension between supporting self-determination and viewing the care recipient/family caregiver dyad as intricately intermeshed. The care recipient's goals and preferences must be determined first (unless he or she does not have decision-making capacity), and then the conjoined needs of the care recipient and family caregiver must be addressed in concert.

2) Every organization providing care in the home must create and maintain a safety culture.

An important aspect of improving the safety of care in the home is increasing the reliability of the care system. The IHI White Paper, *A Framework for Safe, Reliable, and Effective Care*, discusses the need for work in this realm to take place in two equally important foundational domains: the culture and the learning system.[2]

Increasing the safety of care in the home requires more than simply collecting prevention strategies and interventions. It requires an overarching commitment to safety. How can we create a culture of safety in the home setting? We can start by recognizing what a culture of safety looks like in the health care system.

As described in 2005, "In a safe culture employees are guided by an organization-wide commitment to safety in which each member upholds their own safety norms and those of their co-workers."[72] A definition more relevant to the home setting might be: "In a safe culture, care recipients, family caregivers, home care workers, and other personnel who support care in the home are guided by a person- and family-centered commitment to safety in which each person upholds their own safety norms and those of the others in the extended care team." The goal is for safety to be a property of the system of care in the home, rather than an afterthought.

> *In a safe culture, care recipients, family caregivers, home care workers, and other personnel who support care in the home are guided by a person- and family-centered commitment to safety in which each person upholds their own safety norms and those of the others in the extended care team.*

Both the culture of safety and the specific safety practices need to be inclusive, attending to the safety of care recipients and everyone who provides care. Indeed, caring for the family caregiver and home care worker is just as critical to safety as caring for the care recipient. As previously discussed, people who provide care in the home are at risk for experiencing emotional or physical harm as they go about their work. In addition, the home setting harbors risks not generally seen in the health care system, such as isolation. Evidence suggests that health care organizations that focus attention on workforce safety simultaneously improve patient safety.[73]

To significantly improve the safety of care in the home, safety culture and practices need to inform every action and decision associated with that care. For instance, in the hospital setting, safety culture surveys are routinely conducted to assess practices and improve safety. Such surveys should be routinely adapted for use in the home setting as well. Otherwise, safety may come to be considered an "add-on" — one more item on the list of services provided by a home care agency or an individual home care worker — rather than being fully integrated into the practice of care.

3) A robust learning and improvement system is necessary to achieve and sustain gains in safety.

A learning system includes leadership (also a component of culture), transparency, reliability, improvement and measurement, and continuous learning.[2] Developing this is essential to improving the safety of care in the home setting.

However, safety practices and techniques that are effective in the hospital setting are not necessarily useful in the home. Individuals and organizations must develop or identify effective strategies to improve safety in the home, and to accelerate change they must quickly share these strategies with peers. For this rapid learning and sharing to take place, we need what we currently do not have: a robust learning system through which to learn, collect, and share data, identify effective interventions using safety science, and spread best practices about safety in the home setting. This learning system must embrace safety science and educate individuals and teams on its core elements, including systems thinking, teamwork, balancing "no blame" with accountability, the human factors involved, improvement science, high reliability, and safety culture. In contrast to an improvement collaborative, which has a specified end date, this learning system would be an ongoing project to exchange data on multiple sources of harm and share best practices related to preventing them.

System for measurement. As previously mentioned, one of the most significant gaps in research on care in the home is the lack of a common system for measuring safety among all who provide care in this setting. Identifying and vetting a standard set of metrics is essential for substantial movement forward. It would be prudent to begin with a simple set of measures that identify the most prevalent adverse events occurring in the home. From there, the measure set could evolve as the field matures and more is known about the harms that occur in the home.

Sharing data. Experience with Solutions for Patient Safety (SPS), a network of more than 130 children's hospitals that work collaboratively toward the goal of zero harm, has demonstrated that widely sharing safety data and best practices can significantly improve pediatric patient safety across multiple health care organizations. SPS shows that it is possible to build a learning system with data sharing, a social network, and a shared goal. Data collected from early adopters can be instrumental in turning attention to the scope of the health care harm occurring in the home and motivating other organizations to improve.

Improvement skills. If safety in the home is to improve, all home care workers must have the requisite improvement skills, such as the ability to effectively define the problem and test an intervention. They must "own" safety efforts and understand the importance of their engagement in safety-related activities. The acquisition of improvement skills has been an important component of progress in patient safety within the hospital setting and must not be overlooked as a strategy to improve safety in the home. It is essential to teach improvement skills, safety science, systems thinking, and awareness of human factors within the context of a systemic improvement model, such as Lean, Six Sigma, or the Model for Improvement. Providing access to improvement coaches and collecting and sharing data are also critical aspects of improving safety in the home.[2]

A collaborative of organizations. Another important element in advancing improvement in home safety is the development of a collaborative of organizations. Such a collaborative would collect and disseminate lessons learned, best practices, and data, paving the way for other organizations to take on this improvement work. With the support of faculty with expertise in implementation science, the collaborative would train participants and showcase the effectiveness of a scientific approach to improvement.

Because of how frequently safety issues related to medication arise and the wide swath of care recipients at risk, the expert panel suggested medication safety as an ideal focus for initial collaboratives. (See Appendix B for suggested tactics for advancing medication safety that could be used to support early collaboratives.)

4) Effective team-based care and care coordination are critical to safety in the home setting.

The expert panel identified poor care coordination as the most important clinical problem affecting care safety in the home setting. The current health care system does not sufficiently enable teamwork among the many professionals involved in a person's care, including nurses, therapists, physicians, social workers, managers, and administrators. Although home care workers often provide care alone, there must be a coordinated team and infrastructure to support them, providing supervision, management, and accountability.

By improving care coordination, team-based care with effective communication can reduce the risk of errors, especially at care transitions, as well as the need for family caregivers to take on the stressful and exhausting role of care coordinator. In addition, community care resources need to be integrated into the care plan to ensure that available resources are utilized and coordinated with other care services. Effective care coordination is especially important for care recipients with mental, behavioral, or cognitive conditions. Using tools such as standardized handoff templates and the Teach Back method can be helpful in optimizing care coordination.

It is not only home care workers whose ability to provide well-coordinated care often encounters obstacles. Other professionals within the larger health care system also face challenges, such as those related to staffing, regulations, and policies. Nursing, therapy, administrative, and management personnel must be considered in any strategy to improve the safety of care in the home.

5) Policies and funding models must incentivize the provision of high-quality, coordinated care in the home and avoid perpetuating care fragmentation related to payment.

Current regulations and payment models often increase care fragmentation. In general, services paid via fee-for-service models tend to be siloed, leaving important needs unmet. For example, Medicaid waivers cover only certain services. This payment structure can lead to narrowly focused care and create perverse incentives to use higher-intensity, more expensive services. Home- and community-based service organizations must be incentivized to provide high-quality care that is coordinated and provided in accordance with the values of the care recipient and family members.

The administrative burdens associated with regulations related to payment for care provided in the home can overwhelm staff and syphon resources away from care provision. CMS has taken steps to address this overload by reducing the required fields in OASIS, yet much more needs to be done.

Recommendations

To achieve the optimal state described by the guiding principles, the expert panel made the following recommendations, numbered to correspond with the five principles. A wide array of stakeholders would be responsible for enacting these recommendations:

- Care recipients
- Clinicians
- Family caregivers
- Health care organization leaders
- Home care workers
- Home health agency leaders
- Payers
- Pharmacists
- Policymakers
- Researchers
- Technology vendors

These stakeholders must work collaboratively to ensure that their implementations of these recommendations effectively support the guiding principles and advance the safety of care in the home.

Principle 1: Self-determination and person-centered care are fundamental to all aspects of care in the home setting.

Recommendation 1.1: Improve communication with care recipients and family caregivers.

Sample Tools, Strategies, Resources, and Tactics
a. Create a Care Recipient Bill of Rights. See related resource: Patient's Bill of Rights
b. Include asking care recipients, "What matters to you?" as a routine component of care. Conduct a "safety consult" with care recipient, family, and others living in the home after the care recipient has set goals of care.
c. Ensure home care workers query the care recipient early in the treatment course about the role of family caregivers in treatment and decision making. • Include the name of the family caregiver(s) in the health record, in accordance with the CARE Act. • Consider identifying a medication safety manager for each care recipient; if capable, a family caregiver could fill this role. The medical safety manager could help ensure the accuracy of medication reconciliation and regularly inquire as to whether all medications are needed.
d. Provide communication tools for staff at hospital discharge to educate the care recipient and family caregivers and identify available resources during care transitions.

Sample Tools, Strategies, Resources, and Tactics
e. Communicate clearly with potential family caregivers about how their role would be defined and determine their availability for providing various levels of care. Create and distribute instructional videos for family caregivers on complex care tasks.

Recommendation 1.2: Provide meaningful, relevant education for care recipients and family caregivers.

Sample Tools, Strategies, Resources, and Tactics
a. Create educational tools (e.g., a one-page information sheet) about self-determination of risks and safety issues in the home. Provide tools at inpatient discharge and at first visit to the home. See related resource: CARE Act
b. Raise awareness of local support groups and other resources for family caregivers. Consider developing a volunteer "time bank" for family caregivers by which community volunteers can offer blocks of time to allow caregivers short-term respite from caretaking roles. See related resource: TimeBanks Best-practice example**:** Dementia Care Services Program in North Dakota
c. Co-develop meaningful educational tools to assist the care recipient and family caregivers in identifying potential hazards and knowing what actions to take if the care recipient needs urgent or additional care. • Education about action steps for accessing urgent or additional care can help avoid unnecessary use of higher-intensity services. • Consider the use of training consultants.

Sample Tools, Strategies, Resources, and Tactics

d. Ensure that the care recipient and family caregivers receive appropriate tools and education about care, including medication safety.

Imparting education and tools is especially important if no family caregivers are available for the care recipient or a family caregiver cannot be present 24/7.

- Use the Teach Back method.
- Encourage the use of the Ask Me 3 questions to improve communication.
- Provide education for family caregivers as well as care recipients.

Best-practice example: The One Care program for dual-eligible individuals ages 21 to 64 living in Massachusetts includes principles of independent living in its contract, provides person-centered care, and involves the care recipient in creating the care plan.

Connect with existing efforts that reframe the language used in conversations about care, such as the Age-Friendly Health Systems initiative, The Conversation Project, and the Solutions for Patient Safety (SPS) network.

See related resources:

- Helping Older Adults Improve Their Medication Experience (HOME) by Addressing Medication Regimen Complexity in Home Healthcare

- HomeMeds Program in Los Angeles

Ensure access to certified shared decision-making tools.

Best-practice examples:

- Operation Family Caregiver, managed by the Department of Veterans Affairs, provides coaching for family caregivers. (See Appendix A for more information on this exemplar program.)
- North Dakota Dementia Care Services provides education about dementia, referrals to relevant agencies, and support to the caregivers of people with dementia. (See Appendix A for more information on this exemplar program.)

Recommendation 1.3: Develop tools to improve person-centeredness in systems of care.

Sample Tools and Strategies

a. Create a standardized assessment of the care recipient's functionality and needs (based on his or her values) that is accessible and can be used by family caregivers and home care workers.

- Include a comprehensive assessment of the care recipient's health and functional abilities, socioeconomic status, and the home environment.
- Ensure that assessment areas align with the care recipient's goals.
- Use professional teams to conduct assessments (e.g., EMS personnel, nurses, behavioral health specialists).
- Educate home care workers about home assessments.

b. Address legal liability issues that may be barriers to respect for self-determination.

Create disclosures related to safety and risk mitigation in the home to address the legal concerns of home care workers.

Sample Tools and Strategies
c. Include care recipients (when they are able) and family caregivers in the care team. Collaborating and working with family caregivers is essential to effective, safe care.
d. Engage care recipients — and when appropriate, their family caregivers — in co-creating their care and safety. Use motivational interviewing to facilitate engagement and better understand barriers to change. Best-practice example: Aligning Forces for Quality See related resource: 5 Questions to Ask about Your Medication
e. Promote agency policies that support the assignment of a consistent home care worker.
f. Ensure that functional status measures include a comprehensive scan of the abilities of the care recipient. Create functional status assessments that measure more than mobility (e.g., executive function and other cognitive metrics).
g. Use focus groups and participatory research to understand the priorities of people receiving home care and their families.
h. Ensure that a member of the care team is available 24/7 to answer the care recipient/family caregiver dyad's questions. • Ensuring the availability of a care team member to answer questions can help avoid ED visits. • Seek mechanisms to minimize the cost to the care recipient, recognizing that easy access to a care team member can prevent more costly care.

Principle 2: Every organization providing care in the home must create and maintain a safety culture.

Recommendation 2.1: Create a vision for a safety culture in the home health and personal care fields.

Sample Tools, Strategies, Tactics, and Resources
a. Convene a group of innovator organizations to test strategies for defining and developing a culture of safety that is effective for the field of home care. • Provide access to experts in reliability from other industries to guide testing and gaining consensus on an effective strategy for changing culture. • Ensure the development of a dissemination plan to enable the replication of successful innovations by others.
b. Consider and discuss safety issues and harm prevention at every encounter with the care recipient and family members. Consider safety in the design of technology, communication tools, training, monitoring, and other aspects of the home care system.

Sample Tools, Strategies, Tactics, and Resources
c. Acknowledge and highlight the need for balancing safety and risk in the home setting for care recipients, family caregivers, and home care workers. Emphasize that balancing safety and risk is essential to providing person-centered care and enabling self-determination.
d. Prioritize human and financial resources to improve the safety of care in the home. Ensure that home care workers have access to electronic health records and any other tools necessary for providing safe care.
e. Adapt or create and disseminate a home care safety culture survey. Suggest using the Home Care Safety Culture Survey, adapted from the Agency for Healthcare Research and Quality (AHRQ) Safety Culture Survey by the Center for Patient Safety.
f. Ask care recipients and family caregivers about potential safety gaps and develop tools to reduce errors.
g. Provide standardized tools for assessing, developing plans for, and executing a sustainable way to improve safety culture. Request that AHRQ support the development of a standardized toolkit for home care safety that would be used across the country.
h. Ensure the inclusion of the care recipient and the person providing care when developing interventions to improve safety. Focusing on the partnership between the family caregiver and the home care worker can help ensure that comprehensive and effective interventions are developed.
i. Create a readiness assessment for home care–related organizations to identify barriers to adopting safety culture.

Recommendation 2.2: Ensure the emotional and physical safety of family caregivers and home care workers.

Sample Tools, Strategies, Tactics, and Resources
a. Develop tools to assess the capacity of the family caregiver(s) to provide care in the home.
b. Ensure the availability and use of personal protective equipment for family caregivers and home care workers.
c. Provide effective training for home care workers and assess learning.   - Create an inventory of current safety training programs and then, based on consensus, develop a comprehensive modular training program from existing materials.   - Consider including conflict resolution, infection control, personal safety, the use of personal protective equipment, and violence.   - Consider accreditation requirements regarding the content of training, not just the completion of training.

Sample Tools, Strategies, Tactics, and Resources

d. Ensure the support and supervision of home care workers.

- Identify and spread best practices related to workforce supervision; include regulatory agencies and private care organizations.
- Foster peer communication (both face-to-face and virtual) to address professional isolation.
- Develop a system for measuring performance to ensure accountability.

e. Reduce the risk of injury to home care workers due to crime when working or traveling to and from the home setting.

Offer de-escalation and self-defense training and consider security personnel for high-risk areas.

Principle 3: A robust learning and improvement system is necessary to achieve and sustain gains in safety.

Recommendation 3.1: Build a measurement and reporting infrastructure.

Sample Tools, Strategies, Tactics, and Resources

a. Develop a taxonomy of home care as the foundation for a robust reporting system.

b. Support a population-based study to determine the prevalence and types of harm.

- Ensure the adoption of a standard taxonomy related to care in the home.
- Involve AHRQ for funding research.
- Include preliminary work to determine the optimal ways to collect and report data regarding all care in the home, including identification of the care team members responsible for these tasks.

c. Develop an initial measurement set that is relatively simple to adopt and captures the majority of harm that occurs in the home setting, based on population-based studies of harm prevalence. Anticipate that the metrics may evolve over time as understanding of the problem becomes more nuanced.

- Leverage OASIS as a starting point for measures related to home health; add measures relating to other components of care in the home.
- Ensure inclusion of the spectrum of harm, including emotional harm, and include events that do not result in harm (i.e., near misses).
- Align with existing or emerging work on measures — for example, the IHI Skilled Nursing Facility Trigger Tool for Measuring Adverse Events.
- Consider unintended consequences, such as the cost and administrative burden of data collection, which could ultimately increase the cost of home health care and render it unaffordable to care recipients.

See related resource: National Home-Based Primary and Palliative Care Network, which includes home-based medical practices, professional societies, and patient advocacy groups[74]

d. Ensure that quality of life is measured, to balance other quality metrics.

Create new Consumer Assessment of Healthcare Providers and Systems (CAHPS) measures to include metrics of autonomy and expand metrics of quality of life.

See related resource: Consumer Assessment of Healthcare Providers and Systems (CAHPS) Home and Community-Based Services Survey

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Sample Tools, Strategies, Tactics, and Resources

e. Create robust reporting systems for capturing adverse events in the home, building on OASIS as an existing resource.

- Enable reporting by care recipients and family caregivers, as well as by home care workers.
- Include the capability for real-time measurement.
- Improve the processes used to detect safety hazards in the home.

f. Develop a process for evaluating the effectiveness of interventions to improve safety in the home.

Recommendation 3.2: Share data on safety in the home.

Sample Tools, Strategies, Tactics, and Resources

a. Create a culture and expectation of transparency.

See related resource: IHI/NPSF Lucian Leape Institute report, Shining a Light: Safer Health Care Through Transparency

b. Create a communications strategy to share data widely using standard measurement sets and any related research studies as close to real time and as frequently as possible.

For example, share analyses of relevant OASIS data.

c. Create materials in a variety of media that explain the need for improvement, making a case for individuals to adopt the actions and attitudes necessary to improve safety.

d. Based on consensus, develop a comprehensive modular training program from existing materials.

e. Encourage voluntary reporting of errors in the home to patient safety organizations.

Recommendation 3.3: Teach safety and improvement skills across the home health and personal care fields and evaluate competency in these skills.

Sample Tools and Strategies

a. Teach improvement skills and safety science (e.g., human factors, high reliability) to all who provide care and ensure access to improvement coaches.

Teach improvement skills within the context of a systemic improvement model, such as Lean, Six Sigma, or the Model for Improvement.[2]

See related resources:
- The IHI Open School offers education through online courses, connection with local chapters, and guided improvement projects to build skills in improvement, safety, system design, and leadership.
- The IHI/NPSF Patient Safety Curriculum, an online course, provides the context, key principles, and competencies associated with the discipline of patient safety.

Sample Tools and Strategies
b. Provide action-based and simulation courses to develop leaders with intermediate and advanced skills.
Include both in-person and distance learning (online) options.
c. Assess competency with improvement skills on a regular basis.

Recommendation 3.4: Create an intensive improvement collaborative for early adopter organizations.

Sample Tools, Strategies, Tactics, and Resources
a. Identify organizations to participate in an improvement collaborative targeting harm reduction in the home.
b. Ensure that collaborative members use improvement science and carefully document results.
Focus the initial collaborative on reducing a particular type of risk.
c. Widely share data and lessons learned in the collaborative to encourage other organizations to adopt best practices.
d. Consider focusing an initial collaborative on improving medication safety.
See Appendix B for more information on advancing medication safety.

Recommendation 3.5: Create a learning system for identifying and sharing best practices related to care in the home.

Sample Tools, Strategies, Tactics, and Resources
a. Develop a system for identifying models that are successful in improving safety.
b. Create a mechanism for disseminating successful models.
c. Engage researchers to identify pockets of excellence and create aims based on high-performing groups.
d. Foster the creation of learning networks.   - Willing organizations can share a common goal of eliminating harm across home care, share all data transparently with each other, and use an "all teach, all learn" approach to identify practices associated with lower rates of harm and adopt these as standards until better practices are identified. Lessons learned should be shared widely within and outside the learning network.   - Build on the experience of existing networks in other environments, such as the SPS Network and the Hospital Engagement Network.

Principle 4: Effective team-based care and care coordination are critical to safety in the home setting.

Recommendation 4.1: Create a common, longitudinal care plan based on the goals of the care recipient or a care recipient/family caregiver dyad.

Sample Tools, Strategies, Tactics, and Resources
a. Consider the care recipient and the family caregiver as a dyad when designing care plans, policies, and workforce training.
b. Use the hospice and palliative care structure as a model, especially focusing on the interdisciplinary collaboration, the shared approach to goal-setting, and the communication methods used.
c. Develop a process for creating and sharing a common, longitudinal care plan. • Enlist family caregivers to shape the care plan of care recipients who cannot verbalize their goals owing to mental, behavioral, or cognitive conditions. • Schedule regular reviews to ensure that the plan remains relevant and supportive of the care recipient's needs and preferences. • Consider the hospice model as a best practice in care plan development and communication. Review the existing model of Medicaring.org. Best-practice example: Mobile integrated health care uses physician-led interprofessional teams to manage care transitions and chronic care services on-site in patients' homes or workplaces.[75] See related resource: Care Plan 2.0
d. Develop processes to communicate elements of the care plan to the care recipient/family caregiver dyad and the home care workforce. Adapt and use standardized templates for handoffs between care team members, for example, such as I-PASS.
e. Develop and regularly share standardized safety messages at every visit. Use repetition and the Teach-Back method to reinforce and confirm that messages have been understood.

Recommendation 4.2: Develop and test new models of team-based care.

Sample Tools, Strategies, Tactics, and Resources
a. Support a strong relationship between the care recipient and the home care worker by striving for the consistent assignment of a worker to a particular care recipient.

Sample Tools, Strategies, Tactics, and Resources

b. Build new models of service coordination, making sure to include personal care aides and other home care workers, as well as clinicians ordering home care, on the care team.

- Pilot and test new models, test with other populations, and spread best practices.
- Include interdisciplinary team house calls (e.g., from physicians, nurses, or social workers) and ensure that behavioral health professionals are included for care recipients with mental, behavioral, and cognitive conditions.
- Consider primary medical care in the home and alternatives to hospitalization.
- Consider using a tool to track family caregiver and home care workforce hours (existing model: Medicaring.org).
- Ensure that in the tested model, all members of the workforce are practicing at the top of their licenses.
- Use common metrics to assess effectiveness.

Best-practice examples:

- Hospital at Home, which provides care for frail older people at home, decreased costs by 30 percent.[76] (See the case study in Appendix A.)
- Research is available from an INTERACT (Interventions to Reduce Acute Care Transfers) intervention to strengthen the relationship between RNs in skilled nursing facilities (SNFs) and emergency departments (EDs) to work together to reduce the 30-day readmission rate. The strengthened relationships had a positive impact beyond the immediate problem.[77]
- The Paraprofessional Healthcare Institute created an advanced aide position to provide home care aides with coaching and support; the result was an 8 percent drop in ED visits and improved job satisfaction.
- In the CAPABLE program for aging in place, an occupational therapist, a nurse, and a handyman work together to understand the care recipient's goals and make alterations in the home to support them. A video case study is available online. (See the case study in Appendix A.)

See related resource: For an evidence-based list of questions helpful at care transitions, see Figure 8.1 in McLaughlin-Davis's paper "Case Management Guide to Population Health Management Across the Continuum of Care."[79]

c. Develop systems to help care recipients receive coordinated care services (e.g., with care managers).

- Designate a "leader" on the care team who communicates with all people providing care in the home to ensure a coordinated "package" that reflects the care recipient's values. In addition, offer a peer navigator (a volunteer with lived experience) to assist the care recipient.
- Ensure that the longitudinal care plan identifies a specific family caregiver, if available, with whom to communicate.
- Build collaborations to improve medication management, similar to the Pharm2Pharm care transition program and the Community Care of North Carolina project. (For more information on these exemplar programs, see Appendix A.)

Best-practice example: The existing model in primary care of using care managers has been shown to reduce caregiver burden and increase the care recipient's functional ability.[78]

d. Expand medication reconciliation to include reviewing medication containers in the home (and checking their contents).

Recommendation 4.3: Ensure the visibility and use of community-based and underutilized resources.

Sample Tools, Strategies, Tactics, and Resources
a. Create a handbook for clinicians and other health care professionals using relevant community-based resources. • Ensure that resources for behavioral health are included. • Annotate the list to assist users in understanding the circumstances under which each resource is best utilized and why.
b. Include "social prescribing" — referrals of care recipients to a range of local nonclinical services — in the care plan. Best-practice examples: • A prescription for social services such as Meals on Wheels • UK Social Prescribing Initiative
c. Engage emergency medical services and firefighters in home safety assessments and other forms of care in the home. See related resource: See Appendix A for more information on MedStar, an exemplar EMS program.

Recommendation 4.4: Utilize technology to support team-based, coordinated care.

Sample Tools, Strategies, Tactics, and Resources
a. Reconsider the use of the medical record for home health care. Consider block chain technology (a decentralized ledger for transferring data without going through a central clearing source) to allow for communication among team members, the care recipient, and family caregivers outside the constraints of the electronic health record.
b. Leverage existing data to signal when a care recipient is at higher risk for harm (e.g., polypharmacy). Best-practice example: Collate pharmacy and other data regarding medications to identify potential medication risks in real time.
c. Expand telehealth programs. Solicit input from end users for design and use.

Principle 5: Policies and funding models must incentivize the provision of high-quality, coordinated care in the home and avoid perpetuating care fragmentation related to payment.

Recommendation 5.1: Align payment models with the goals of whole-person, community-based, coordinated care.

Sample Tools, Strategies, Tactics, and Resources

a. Encourage CMS and commercial payers to test new payment models in demonstration projects and spread effective models.
 	
• Consider financing through community-based organizations rather than the health care system and identify ways to increase the care recipient's input on where funds are spent.
• Consider a payment structure similar to that of Medicare Advantage, which requires coordination with community-based groups.
• Involve:
  o Quality Innovation Network–Quality Improvement Organizations (QIN–QIO)
  o Physician-Focused Payment Model Technical Advisory Committee (PTAC)
  o Center for Medicare & Medicaid Innovation
  o Agency for Healthcare Research and Quality

b. Identify and address payment strategies for aspects of care that are currently not covered by governmental or commercial payers. Include care for people with mental, behavioral, or cognitive conditions.
c. Address needs for funding long-term home care for populations in need of these services.

Recommendation 5.2: Reduce the regulatory burden.

Sample Tools, Strategies, Tactics, and Resources
a. Identify the key regulatory burdens and advocate for reducing them. Continue streamlining OASIS by reducing the number of necessary data fields.

Conclusion

There is no place like home, and people who need care often prefer the home setting to more clinical environments. Today more of that care is being provided in the home, including progressively more complex care. For this reason, safety in the home is becoming an increasingly important issue to address. Given the nature of the home — an individual's sanctuary and a setting not under the control of the health care system — we cannot simply apply in the home the safety principles and strategies that are effective in health care settings.

Gains made by the home health and hospice and palliative care fields have laid a foundation on which to build, but if safety in the home is to advance, we must pay greater attention to this issue and follow up with action. We currently do not have a complete understanding of the nature and prevalence of the risks in the home or full information about the optimal ways to improve safety in this setting.

What we do know is that a lack of standard measurement across all services, a lack of standard training and supervision of all members of the home care workforce, and a lack of consistently effective communication and care coordination represent some of the most pressing safety problems in this environment. In addition, where best practices are known, they have not been widely spread and adopted. These are deficits we must address.

As detailed in this report, five key principles shaped the expert panel's recommendations for advancing safety in the home:

1) Self-determination and person-centered care are fundamental to all aspects of care in the home setting.

2) Every organization providing care in the home must create and maintain a safety culture.

3) A robust learning and improvement system is necessary to achieve and sustain gains in safety.

4) Effective team-based care and care coordination are critical to safety in the home setting.

5) Policies and funding models must incentivize the provision of high-quality, coordinated care in the home and avoid perpetuating care fragmentation related to payment.

Safety in the home is an aspirational goal — one that needs to be established as a core value by organizational leaders and prioritized as well worth the time, effort, and resources. Safe care in the home is the care that each of us wants for the people we care about and for ourselves. Now is the time to begin.

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Appendix A: Case Studies

Community Aging in Place: Advancing Better Living for Elders (CAPABLE)

I. Background of the Problem

For disabled older adults, in particular, caring for themselves (dressing, bathing, toileting, cooking, and moving about safely) is critical to their ability to remain independent and safe in their home setting. Insurance and publicly funded programs, however, typically do not cover support services to help people with such activities. Moreover, medical care delivery in the home often does not include a comprehensive assessment of a client's functional abilities in the home environment and the implications for their safety, nor does it develop an implementation plan that focuses on the values and priorities that matter most to clients.

II. Description of the Program

Community Aging in Place: Advancing Better Living for Elders (CAPABLE) is a program developed at the Johns Hopkins School of Nursing under the direction of Sarah L. Szanton, PhD, and adapted from the Advancing Better Living for Elders (ABLE) program[1] developed by Laura N. Gitlin, PhD. Designed to help low-income older adults to safely age in place, the program aims to maintain the client's independence and safety by modifying the home to promote mobility, managing medications and health conditions, developing physical strength and balance, and decreasing isolation and depression. The goal of these strategies is to maximize the client's health and function, and ultimately to save money by preventing hospital admissions, reducing injuries from falls, and avoiding expensive care such as skilled nursing home care. CAPABLE has received funding from the National Institutes of Health, the Center for Medicare & Medicaid Innovation, the Robert Wood Johnson Foundation, the AARP Foundation, the John A. Hartford Foundation, and the Rita & Alex Hillman Foundation.

The program includes these components:

- A **focus on the individual's goals and strengths** in self-care, including activities of daily living (ADLs) such as eating, bathing, dressing, toileting, walking; and instrumental activities of daily living (IADLs) such as cooking, shopping, doing housework, and laundry

- A **comprehensive assessment** of the client's goals and the client's medical, functional, and environmental needs

- A **philosophy of providing client-directed interventions**, based on what is most important to the client

- An **interdisciplinary, collaborative team** — including a handyman, nurse, and occupational therapist — who make regularly scheduled visits over a four-month window to address the client's needs, work with the client to solve problems, and assess progress

How the Program Works

CAPABLE targets clients who are age 65 or older, are low-income, have challenges with at least one ADL, and are cognitively able to follow the plan to achieve their functional goals. The team initiates the CAPABLE service model by asking clients what is most important to them. For example, their

responses might include getting out of bed without assistance, taking a bath on their own, cooking dinner, or safely walking up and down stairs.

Each team member has a specific role:

- The **occupational therapist** assesses the client's functional abilities and goals to educate the client on strategies to enhance mobility, including the proper use of assistive devices. The therapist also conducts a home safety assessment to identify opportunities for home improvements.

- The **nurse** assesses the client's priorities and goals and determines how the client's health conditions, medications, pain, depression, strength, balance, and nutrition affect daily activities. In coordination with the client, the nurse develops an action plan that includes medication reconciliation, health education and coaching, and motivational interviewing. The nurse also communicates with the client's health care provider or a pharmacist as indicated.

- The **handyman**, in collaboration with the occupational therapist and based on the client's concerns, performs home modifications (such as repairing flooring and installing better lighting, stair handrails, bathtub grab bars, and raised toilet seats) to help the client navigate the home environment more easily and safely.

During four consecutive months, the program allocates 10 one-hour visits by team members (four nurse visits and six occupational therapist visits) and up to $1,300 for handyman services to implement the home improvements, based on the occupational therapist's recommendations and the client's priorities (see Figure 1). The program costs approximately $3,000 per client.

Figure 1. Timeline of CAPABLE Program Visits During Four Consecutive Months
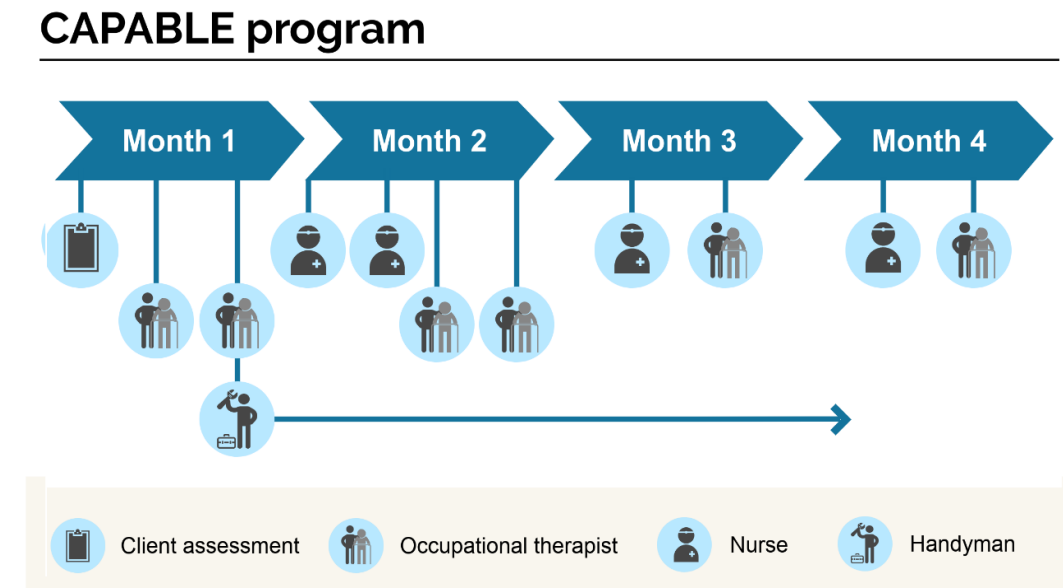
III. Program Results

The CAPABLE program has achieved improvements in the quality of care for clients, as well as cost savings through reductions in hospitalizations and Medicare expenditures. Twenty sites in nine states have implemented the program.

Demonstrated results include the following:

- After 281 adults (age 65 and older) who were dually eligible for Medicare and Medicaid completed the 2012–2015 pilot program, 75 percent achieved improved performance of ADLs. At baseline, participants had difficulty with an average of 3.9 out of eight ADLs, compared to difficulty with two ADLs after the program, representing a 49 percent improvement in physical functioning. Participants also experienced reduced difficulty with IADLs.[2]

- Depressive symptoms improved in 53 percent of pilot participants.[2]

- Home hazards in the pilot decreased from an average of 3.3 hazards to 1.4 hazards.[2]

- The average cost of the program was $2,825 per participant.[2]

- In an independent program evaluation involving 171 participants, the CAPABLE program decreased their total Medicare expenditures by reducing inpatient and outpatient expenses, including reduced readmissions and observational stays.[3]

- Client confidence in self-care management and behaviors increased.[3]

IV. Additional Resources

- Johns Hopkins University School of Nursing website. Community Aging in Place: Advancing Better Living for Elders (CAPABLE) [Web page].
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- Johns Hopkins Medicine: HealthCare Solutions website. CAPABLE: Aging in Place [Web page]. https://www.johnshopkinssolutions.com/solution/capable

- Institute for Healthcare Improvement website. WIHI: Aging in Place with a Disability and Dignity [podcast]. February 22, 2018.
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Community Care of North Carolina: CPESN® Network

I. Background of the Problem

Medication safety issues represent a significant patient safety concern in the home setting, especially among patients with complex medication regimens for chronic illness. Community pharmacists, who interact frequently with these patients when they pick up their prescriptions, have the expertise to detect and address drug therapy problems and potential adverse drug events and therefore can be an important safeguard against medication safety events in the home. Historically, however, community pharmacists have generally had a limited role in coordinating care and ensuring patient safety.

II. Description of the Program

Community Care of North Carolina (CCNC), a patient-centered medical home partnership that serves the entire state of North Carolina, launched a Community Pharmacy Enhanced Services Network (CPESN® Network) in 2015 through a Health Care Innovation Award Round Two from the Center for Medicare & Medicaid Innovation. CCNC care management patients visit a community pharmacy an average of 35 times each year (compared with only three visits to a primary care provider). The CPESN approach brings together an extensive network of community pharmacies that provide enhanced medication management services to patients with complex medical and behavioral health needs. The services go beyond the traditional community pharmacy model of dispensing medications. The goal of CPESN is to increase care coordination with CCNC health care providers and thereby improve medication safety and patient outcomes.

The program includes these components:

- Close **collaboration** of community pharmacists with CCNC care managers and other health care staff, who refer patients to CPESN pharmacies and collaborate with CPESN pharmacists to address patients' medical, social, behavioral, and medication safety–related needs.

- **In-depth patient assessments** are conducted by specially trained CPESN pharmacists in the community pharmacy or home setting to identify medication safety issues and barriers to care or medication adherence.

- **Enhanced medication management services**, such as home delivery or programs to support medication synchronization (filling all prescriptions at the same time each month), are designed to promote medication adherence and safety. An **electronic pharmacist care plan** that uses Health Level-7 (HL7) standards has a uniform framework for communicating electronic health information, and contains information about a patient's medication regimen and the pharmacist's recommendations in a form that can be shared with other health care team members.

- There is a per member per month (PMPM) **value-based payment model** to CPESN-participating pharmacists based on patient adherence and risk-adjusted cost and utilization outcomes.

How the Program Works

- CPESN pharmacies serve Medicaid and Medicare beneficiaries who have at least one chronic health condition. CPESN pharmacies identify eligible patients through referrals from CCNC health care providers or care coordinators, as well as through analysis of Medicaid and Children's Health Insurance Program (CHIP) claims data.

- After a patient is deemed eligible for CPESN support, a specially trained CPESN pharmacist conducts an initial in-depth, 60- to 90-minute assessment with the patient. The pharmacist may use laboratory, medical, and pharmacy claims data to review the patient's health conditions and medications. The assessment focuses on identifying drug therapy problems, medication side effects, adverse events, and barriers to medication adherence. Assessments occur in person at the CPESN pharmacy, by telephone, or in the patient's home.

- Based on the assessment, the pharmacist works with the patient and, as relevant, CCNC staff to address any medical, social, behavioral, and medication safety–related needs. Possible steps may include enhanced medication management services, such as home delivery of medications or support for medication synchronization. Pharmacists may also work with CCNC staff to adjust medication regimens, develop strategies to support patient self-management, or refer the patient for behavioral health services or other home- or community-based services.

- After the initial assessment, the CPESN pharmacist follows up with the patient at regular intervals (typically ranging from monthly to quarterly) on an ongoing basis, based on patient need. These follow-up assessments provide an opportunity to evaluate new medication safety problems and check on the status of previously addressed issues.

- CPESN pharmacists document all findings from their initial and follow-up assessments in an electronic pharmacist care plan. The care plan is either made available via the CCNC electronic community health record or embedded in the workflow of the eight vendor systems commonly used by CPESN pharmacies. The care plan uses existing HL7 standards, thus facilitating integration with the electronic medical records used by other health care providers. The care plan details the patient's medication regimen, the patient's health concerns (including drug therapy problems and medication support needs), and the pharmacist's recommendations and interventions.

- Pharmacists receive a PMPM payment for their services under a value-based payment model developed specifically for CPESN pharmacies. The payment model adjusts PMPM payments based on performance on three Medicare Star adherence measures (antihypertensive, diabetes, and statin medications), as well as three risk-adjusted outcomes: total cost of care, inpatient hospitalizations, and emergency department visits. PMPM payments are contingent on pharmacists completing the electronic care plan.

III. Program Results

Nationwide, 38 other networks representing 35 states have replicated the CCNC CPESN Network model.

CCNC has successfully scaled the CPESN model across North Carolina, a geographically and demographically diverse state. As of August 2017, the CCNC CPESN Network consisted of 227 pharmacies, which had collectively provided enhanced medication services to roughly 15,000 individuals. The program has served patients with a wide range of complex health conditions, demonstrated the feasibility of electronically exchanging information between pharmacists and other providers, and shown preliminary evidence of improved patient medication adherence.

Evidence includes the following:

- According to an independent analysis of CPESN participants at baseline,[4] more than 70 percent were Medicare-Medicaid dual-eligible, signifying a high level of social need. Moreover, CPESN participants had poorer health status and greater need for care than the general Medicare fee-for-service population. Finally, CPESN participants had higher expenditures, rates of acute care hospitalizations, and rates of outpatient emergency department visits relative to national and North Carolina averages for Medicare fee-for-service beneficiaries.

- According to unpublished data from CCNC, CPESN pharmacists had exchanged more than 20,000 care plans with health care providers and payers as of June 2017.[5]

- According to unpublished data from CCNC, baseline results showed 4 to 5 percent higher medication adherence rates (based on proportion of days covered greater than 80 percent) among patients served by CPESN pharmacies, compared with patients served by non-CPESN pharmacies.[5]

IV. Additional Resources

- Community Care of North Carolina website. Community Pharmacy Enhanced Services Network [Web page]. https://www.communitycarenc.org/what-we-do/pharmacy/cpesn

Hospital at Home®

I. Background of the Problem

Hospitalization, especially for older adults, can present significant patient safety risks related to patients' immobility and susceptibility to iatrogenic disease and injury. Falls, pressure ulcers, functional decline, nutritional deficit, loss of muscle mass, health care–associated infections, confusion, and delirium are all risks associated with the hospital environment. In contrast, the home environment provides a familiar and lower-risk setting that enables the older adult to maintain personal comfort, routines, and function.

II. Description of the Program

The Hospital at Home® program, developed in the mid-1990s and launched in the mid-2000s, is championed by Bruce Leff, MD, at the Johns Hopkins School of Medicine. This program is designed to provide hospital-level acute care in their homes for older adults with specific conditions who are at high risk for infection or other potential safety-related adverse events or who refuse hospitalization.

The program includes these components:

- **Assessments** are conducted of a patient who requires hospitalization to determine if the patient's clinical condition, functional ability, and home environment are appropriate for in-home care.

- **Transportation** is provided from an acute or ambulatory care setting to the home, assisted by medical personnel and with medical equipment as needed.

- **Medical care** is delivered in the home by physicians, nurses, and other health care professionals.

- **Medical technology** is brought to the home, such as intravenous fluids and medications, oxygen therapy and other respiratory treatments, blood testing devices, and equipment for x-ray or ultrasound imaging.

- A **comprehensive discharge and follow-up plan** is developed by the care team, patient, and caregiver.

How the Program Works

- Hospital at Home targets older adults who present to an emergency department or ambulatory care site with a clinical condition that requires hospitalization.

- Physicians determine if the patient's condition could be treated in a home setting by applying validated eligibility criteria (e.g., community-acquired pneumonia, or exacerbation of a

chronic condition such as heart failure or chronic obstructive pulmonary disease) and exclusionary criteria (e.g., suspected heart attack).

- In addition to considering the patient's clinical condition, staff assess whether the patient's home is suitable for care (e.g., sufficient utilities), the patient's functional ability, and the patient's interest in the program.

- After the patient provides consent, the staff develops a care plan, and the patient is safely transported home, usually by ambulance, and provided with needed medical equipment, medications, and devices for vital sign monitoring and communication.

- The treatment care plan is implemented by:

  o Physicians — who initially evaluate the patient in the home, provide daily or more frequent visits, and are available 24/7 for urgent or emergent care needs

  o Nurses — who visit daily or more frequently based on the care plan

  o Home health care staff — who provide medical equipment, oxygen support, skilled therapies (e.g., physical therapy), and pharmacy support

- Emergency access via an emergency call button is provided to patients who lack support from family or caregivers.

- After the patient is stable and no longer requires Hospital at Home care, the care team develops a comprehensive discharge and follow-up plan with the patient and shares it with the patient's primary care physician.

III. Program Results

The Hospital at Home program has been adapted by other health systems and in many Veterans Affairs (VA) medical facilities. The Center for Medicare & Medicaid Innovation funded a grant to the Icahn School of Medicine at Mount Sinai to test an adaptation of the Hospital at Home model, called Hospital at Home Plus.[6] In addition, the program sponsors of the adaptation seek to inform possible Medicare bundled-payment options.[7]

The program has demonstrated improvements in the quality of care for patients and cost savings through reductions in hospitalizations and Medicare expenditures. Evidence includes the following:

- ✓ In a study performed in three Medicare-managed care health systems and a US Department of Veterans Affairs medical center involving patients who were age 65 and older:[8]

  o Patients treated in the Hospital at Home model had a shorter length of stay than those in acute care (3.2 versus 4.9 days), based on an intention-to-treat analysis.

  o In three sites studied, 69 percent of eligible patients in two sites chose Hospital at Home care over hospitalization; 29 percent of those in the third site chose it.

  o The mean cost of Hospital at Home care was lower than acute hospital care ($5,081 versus $7,480).

  o The rate of complications was lower in the Hospital at Home patients (e.g., delirium occurring in 9 versus 24 percent of patients, as well as reductions in falls, nosocomial infections, and urinary complications).

  o At eight weeks after admission, there were no differences between hospitalized patients and Hospital at Home patients in their use of health care services, (e.g., emergency

department visits), inpatient readmissions, skilled nursing home admissions, or home health care services.

☑ In New Mexico's Presbyterian Healthcare Services system, a study involving 582 Medicare Advantage and Medicaid patients with a comparison group of similar patients showed that:[9]

o Mean costs for Hospital at Home patients were 19 percent lower than for the comparison group.

o The mean length of stay was 3.3 days for Hospital at Home patients versus 4.5 days for the comparison group.

o The program's patient satisfaction mean score was higher than for comparable hospitalized patients (90.7 versus 83.9).

o Hospital at Home patients had no falls, while falls occurred in 0.8 percent of the comparison group.

☑ In a small randomized controlled trial at two Brigham and Women's Hospital locations:[10]

o Median direct costs for Hospital at Home patients were 52 percent lower than for the control group.

o Hospital at Home patients engaged in more physical activity per day (median 209 versus 78 minutes).

o Hospital at Home care patients had fewer readmissions within 30 days (11 percent versus 36 percent).

IV. Additional Resources

- Hospital at Home website. http://www.hospitalathome.org

- Johns Hopkins Medicine: HealthCare Solutions website. Hospital at Home [Web page]. https://www.johnshopkinssolutions.com/solution/hospital-at-home

- Presbyterian Services and Centers website. Healthcare at Home [Web page]. https://www.phs.org/doctors-services/services-centers/Pages/home-healthcare.aspx

MedStar Mobile Healthcare: Mobile Integrated Healthcare

I. Background of the Problem

Left unidentified and unaddressed, the medical, social, and patient safety concerns that arise in the home can increase the burden on emergency medical services and emergency departments. In particular, patients with complex medical conditions and/or challenging socioeconomic situations may be more reliant on emergency health care resources because they may face multiple barriers to accessing health care and other services, have unmet medical and social needs, or grapple with unsafe home conditions. Paramedics are proficient in interacting with patients in home settings and can respond quickly when patients need help. Paramedics thus represent an important resource for providing critical support and services to individuals who face safety and health care challenges at home.

II. Description of the Program

MedStar Mobile Healthcare, an EMS provider in the greater Fort Worth, Texas, area, developed a suite of programs designed to leverage the skills and expertise of paramedics to intervene with high-risk, high-need patients in home settings. These Mobile Integrated Healthcare (MIH) programs aim to ensure that patients receive safe, effective care in the most appropriate setting.

Each of the MIH programs includes these components:

- **Processes to identify patients** who are eligible for the program.

- **In-depth, home-based visits** are conducted by specially trained Mobile Healthcare Paramedics (MHPs) to identify patients' medical, social, behavioral, and safety-related needs.

- **Bimonthly care coordination meetings** are held in which a MedStar program coordinator confers with hospital caseworkers, community service agencies, and other care providers to review the needs of enrolled patients.

- **Alternative services** help patients avoid having to call for EMS, including the ability to request a home or telephone visit from an MHP instead of calling 911.

- A continuously updated **electronic medical record** provides mobile access to information about the patient's entire course of assessments and treatments while participating in the program.

- **Contractual arrangements** exist between MedStar and hospitals, commercial insurers, and other health care service organizations to receive payments for the MIH services.

- MedStar identifies patients who qualify for its MIH programs using a variety of approaches and data sources:

  o MedStar identifies patients for the High Utilizer Program (those who have called 911 at least 15 times in the past 90 days) by analyzing 911 utilization data and receiving referrals from emergency departments, frontline MedStar staff, and other first-responder agencies, as well as agencies and payers partnered with MedStar.

  o Participating hospitals and physicians refer patients assessed as being at high risk for readmission within 30 days of discharge to the Readmission Prevention Program.

  o Agencies partnered with MedStar refer patients to the Home Health Partnership Program, the Hospice Revocation Avoidance Program, and the Observation Admission Avoidance Program.

- After a patient is deemed eligible for one of MedStar's MIH programs, a specially trained MHP or a representative from a partner organization contacts the patient to explain the benefits of the program. If the patient agrees to participate, the patient signs a consent form authorizing the appropriate parties to share relevant patient information via the electronic medical record system.

- The MHP conducts an in-depth, in-home visit with the patient, family members, and caregivers. During the visit, the MHP performs a full medical assessment, evaluates the patient's home environment and safety-related factors, and identifies opportunities to enroll the patient in other programs to help meet the patient's clinical, social, or behavioral health needs (e.g., medication compliance, nutritional support, healthy lifestyle changes).

- Based on the assessment findings, the MHP works with the patient and family to develop or reinforce an individualized care plan, in coordination with the patient's primary care network. This plan outlines the patient's needs, associated goals, and steps needed to reach the goals. The patient and family members receive a copy of the plan, which is entered into the electronic medical record system and thereby is readily accessible to MHPs and other providers.

- The patient receives a telephone number to use to request an MHP home or telephone visit as an alternative to calling 911. Because MedStar is the 911 provider in the service area, if the patient calls 911, the MHP is dispatched to the patient's location, along with the normal EMS system response. Once on scene, the MHP may apply established care protocols to address the patient's needs, thereby preventing an unnecessary ambulance transport.

- The MHP conducts periodic follow-up visits with patients based on their needs. These visits provide an opportunity to evaluate any new medical or safety needs, monitor progress in meeting care plan goals, and provide the patient with additional supports or referrals.

- A MedStar MIH program coordinator meets bimonthly with hospital caseworkers, community service agencies, and other care providers to review the needs of patients who are enrolled in the program and to coordinate resources.

- Some of MedStar's MIH programs have a formal "graduation" process for patients whose social and safety needs have been addressed and who can manage their own health care needs.

III. Program Results

MedStar's MIH programs have garnered domestic and international interest as a promising strategy to address the health care and home safety needs of patients with complex medical conditions. MedStar has hosted site visits by representatives of more than 221 communities from 46 states and seven other countries who are interested in learning how the MIH programs work and replicating the MIH model.

Across its portfolio of MIH programs, MedStar has "graduated" more than 8,500 patients. MedStar's MIH programs have improved the quality of life for enrolled patients and reduced EMS transports to the hospital, ED visits, and hospital admissions, suggesting that the health of these patients is better because their health and safety needs were addressed at home.

Evidence includes the following:

- A retrospective evaluation assessed pre- and post-intervention data for 64 patients who completed MedStar's MIH High Utilizer Program.[11] The evaluation showed that:
  - o Patients who had reported problems with mobility, pain control, and ability to perform activities of daily living before participating in the program reported improvements in these areas (38, 42, and 58 percent, respectively) after participation.
  - o After participation, 73 percent of patients rated their health as improved.
  - o Patients had 61 percent fewer EMS transports, 66 percent fewer ED visits, and 56 percent fewer hospital admissions.

- A MedStar report analyzed trends in pre- and post-enrollment utilization data among 581 patients enrolled in the MIH High Utilizer Program between October 2013 and March 2018.[12] The analysis showed that:
  - o Ambulance transports to the ED were reduced by 5,133 (58 percent), and ED visits and hospital admissions were reduced by 2,395 and 462, respectively.
  - o The reductions in utilization decreased health care spending by $9.3 million during the evaluation period, for a savings of $16,046 per enrolled patient.

- MedStar found a total expenditure savings of more than $14 million across all MIH programs between June 2012 and March 2018.[13] This represents savings of about $3.2 million in ambulance transport, $4.5 million in ED visits, and $6.4 million in hospital admissions.

- Between September 2013 and March 2018, 388 patients identified by a hospice agency as likely to disenroll from hospice were enrolled in MedStar's Hospice Revocation Avoidance Program. Of those, only 18 percent had a disenrollment.[14]

- The patient experience across MedStar's MIH programs was favorable, with overall average ratings ranging from 4.69 to 4.84 on a 5-point Likert scale assessing 12 items related to patient experience.[15]

- Between October 2013 and July 2017, 295 patients with a prior 30-day readmission were identified as being at high risk for another 30-day readmission and enrolled in the Readmission Prevention Program. Of those, 47.5 percent had a 30-day readmission, which evaluators considered lower than would have been expected.[16]

IV. Additional Resources

- MedStar Mobile Healthcare website. Mobile Healthcare Programs: Overview [Web page]. http://www.medstar911.org/mobile-healthcare-programs

- MedStar Mobile Healthcare website. MIH-CP (Mobile Integrated Healthcare–Community Paramedicine) Outcome Measures Project [Web page]. http://www.medstar911.org/mih-cp-outcome-measures-project

North Dakota Dementia Care Services Program

I. Background of the Problem

Caregiver safety is essential for patient safety.[17] Approximately 16.1 million Americans provided unpaid care for people living with Alzheimer's disease or other dementias in 2017. These caregivers address a broad range of needs, such as assisting with activities of daily living, care coordination, and medication management.[18] Collectively, caregivers provided an estimated 18.4 billion hours of care in 2017, valued at more than $232 billion.[19]

The toll of dementia caregiving is well documented. For example, more than 60 percent of caregivers report facing high or very high stress, and one in four reports clinically significant anxiety. They are four times more likely to experience depression than noncaregivers and six times more likely to develop dementia themselves.[20] Such risks, coupled with anticipated new dementia cases (14 million Americans are expected to have Alzheimer's disease by 2050, up from 5 million today),[21] make managing caregiver burden an urgent patient safety and public health issue.

Caregivers for people with Alzheimer's disease face special challenges in North Dakota, the most rural state in the nation.[22] Alzheimer's-related mortality in North Dakota doubled between 1999 and 2014, distinguishing the state as having the nation's second-highest death rate from the disease. North Dakota's 30,000 caregivers for people with Alzheimer's disease provided 34 million hours of unpaid care in 2017; they face high levels of stress and depression that impair their own health and financial security.[23]

II. Description of the Program

Established and funded by the North Dakota Legislature in 2009, the Dementia Care Services Program seeks to help those with dementia and their caregivers understand and safely manage the disease while reducing caregiver burden. The program does this by assessing needs, identifying concerns, locating available community services, developing a care plan, providing referrals, offering support and education about dementia, and following up with families. The program seeks to help people stay in their homes longer, rely less on emergency and acute care services, delay premature nursing home placement, decrease rates of caregiver depression symptoms, increase caregiver empowerment, and increase family support.

The program includes these components:

- **Care consultants**, social workers or nonclinical staff, receive on-the-job training by serving as apprentices to program leadership.

- An initial **in-depth needs assessment** is conducted, with ongoing assessments.

- A **tailored care plan** describes specific action steps for the caregiver.

- **Emotional support and education** is provided for patients and caregivers, including (see Figure 1):

  o Access to a consultant via the national Alzheimer's Association 24/7 Helpline (800-272-3900)

  o Consultant follow-up by phone or in person, as needed

  o Ongoing consultation sessions, as needed

  o Referrals to community services

Figure 1. North Dakota's Dementia Care Services Program: Services for Caregivers
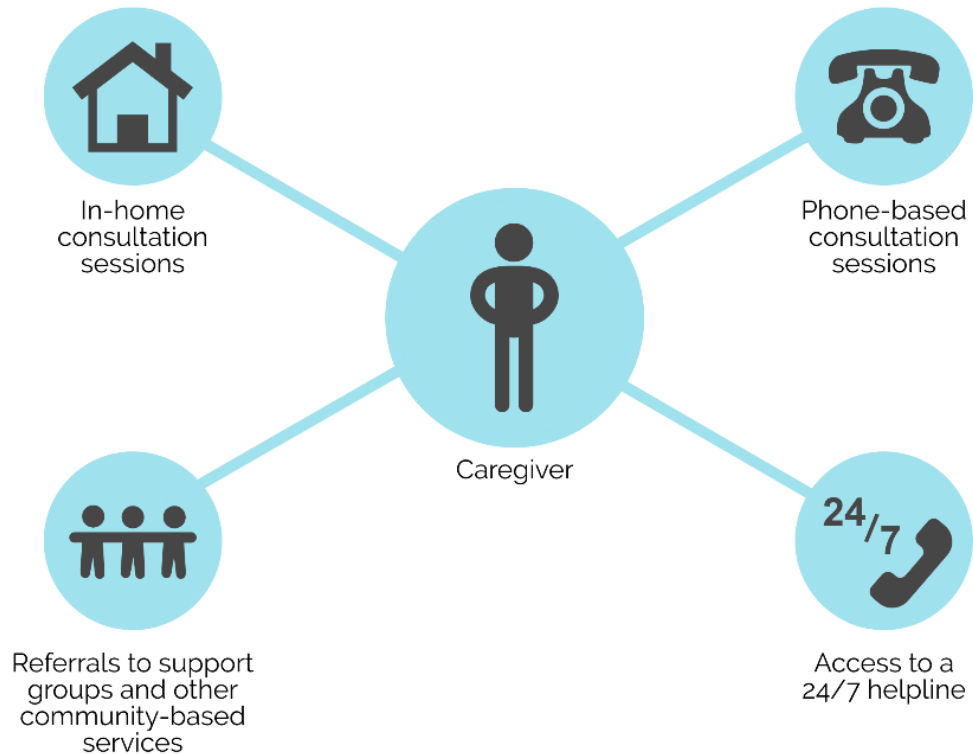
How the Program Works

- **Recruit caregivers.** Trained care consultants with the Alzheimer's Association Minnesota–North Dakota Chapter, which administers the program, offer classes at community centers throughout the state to educate people with dementia and their caregivers about care planning and program resources. The program is publicized through social services agencies, health care providers, Veterans Affairs medical centers, senior centers, the media, and word of mouth.

- **Engage caregivers.** Alzheimer's Association care consultants connect with interested caregivers and schedule a time to meet for a consultation.

- **Perform needs assessment and consultation.** Care consultants conduct a 60- to 90-minute initial consultation session, usually in the caregiver's home. The consultant offers ways to address safety concerns (such as fall risks or dangers posed by impaired driving). In addition, the consultant suggests new coping strategies and provides emotional support, education about dementia, and referrals to support groups and other community-based services. The consultant also collects information detailing the caregiver's view of how this role affects his or her health, family dynamics, and professional life.

- **Develop a tailored care plan.** At the conclusion of the consultation, the consultant outlines a care plan and specific steps for the caregiver to take.

- **Conduct follow-up consultation.** Care consultants conduct one or more follow-up sessions (either in person or via telephone) — ideally, three times during the first six months. The consultant assesses caregiver progress with the care plan and helps the caregiver overcome any barriers to care plan implementation.

III. Program Results

A formal evaluation by the University of North Dakota School of Medicine[20,24] found:

- Over a three-year period, the Dementia Care Services Program staff provided nearly 3,000 consultations with 1,750 caregivers.

- In survey responses and other self-reported data, the unpaid caregivers credited the assistance program with helping them feel more empowered. The caregivers had a mean score of 4.2 (out of a possible 5) when asked to rate the statement: "This program made me feel better equipped to manage this disease."

- Program operation cost the state $1.2 million. Estimated savings were $39.2 million from delayed long-term care placement and $834,000 from reduced use of medical services, such as hospital stays, emergency department visits, ambulance service, and 911 calls.

- Participation in the Dementia Care Services Program was associated with:

   o A 215 percent increase in registration for a commercial location service that offers 24-hour emergency response for people with dementia

   o A 71 percent increase in attendance of dementia education classes

   o A 29 percent increase in establishing health care advance directives

   o A 24 percent increase in power of attorney designations

Michigan replicated the program as a three-year pilot in three counties starting in December 2014. The Michigan Dementia Care and Support Program, which targeted individuals with mid- to late-stage Alzheimer's disease and their caregivers, was evaluated by the University of Michigan School of Social Work.[25] Among the program's 155 caregivers, the evaluators found:

- The percentage of caregivers who said that they received professional support increased from 62 percent in the initial assessment to 92 percent in follow-up assessments.

- The percentage of caregivers who reported feeling confident about dealing with wandering increased from 22 percent to 46 percent; for helping the care recipient with eating issues, the percentage increased from 55 percent to 67 percent.

- The program averted an estimated 35 long-term care placements, saving nearly $3 million and yielding a 434 percent return on investment.

IV. Additional Resources

- Michigan Department of Health and Human Services website. Caring Sheets [Web page for 24 informational "caring sheets" that provide information about dementia and guidance for caregivers]. http://www.michigan.gov/mdhhs/0,5885,7-339-71550_2955_29193_85984---,00.html

- Alzheimer's Association website. Michigan Dementia Care and Support Program [informational flyer]. https://www.henryford.com/-/media/files/henry-ford/patients-visitors/care-and-support-pilot-flyer.pdf

- Klug M. *Assessment of the North Dakota Dementia Care Services Program: January 2010 to June 2013*. Grand Forks: University of North Dakota School of Medicine and Health Sciences, Center for Rural Health; July 2013. https://ruralhealth.und.edu/pdf/assessment-of-the-north-dakota-dementia-care-service-program.pdf

Operation Family Caregiver

I. Background of the Problem

Families and friends of returning military service members and veterans (numbering an estimated 5.5 million in the United States[26]) often face challenges in providing care, assistance, and support to service members and veterans who were injured during active duty. In particular, caregivers may be untrained to deal with the service member's or veteran's chronic conditions, such as traumatic brain injury, post-traumatic stress disorder, or other disability. Caregiver burden and stress is an important issue for patient safety in the home; caregivers for injured service members and veterans are at high risk of both emotional and physical harm.

II. Description of the Program

Operation Family Caregiver, developed in 2012 by the Rosalynn Carter Institute for Caregiving, receives financial support from Johnson & Johnson, the Bristol-Myers Squibb Foundation, and the Bob Woodruff Foundation. This free program seeks to provide support, counseling, and skills to the families and friends of newly returning and injured service members and veterans, with a goal of helping caregivers manage the challenges involved in the transition to the home environment. The program aims to help caregivers by reducing their perception of burden, decreasing depression and other health symptoms, improving their life satisfaction, and increasing their problem-solving skills.[27]

The program includes these components:

- **Coaches** who understand military culture, serve military families, possess excellent communications skills, and preferably have prior military experience.

- **Training for coaches** in using Operation Family Caregiver resources, guides, and tools.

- **Training for families** on effective problem-solving processes, self-care, and safety.

- **Broad program access** through in-person or virtual communications.

How the Program Works

The program is customized to the individual needs of the caregiver and family but the intervention generally includes the following activities over a four- to six-month period:

- Following a referral to the program, the coach reviews background information about the caregiver and family.

- During the first week of the program, the coach meets with and begins to establish rapport with the caregiver (in the caregiver's home, at a program service center, or through a virtual communications platform).

- In weeks 2 to 4, in face-to-face interactions, the coach introduces resources and the problem-solving process to the caregiver. Based on the caregiver's assessment and prioritization of problem areas, the coach works with the caregiver to identify realistic solutions that could solve the problems identified.

- The coach helps the caregiver assess both the positive and negative effects of the solutions identified, supports the caregiver using role-play, and aims to instill confidence that the caregiver has the strengths and experiences needed to carry out the solutions.

- In weeks 5 to 7, the coach makes follow-up telephone calls to encourage and counsel the caregiver and receive status updates.

- In weeks 8 to 10, the coach meets face-to-face with the caregiver to discuss how to apply the problem-solving process to the solutions and to reinforce the importance of the caregiver's self-care.

- In weeks 11 to 12, the coach makes follow-up telephone calls to encourage and counsel the caregiver and receive status updates.

- In weeks 13 to 15, the coach meets face-to-face with the caregiver to review the problem-solving process, reinforce the caregiver's self-care strategies, and address safety issues, including helping the caregiver develop a personal safety plan. As a part of the safety alerts protocol, caregivers gain knowledge about suicide prevention, including signs of suicidal ideation in the care recipient and methods for responding effectively.

- In weeks 16 to 18, the coach makes follow-up telephone calls to encourage and counsel the caregiver and receive status updates.

- In weeks 19 to 24, the coach meets face-to-face with the caregiver to review the program components and acknowledge the caregiver's achievements and progress.

III. Program Results

The Operation Family Caregiver Program has nationwide reach through 11 service center locations and provides caregiver access to program staff from anywhere in the United States via a virtual communications platform (see Figure 1).

Figure 1. Operation Family Caregiver Program Locations

Service centers

Access to program staff via virtual communications platform from any U.S. location (map shows examples only)

RCI   Rosalynn Carter Institute for Caregiving (national office)

A two-year pre-post research design study at nine sites included 128 caregivers for military service members and veterans in the Operation Family Caregiver Program.[27] Results showed the following changes in instrument scores at follow-up compared with baseline (statistically significant, $p <$ .0001, except as noted):

- Caregiver burden was reduced (–1.94 change in mean score on the Zarit Burden Scale).

- Depression levels for caregivers were reduced (–7.8 mean score on the Center for Epidemiologic Studies Depression Scale).

- Caregivers reported fewer physical symptoms (–9.69 mean score on the Pennebaker Inventory of Limbic Languidness Scale).

- Caregiver negative problem-solving orientation was reduced (–6.47 mean score on the Social Problem Solving Inventory NPO).

- Caregiver positive problem-solving orientation was increased (+5.29 mean score on the Social Problem Solving Inventory PPO).

- Caregivers reported greater satisfaction with life (+3.34 mean score on the Satisfaction with Life Scale).

- Parental reports of child anxiety were not significantly reduced (–1.69 mean score (p = .07) on the Spence Children's Anxiety Scale: Parent Version).

IV. Additional Resources

- Operation Family Caregiver website. http://www.operationfamilycaregiver.org

- Rosalynn Carter Institute for Caregiving website. Operation Family Caregiver [Web page]. http://www.rosalynncarter.org/OpFamCaregiver/

- Blue Star Families website. Operation Family Caregiver Coaching Program [Web page]. https://bluestarfam.org/resources/family-life/operation-family-caregiver

- Florida State University: College of Social Work website. Operation Family Caregiver [Web page]. https://csw.fsu.edu/service/operation-family-caregiver

- Riverside Health System: Center for Excellence in Aging and Lifelong Health website. Operation Family Caregiver [Web page]. https://www.riversideonline.com/cealh/services/operation-family-caregiver.cfm

Program of All-Inclusive Care for the Elderly (PACE)

I. Background of the Problem

As a way to optimize the care of nursing home–eligible individuals receiving care at home or in a community-based setting, in 1990 the federal government began offering states Medicaid waivers to enable experimentation with value-based service models. The Program of All-Inclusive Care for the Elderly (PACE), an initiative originally developed by San Francisco's On Lok Senior Health Services, was among the first programs. PACE aims to avoid nursing home placement by providing a broad range of care services to Medicare and Medicaid beneficiaries who clinically require a nursing home level of care. The program provides flexibility for caregivers; offers tailored services that manage the complex medical, functional, and social needs of frail elders; and promotes adherence to home safety standards.

Congress authorized 10 PACE replication sites in 1986 and codified PACE as a permanent Medicare program in the Balanced Budget Act of 1997. To date, 31 states offer PACE options to frail elders; 90 percent of PACE enrollees are eligible for both Medicare and Medicaid.[28]

II. Description of the Program

For individuals who are deemed eligible for a nursing home level of care by their state's administering agency, PACE offers an alternative option: living in their homes and communities while receiving coordinated, highly tailored health care services spanning the care continuum. Eligible seniors are assigned to a specific PACE organization that includes an interdisciplinary team comprising clinicians and support service providers. The interdisciplinary team is responsible for conducting initial and periodic participant assessments, performing care planning, and coordinating 24-hour care delivery.

The program includes these components:

- **Initial and ongoing assessments** by the interdisciplinary team

- **PACE center services** (such as adult day and social programs, primary and preventive care, restorative therapy, nutrition services and meals, pharmacy, social services)

- **Transportation** for participants

- **Mental health care services**

- **Care coordination**

- **Assistance with activities of daily living**

- **Prescription medications**

- **Emergency services**

How the Program Works

PACE organizations provide a wide range of services, including adult day programs, primary and preventive care, nutritional support, pharmacy services, social services, transportation, and other support services. Members of the interdisciplinary team (see Figure 1) coordinate services, based on a comprehensive baseline needs assessment. Within 30 days of enrollment, beneficiaries receive in-person assessments conducted by the interdisciplinary team, including an in-home assessment by a team member. Additional assessments are conducted at least every six months

thereafter. Care is provided at PACE centers, at home, or in the community through contracts with other community-based providers. PACE center safety standards, outlined in federal regulations, address wheelchair accessibility, handrails, safe water temperatures, housekeeping chemical storage, cleanliness, and infection control protocols.

Figure 1. Members of the PACE Interdisciplinary Team
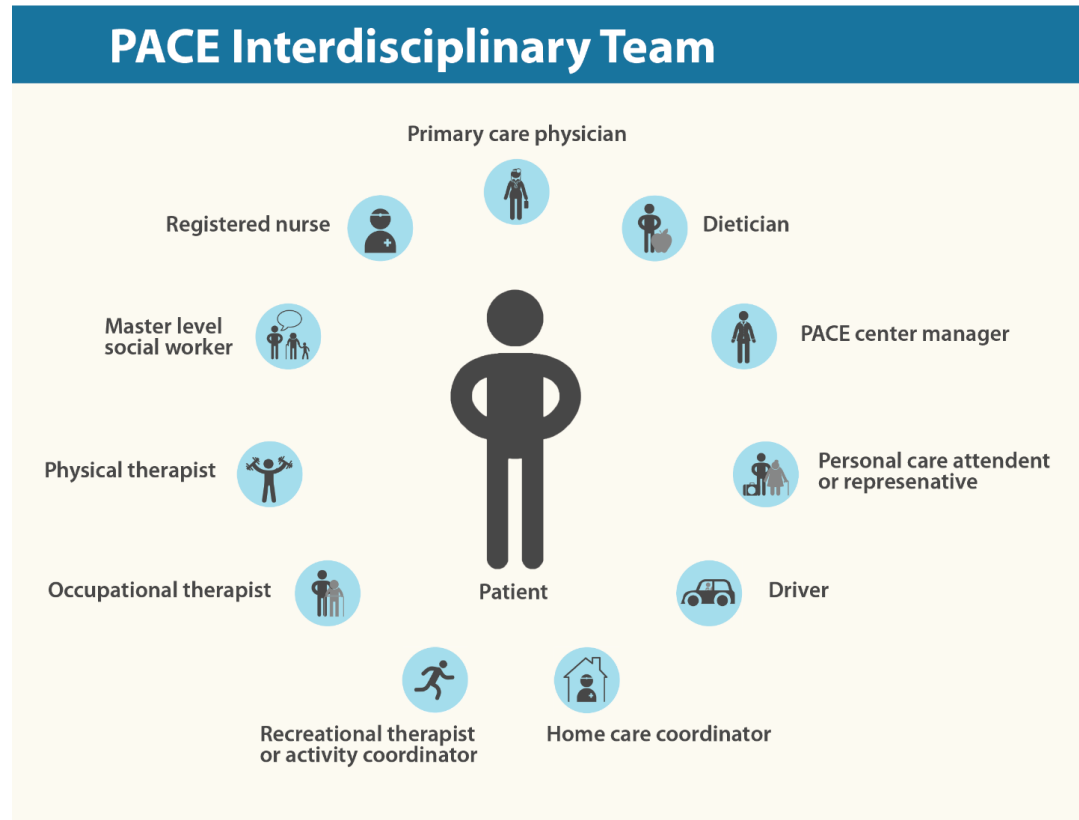
At a minimum, the assessments address the following health and safety concerns:

- The home environment, including the ability to safely enter and leave the home

- Physical and cognitive function

- Medication use

- Participant and caregiver preferences for care, including advance care planning and participant goals of care (person-directed care)

- Socialization and availability of family support

- Current health status and treatment needs

- Nutritional status

- Participant behavior

- Psychosocial status

- Medical and dental status

- Participant language and cultural needs

Based on the assessment findings, the interdisciplinary team creates a tailored care plan with a strong prevention component. If the participant is hospitalized or enters a skilled nursing facility, the interdisciplinary team often participates in clinical rounds that involve the participant.

The program is funded by a combination of sources, including Medicare, Medicaid, and private payers. Reimbursement is a fixed per member per month fee that covers the entire spectrum of participant-tailored services that care for the whole person. Because PACE assumes the full risk of the participant, the organization may find it cost-effective to provide interventions that are not traditionally covered by Medicare or Medicaid. For example, if the interdisciplinary team determines that a participant needs to have an air conditioner installed in his or her apartment perhaps because of a pulmonary condition, the program could cover that expense.

III. Program Results

- A 2014 federally supported evidence review suggested that PACE is cost-neutral relative to traditional Medicare.[29] It also noted that PACE enrollees experience fewer hospitalizations than their counterparts in fee-for-service Medicare. Of the studies included in the review, the one with the strongest evidence rating found that PACE enrollees were nearly 30 percent less likely to be hospitalized than a matched comparison group.[30]

- A 2016 Commonwealth Fund report suggested that the original (On Lok) PACE program's 30-day readmissions rate was half that of other Medicare beneficiaries.[31]

- A 2015 study found that PACE enrollees had a 31 percent lower risk of long-term nursing home admission than enrollees of Medicaid home- and community-based waiver programs, suggesting that PACE may help reduce long-term nursing home utilization.[32]

- Approximately 93 percent of PACE participants report that they would recommend the program to a friend or relative. [31]

IV. Additional Resources

- National PACE Association website. Helpful Links [Web page]. https://www.npaonline.org/policy-advocacy/state-policy/helpful-links

- National Archives and Records Administration, Office of the Federal Register. Part 460: Programs of All-Inclusive Care for the Elderly (PACE). *Electronic Code of Federal Regulations* (eCFR). https://www.ecfr.gov/cgi-bin/text-idx?SID=d0ac3a6d03cfe28139f1b3ebc3b6cc7d&mc=true&node=pt42.4.460&rgn=div5

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Pharm2Pharm: Pharmacist-to-Pharmacist Care Transitions Program

I. Background of the Problem

Medication errors and adverse drug events represent a significant patient safety concern, particularly for older adults. Medication-related safety issues arise frequently, especially following discharge from a hospital when hospital staff adjust medications to address the acute reason(s) for hospitalization. Without close monitoring and follow-up after an individual is discharged home, these issues can lead to additional hospitalizations that not only are often preventable, but routinely result in unnecessary medical spending and heightened risks to safety and health that would otherwise have been avoidable.

II. Description of the Program

The University of Hawaii developed the Pharmacist-to-Pharmacist (Pharm2Pharm) Care Transitions Program through a Health Care Innovation Award Round One from the Center for Medicare & Medicaid Innovation, in collaboration with the Hawaii Community Pharmacist Association (an organization that is no longer active). In operation from 2012 to 2016, the program aimed to avoid preventable hospitalizations by addressing medication management issues that can arise for high-risk older adults (ages 65 and older) during transitions of care from the hospital to home and during subsequent follow-up care in the home setting.

The program includes these components:

- A formal model of **care coordination** between hospital and community pharmacists includes tracking of medication safety issues for up to a year after hospital discharge.

- **Specialized training** of hospital and community pharmacists enables them to play a more proactive and integrated role in medication management during and after the transition from the hospital to home.

- **Communication and collaboration** with the patient's primary care physician or other health care providers helps identify and resolve drug therapy problems.

- A **health information technology system** supports medication management by allowing pharmacists to access the information needed to identify and resolve drug therapy problems and communicate electronically.

- A new **payment approach** for community pharmacists that is based on minimum performance standards.

How the Program Works

The Pharm2Pharm program includes these activities (see Figure 1):

- Pharm2Pharm targets older adults who have been hospitalized and discharged to home and are most at risk for subsequent medication-related hospitalizations and emergency department visits. Criteria for the target group include taking 15 or more medications, having a history of medication-related hospitalization, or being newly diagnosed with a condition such as heart failure or diabetes that requires new medication regimens for disease management.

- Specially trained hospital consulting pharmacists (HCPs) determine patient eligibility for the Pharm2Pharm program using standardized eligibility criteria. Eligible patients are identified by review of hospital admission data, referral by hospital care team members, or outpatient physician referral.

- The HCP introduces the Pharm2Pharm program to the patient. If the patient agrees to participate, the HCP conducts an in-depth review and reconciliation of the patient's medications, provides education about the medications, and discusses any new medications that were ordered for the patient during the hospitalization.

- Prior to hospital discharge, the HCP works with the patient to schedule a follow-up appointment with a community-consulting pharmacist (CCP). After discharge, the HCP electronically communicates relevant information to the CCP and calls the patient to ensure that the patient has necessary medications, answer medication-related questions, and remind the patient of the appointment with the CCP.

- The CCP has follow-up visits with the patient as needed over the course of the subsequent year, with the goal of ensuring ongoing medication safety in the home setting. The CCP conducts these visits in person, in the community pharmacy or patient's home, or by phone if requested by the patient. During the visits, the CCP reconciles the patient's medications and — based on clinical information available through the state health information exchange and other health information technology systems — systematically identifies and resolves drug therapy problems.

- The CCP communicates with the patient's primary care provider at least quarterly to summarize his or her visits with the patient. This summary includes the advice given to the patient, recommendations for the patient's treatment plan, and pharmacist contact information. As needed, the CCP also contacts the primary provider if the patient has a significant change in health status or medications, or to resolve any clinically significant medication safety issues.

- The CCP uses a standard tool to document interventions and bill for services. A CCP receives four fixed payments per patient over the course of the year based on meeting minimum performance standards related to the frequency of patient visits, the timeliness of the first visit and medication reconciliation post-discharge, and contact with primary providers.

Figure 1. How the Pharm2Pharm Program Works
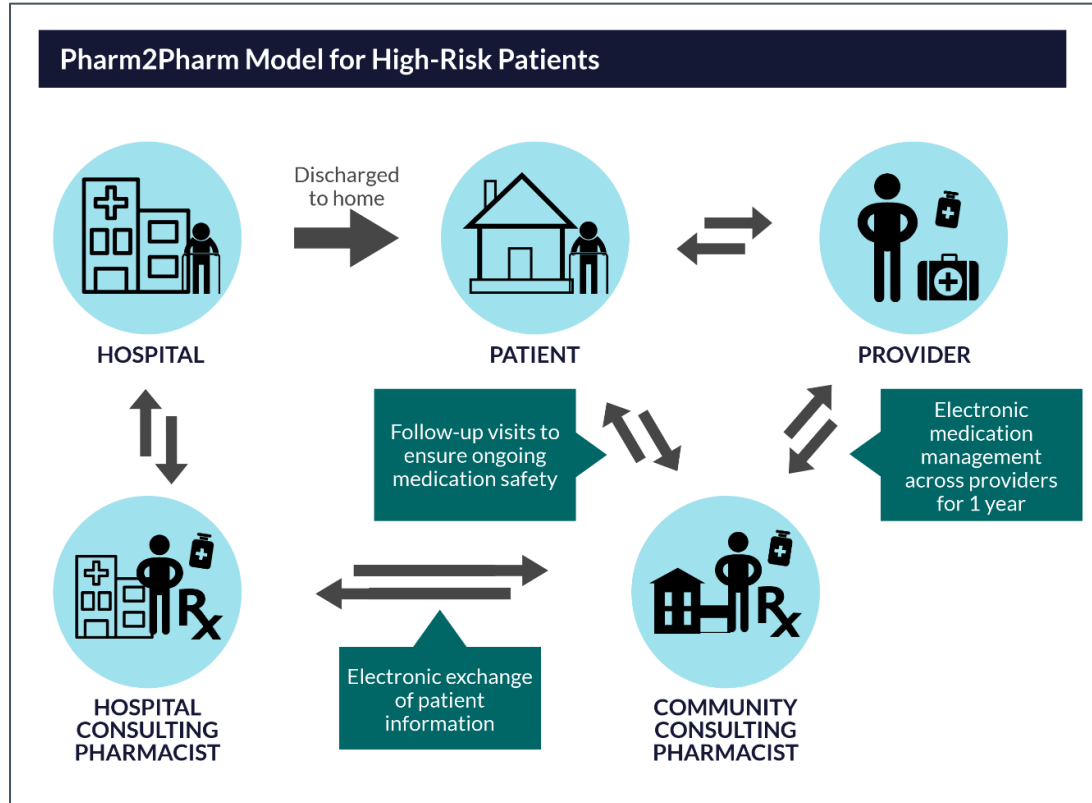
III. Program Results

The program has reduced preventable medication-related hospitalizations, and the associated cost savings have well exceeded program costs. Additionally, the program has captured valuable information about the reasons behind preventable medication-related hospitalizations and shown that pharmacists can successfully use health information technology to support medication management.

Evidence includes the following:

- In a quasi-experimental study of individuals ages 65 and older (the target population for Pharm2Pharm) comparing the six hospitals that implemented the Pharm2Pharm program to five control hospitals:[33]

  o Medication-related hospitalizations were 36.5 percent lower in hospitals that participated in Pharm2Pharm than in comparison hospitals (46 per 1,000 versus 72 per 1,000, respectively).

  o Estimated cost savings resulting from hospitalization reductions were $6.6 million per year, exceeding the $1.8 million annual costs of the HCPs and CCPs in the Pharm2Pharm program.

- In an analysis of hospitalizations that did occur among Pharm2Pharm patients after enrollment in the program:[34]

  o Of 401 hospitalizations, 26 percent were determined to be medication-related and potentially preventable, with the most common reasons being nonadherence due to

patient choice (23.8 percent), untreated condition for which medication is indicated (13.3 percent), dose too high (10.5 percent), and dose too low (10.5 percent).

- o The percentage of hospitalizations that were medication-related and potentially preventable was significantly higher in more rural areas (30 percent) than in urban areas (17 percent).

- ✓ Descriptive statistics demonstrated that the pharmacists adopted and meaningfully used health information technology to support the medication management processes, including:[35]

  - o A prescription fill history query tool to support medication reconciliation

  - o The community health record, which includes outpatient lab results and information from acute care episodes, to support the identification and resolution of drug therapy problems

IV. Additional Resources

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- University of Hawai'i at Hilo. Pharm2Pharm Technology HD [video]. https://www.youtube.com/watch?v=QUAZrPVDvnM

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Appendix B: Suggested Tactics for Advancing Medication Safety in the Home

As mentioned in the body of the report, medication safety could serve as an ideal focus for initial collaboratives, whose activities could be informed by the suggested tactics described below.

- Raise awareness about medication-related harm.

  o Expand education on medication safety for care recipients and family caregivers.

  o Create educational materials on medication safety in the home for family caregivers.

  o Develop and launch a national campaign on safe medication use in the home to include high-risk medications, polypharmacy, and safe medication disposal.

  o Consider the Centers for Disease Control and Prevention as a source, using data and materials from the Institute for Safe Medication Practices (ISMP) and other pharmacy groups.

  o Tie efforts to the work of the World Health Organization on medication safety.

  o Roll out the education campaign to the public, home health agencies, and other relevant groups.

  For existing work, see: NHS Scotland Polypharmacy Guidance

- Gather data on medication-related harms and effective safety strategies.

  o Gather data on factors that lead to medication-related harm in the home.

  o Analyze successful community models and the effectiveness of efforts to scale to larger groups; spread effective models.

  o Encourage home care workers to report medication-related events to the Institute for Safe Medication Practices (ISMP) and the US Food and Drug Administration (FDA).

  For existing work, see: Institute for Safe Medication Practices

- Analyze successful community models and the effectiveness of efforts to scale to larger groups.

  o For example, the Program of All-Inclusive Care for the Elderly (see the case study in Appendix A).

- Optimize medication treatment.

  o Use a co-developed treatment plan.

  o Reduce inappropriate polypharmacy.

  o Improve adherence to medication treatment plans through improved health literacy.

  o Assess ability to access needed medication.

- o Proactively address barriers to optimal treatment, such as inability to reach a pharmacy with the required medication because of physical limitations, socioeconomic issues, or lack of transportation.

- Expand the use of currently available resources.

    - o Expand medication reconciliation to include a review of medication bottles (and a check of their contents) in the home.

    For existing work, see: Visiting Nurses Association of America Blueprint for Excellence (materials on medication reconciliation)

- Expand and promote safe medication disposal programs.

- Consider linking efforts with water protection groups.

- To avoid the diversion of medications, advocate for policy changes to allow palliative care personnel to dispose of opioids and other drugs after the death of a care recipient.

    For existing work, see: Dispose My Meds program from the National Community Pharmacists Association Foundation

- Expand the role of community pharmacists and pharmacy students by, for example, involving them in medication reconciliation, counseling, education, and checking medications at the bedside.