

Family Caregiving and Transitional Care: A Critical Review

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FAMILY CAREGIVER ALLIANCE®
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This review and critical synthesis demonstrates that promising approaches and tools exist to make family caregivers integral partners with professionals during transitions between health care and community settings, such as from hospital to home. However, it finds that engaging family caregivers deserves higher priority in most transitional care programs. In addition, it makes a case for greater coordination between medical services and long-term services and supports (LTSS) in transitional care. It concludes with recommendations for research, quality measurement, and public policy to more meaningfully engage family caregivers as partners in transitions across settings.

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Executive Summary

Background

This critical review attempts to shine light on transitional care from the perspective of family caregivers, a key but largely unrecognized member of the health care team. The goal is to distill evidence on what is currently known—and what information is still needed—on making family caregivers integral partners with professionals in providing health-related care during transitions across settings, especially hospital to home. It examines the roles family caregivers play in providing care during transitions, how they characterize their experiences and needs for support, and how family caregiver involvement improves outcomes for patients.

A central focus of the paper is on describing major transitional care programs, assessing the extent to which they actively involve family caregivers, and identifying barriers to greater engagement. Promising approaches and tools exist to make family caregivers full partners with professionals during transitions between health care and community settings, such as from hospital to home. However, this review finds that engaging family caregivers deserves higher priority in most transitional care programs. In addition, it makes a case for greater coordination between medical services and long-term services and supports (LTSS) in transitional care. The paper concludes with recommendations for practice, research, quality improvement, and public policy to more meaningfully engage family caregivers as partners in transitions across settings.

What is at stake?

The risks to older adults during care transitions are well established, and can be associated with poor outcomes, as well as costly yet avoidable hospital readmissions and emergency room use. Risks include medication errors, duplicative tests, lack of coordination, poor communication among professionals across settings, problems in the timeliness of care, and lack of access to vital home- and community-based services.

Family caregivers play critical roles in transitions from hospital to home or other post-acute settings. They not only provide the vast majority of personal assistance received by older adults with disabilities in the United State, but also health-related care, including coordination and continuity of care during such transitions. Although family caregivers are usually the persons who will actually implement care plans following release from the hospital, they rarely are actively engaged in discharge planning. Yet the transition decisions made hurriedly at the point of discharge can change the course of patients' lives for years, as well as the lives of their family caregivers.

What is transitional care and why is it important?

Transitional care is one approach to improving care for chronically ill individuals. Other closely related demonstration and pilot programs abound as the country seeks to reduce the fragmentation and complexity of the current health care system. These

programs include care coordination, disease management, and “patient-centered medical homes”, all of which share some similar dimensions and features. Transitional care is distinguished by its specific focus on the movement of patients from one care setting (such as the hospital) to another (such as home or to a skilled nursing facility) and within settings, such as from different units in a hospital. It also is time limited and typically focuses on “at risk” older adults and others with severe disabilities.

Readmissions among older adults soon after hospitalization, some of which may be preventable if transitional care is good, are common, costly, and of increasing concern. For example, the Congressional Budget Office, based on lessons from evaluations of other Medicare demonstration programs, recently identified transitional care programs as potentially helpful in reducing Medicare expenditures and improving quality.

Methods

We conducted a methodical review of literature, including a search of PubMed and MEDLINE®, the Cochrane Database of Systematic Reviews, and the *Journals of the Gerontological Society of America*. The search focused on studies published in English from 2000 to 2012. Our search terms included “family (or informal) caregivers” and “care transitions (or transitional care or discharge planning.”) Because this paper focuses on transitions across care settings by older adults and other adults with physical disabilities, we excluded studies focusing on children and youth.

The literature on transitional care is growing quite rapidly. To help ensure currency and relevance, we then used Internet searches and the review of publications from key governmental, provider, health policy, and consumer organizations. In addition, we asked the developers of leading transitional care programs, as well as several other national experts on transitional care and family caregiving, to review the draft for accuracy.

The seven transitional care programs selected were all identified as evidence-based transition interventions by the Centers for Medicare and Medicaid Services (CMS) and the Administration for Community Living (ACL) Aging and Disability Resource Center Initiative. They included five “**hospital-to-home**” care transitions programs: the Care Transitions Intervention®, known as the “Coleman model, the Transitional Care Model (TCM)®, known as the “Naylor model, BRIDGE, Project RED, and Project BOOST. Two **physician practice-based coordination programs** with specific transitional care components (Guided Care and GRACE) were also reviewed.

Descriptive data on these programs are presented in a series of detailed tables that include:

1. Key characteristics of each program;
2. Summary of evidence on:
 - a. (1) outcomes for patients/providers;
 - b. (2) cost and resource use outcomes, such as reductions in hospital use;
3. Description of the involvement of family caregivers, including whether outcomes for family caregivers have been assessed.

Major Findings

- ***Family Caregivers Receive Inadequate Support*** - Relatively little research has been conducted on how family caregivers perceive their own roles and needs during transitions across settings. However, the evidence that is available indicates they do not receive adequate recognition or support during the discharge process from health care professionals.
- ***Family Caregiver Involvement Can Improve Patient Outcomes and Continuity of Care*** - The evidence base on how family caregiver involvement affects the quality of health care remains sparse but is expanding. It shows that their involvement has improved outcomes for persons with physical, mental, and cognitive disorders, contributes to greater patient satisfaction, and improves continuity of care. However, evidence suggests that family caregivers should not be expected to provide complex medical care in the home, especially without training or in-home support from professionals.
- ***Health Professionals Are Increasingly Recognizing the Need to Work with Family Caregivers*** - Very little research has been conducted on health care professionals' perceptions of family caregivers roles and needs or on their communication with them. However, leading physician, nursing, social work organizations have affirmed family caregivers' contributions and the need to work in partnership with them.
- ***Many Transitional Care Programs Do Not Actively Engage Family Caregivers*** - While four of the seven transitional care programs reviewed do offer specific steps to actively engage family caregivers as partners, in the other three programs they are viewed more passively. In the latter, mention of family caregivers focuses on how they can help patients adhere to discharge instructions or medication regimens, not on how their expertise can be tapped to improve transitional care or how their needs as individuals should be assessed and addressed (both during discharge and for their caregiving role afterward) as part of effective discharge planning. Outcomes for family caregivers, such as reductions in stress, have been reported for only two of the programs.
- ***A Greater Focus on LTSS is Needed*** - Only a few of these programs place substantial emphasis on coordinating care with LTSS after release from the hospital. This part of the care continuum is essential for most of the "high risk" older adults on which the programs focus, and it is the part in which family caregivers play starring roles.
- ***New Teaching Guides and Programs Are Available but Often Not Accessible*** - While there are good methods of and tools for engaging family caregivers in transitional care, they are not yet being used widely. For example, a growing body of teaching programs, guides and checklists is becoming available to assist both patients and family caregivers during transitions. The challenge now is to make these materials easily usable and available when needed, especially at the point of care. New technologies, especially digital personal technologies, hold promise in this regard.
- ***Barriers to Greater Engagement with Family Caregivers Need to be Recognized*** - Barriers to greater engagement of family caregivers as partners during care transitions include financial pressures on hospitals to reduce length of stay (although increasingly patients are older and sicker) and insufficient attention to arranging and integrating LTSS in health care delivery. Patient education materials continue to be written at a

level that most patients and caregivers cannot understand. Further, many patients and families are reluctant to ask questions for fear of being labeled "difficult," and they remain largely unaware of their discharge-related rights during transitions.

Recommendations

We propose a specific framework to encourage patient and family-centered care during transitions across settings, including assessing and addressing family caregiver needs in the plan of care (see Recommendation 1. Adopt a patient and family-centered framework for transitional care, page 45). Other recommendations are to:

- Fund the development of quality measures focused on family caregivers, including their experiences with transitional care, and enroll more family caregivers in transitional care studies. In particular, include more patients and family caregivers of diverse cultures, ethnicities, and races;
- Conduct research on the attitudes of hospital staff and other providers toward family caregivers and the roles they play;
- Urge greater attention to the role of family caregivers in the development of transitional care policy and programs by the Joint Commission, other accreditation bodies, and provider organizations and institutions;
- Change payment policies to support the engagement of patients and families; and
- Expand family caregiver engagement in new programs in the Affordable Care Act that include improving transitional care, such as the Community-based Care Transitions Program and the Independence at Home Demonstration Program, and advocate for adequate funding for them.

Conclusion

As the U.S. continues its pressing search for ways to contain healthcare costs and improve quality, the one group whose role has been largely ignored is the nation's 42 million family caregivers. Transitions between care settings have been identified as points where preventable breakdowns in communication and care processes result in poor outcomes for patients and unnecessary costs. Family caregivers are a critical missing link in improving transitional care for frail older adults with disabilities—with few exceptions, they are the ones who will provide and/or coordinate most of the care received after discharge home. It makes little sense to overlook both their contributions and their needs for support.

What is at Stake

Transitions between settings are recognized as the most vulnerable points in the delivery of health care and long-term services and supports (LTSS).¹ The risks to older adults during transitions are well established, and can be associated with poor outcomes, as well as avoidable hospital readmissions and emergency room use. Breakdowns in care during transitions from hospital to home resulting in negative outcomes have been documented for more than a decade.² Such risks include duplicative tests, medication errors, lack of coordination, poor communication among professionals across settings, problems in the timeliness of care, and lack of access to vital home and community-based services.

Family caregivers play critical roles in transitions from hospital to home or other post-acute settings. They not only provide the vast majority of personal assistance received by older adults with disabilities in the United State, but also health-related care, including coordination and continuity during such transitions. In fact, family caregivers are usually the persons who will actually implement care plans following release from the hospital.

Transition decisions that are made hurriedly at the point of discharge can change the course of patients' lives for years, as well as the lives of their family caregivers. As Dr. Eric Coleman has testified:

"These transfers are often referred to as transitional care, the area of health care that is primarily concerned with the relatively brief time interval that begins with preparing a patient to leave one setting and concludes upon being received in the next setting. Transitional care poses challenges that distinguish it from other types of care. Many transitions are unplanned, result from unanticipated medical problems, can occur at all hours of the day or night as well as on weekends, involve clinicians who may not have an ongoing relationship with the person, and happen so quickly that even the most dedicated health care professionals and family caregivers are not able to

respond in a timely manner. As a result, these persons are largely unprepared for what transpires and are often uncertain about their role. . . .

Care transitions represent a highly vulnerable time for errors that compromise quality and safety.... Our research has found that over 40 percent of older adults transferred out of the hospital experience at least one medication discrepancy. By default, patients and their family caregivers have become the silent care coordinators, performing a significant amount of their own care coordination with no specific preparation, tools, or support."

—[Eric Coleman, Testimony to the Senate Aging Committee, July 2008³].

In addition to being the "silent care coordinators," unpaid family caregivers directly provide most long-term services and supports needed by persons with chronic illnesses and functional limitations, as well as much direct nursing care. They know the strengths and weaknesses of patients and caregivers in chronic care management; accompany patients to physician visits and serve as facilitators of patient-physician communication; are "walking medical records" in emergencies and provide care continuity across settings. They manage behavioral problems; spot early warning signs of symptom changes and medication errors and interactions; are gatekeepers who help decide when and which clinician to call, and when to seek emergency care. They identify patient needs for community-based services as well as medical equipment and assistive devices/technology; are advocates for patients with physicians and other health professionals, and in hospitals and rehabilitation facilities, with home health agencies, and in nursing homes. They monitor costs and deal with insurance claims and denials, and help to express patient goals and preferences for care.

This paper attempts to shine light on transitional care from the perspective of the family caregiver—a key but largely unrecognized member of the health

care team. The goal is to distill evidence on what is currently known—and what information is still needed—on making family caregivers integral partners with professionals in providing health-related care during transitions. It concludes with recommendations for research, quality measurement, and policy.

Background

Readmissions among older adults soon after hospitalization are common and of increasing concern. For example,

one study found that one-fifth of Medicare beneficiaries discharged from hospitals were readmitted within 30 days, and one-third were readmitted within 90 days.

[Jencks, S.F., M. V. Williams, and E.A. Coleman, E.A. 2009⁴.]

Those with multiple chronic conditions experience much higher rates of readmissions. In 2009, 38 percent of Medicare beneficiaries with five or more chronic conditions were re-hospitalized within 30 days, compared to 16 percent of all Medicare beneficiaries.⁵ Some of these readmissions are planned or necessary as follow-up, but many are considered preventable through adequate discharge planning, post discharge follow-up, and improved coordination between hospital and community-based health care teams.⁶

Many readmissions to hospitals are not only preventable but also costly—estimated at roughly \$12 billion per year in Medicare expenditures.⁷ Improving the transitional care process seems to represent relatively “low hanging fruit” in the nation's efforts to improve care and control health care expenditures. A number of the transitional care programs have been found to be cost-effective while improving patient outcomes and satisfaction with care. In addition, hospitals have strong

incentives to reduce preventable readmissions. In October 2012, reductions in Medicare payments to hospitals with high rehospitalization rates for three conditions—congestive heart failure, pneumonia, and heart attack—will begin to be phased in.⁸

The rapid growth in the role of hospitalists—physicians who specialize in the practice of hospital medicine—has been viewed as contributing to fragmentation in the transitional care process. In one study patients under hospitalist care were less likely to be discharged home and were more likely to have ER visits and readmissions than those cared for by a primary care physician.⁹ Another study concluded that the hospitalist model has increased the burden of care coordination on all providers and blurred accountability for the quality of post-discharge care.¹⁰ For their part, hospitalists have not ignored these concerns, having developed one of the transitional care programs discussed in this paper.

Family caregivers play a critical role in supporting family and friends during care transitions, especially after hospital discharge.¹¹ Yet they are rarely involved in the discharge process until patients are about to be released, a period fraught with risk to patients due to hurried “hand-offs”. The immediate period after hospitalization is also precarious for the health of family caregivers themselves, who are then faced with managing care at home.¹² A study of over 500,000 couples enrolled in Medicare found that a spouse's hospitalization is associated with an increased risk of death for the elderly caregiver.¹³

In speaking informally with patients and family caregivers about their experiences with discharge planning, the authors of this paper found that many do not know what discharge planning is. They remember the “discharge” but not the “planning.” Many learn only a few hours before discharge that the care recipient is going home that day and that transportation needs to be arranged. Then they may be handed an illegible list of medications and follow-up instructions, sometimes after all pharmacies in the area are closed for the evening. While this may seem like the worst case scenario,

even health care professionals have described the discharge process as “random events connected to highly variable actions with only a remote possibility of meeting implied expectations”.¹⁴ Only rarely is any professional made responsible for follow-up after discharge, leaving family caregivers to put all of the pieces back together, with little warning and limited information.

{ *The current discharge system is a
national disgrace.* }

[Robert Kane, November 2011.⁴⁴]

Repeated calls have been made for integrating family caregivers as partners in the delivery of health-related care to frail older adults and to persons with disabilities during such transitions.¹⁵ These transitions span from hospital to home or to post-acute care in a rehabilitation facility, skilled nursing facility, or home with Medicare home health services for a limited time, then again when home health service benefits expire and family caregivers are left to carry the load alone.

Methods

Definitions

For this review, we define the following terms:

Family Caregivers Family caregiver refers to any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for an older person or an adult with a chronic or disabling condition.¹⁶

Transitional Care Transitional care is defined here as “a broad range of time-limited services designed to ensure health care continuity, avoid preventable poor outcomes among at-risk populations, and promote the safe and timely transfer of patients from one level of care to another or from one type of setting to another.”¹⁷

Care Transitions In this report, we refer only to transitions from one type of setting to another, not to those from one level of care to another, such as between different units in the hospital. We focus on hospital to home or post-acute care, such as to rehabilitation or home with Medicare home health care services. Very limited research has been conducted on family caregiver roles in transitions from hospitals to nursing facilities, or vice versa.

“Family-centered” care This model was most notably developed in pediatrics and has been adapted in other areas, including cancer, HIV, and palliative and hospice care.¹⁸ It is now beginning to be adapted in care for frail older adults.

One recent definition of patient- and family-centered care is: “Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care, through information sharing, participation in decision-making and collaboration in policy and program development.”¹⁹

Review of Literature

We conducted a methodical review of literature, including a search of PubMed and MEDLINE®, the Cochrane Database of Systematic Reviews, and the *Journals of the Gerontological Society of America*. The search focused on studies published in English from 2000 to 2012. (Extensive reviews, such as that by Naylor et al. 2000, have been published on earlier literature on transitional care.²⁰) Our search terms included “family (or informal) caregivers” and “care transitions (or transitional care or discharge planning.”) Because this paper focuses on transitions across care settings by older adults and other adults with physical disabilities, we excluded studies focusing on children and youth. This method yielded a large number of abstracts. In our review of the abstracts, we excluded studies on transfers within settings, such as different units within hospitals, and on the psychosocial transitions experienced by patients and family caregivers due to the progression of illness or disability, such as among dementia caregivers.

The literature on transitional care is growing quite rapidly. To help ensure timeliness and relevance, we then used Internet searches and the review of publications from key governmental, provider, health policy, and consumer organizations. We adopted a snowball approach in which we examined references in articles included in our initial searches to identify additional sources of potential relevance.

We asked the developers of leading transitional care programs, as well as several other national experts on transitional care and family caregiving, to review the draft for accuracy. Their comments are incorporated in the final paper.

Questions

The following questions were asked:

- What roles do family caregivers play in providing health care, especially during transitions across settings?
- How do family caregivers characterize their experiences providing health care and their needs for support?
- How do health care providers view family caregivers' roles in providing care?
- Does involvement of family caregivers improve outcomes for patients?
- How do transitional care programs compare to other programs for improving care for chronically ill persons, what are their key features and outcomes, and how do transitional care programs engage family caregivers?
 - Comparison to other chronic care programs
 - Key features of transitional care programs
 - What interventions are used in transitional care programs to support family caregivers and use their unique knowledge and skills?
 - Have transitional care interventions improved outcomes of care for family caregivers?

- How can technology be used to engage family caregivers as partners in care transitions?
- What are the barriers to greater engagement of family caregivers in transitional care programs?

Findings

Roles Families Play in Providing Health-Related Care

Historically, most research on family caregivers has focused on their roles in providing LTSS, especially personal assistance in the tasks of daily living. In the mid-1990s, a few experts began studying the medically-oriented care that often falls to family caregivers, especially during post-acute episodes of care.²¹

Table 1, on the following page, shows the multiple roles played by family caregivers including the provision of medical care. These roles were reported in the 2007 Institute of Medicine report, *Retooling for an Aging America: Building the Health Care Workforce*. Caregivers typically play many of these roles simultaneously.

We organized these roles in a framework proposed by Dr. Eric Coleman and Dr. Mark Williams in 2007. Of course, other roles could be added to this list and other organizing frameworks could be used.²² We selected this framework, called DECAF, because family caregivers often seem invisible to hospital staff. This acronym is an easily remembered way for busy hospital staff to identify the types and intensity of family caregivers' contributions.²³ It is not intended to be an assessment of family caregiver needs, which should also be part of transitional care and is discussed below.

DECAF = (**D** - Direct care provision; **E** - Emotional support; **C** - Care coordination; **A** - Advocacy; **F** - Financial).

Table 1: Family Caregiver Roles in Health Care

Direct Care Provision	Emotional Support	Care Coordination	Advocacy	Financial Help
Role: Homemaker Function: Manage household activities. Example: Inventory, purchase food and medications, prepare meals	Role: Companion Function: Provide emotional support. Example: Discuss ongoing life challenges, troubleshoot problems	Role: Coordinator Function: Coordinate care across settings & providers. Example: Ensure flow of information among providers	Role: Coach Function: Encourage patient self-care activities. Example: Encourage patient's engagement in health care, lifestyle (diet, exercise) and treatment adherence.	Role: Financial Manager Function: Handle financial issues. Example: Help to acquire insurance and choose benefit levels; resolve issues re: insurance claims; secondary claims, co-pays and benefit limits
Role: Health Provider Function: Deliver medical care. Example: Administer medications; operate equipment.		Role: Scheduler Function: Arrange medical care. Example: Schedule tests, procedures, and services.	Role: Patient Extender Function: Facilitate provider understanding. Example: Attend appointments; clarify and expand on patient history, symptoms, concerns; introduce topics to provider.	
Role: Attendant Function: Provide task assistance. Example: Hands-on personal care task assistance.		Role: Driver Function: Facilitate transportation. Example: Provide transportation to medical appointments and emergency hospital visits.		
Role: Monitor Function: Assess health status. Example: Ensure that changes in health status are noted and properly addressed.		Role: Technical Interpreter Function: Facilitate patient understanding. Example: Clarify providers' explanations, technical terms; record and remember discussions with providers.		
		Role: Decision-Maker Function: Make medical decisions. Example: Select among treatment alternatives; decide among settings of care.		

Sources:

Wolff, J. L. 2007 (unpublished). Supporting and sustaining the family caregiver workforce for older Americans. Paper commissioned by the IOM Committee on the Future Health Care Workforce for Older Americans.

Coleman EA, Williams MV. Executing High Quality Care Transitions: A Call to Do It Right. *Journal of Hospital Medicine*. 2007; 2(5):287-290

How Families Characterize their Experiences Providing Health Care and their Needs for Support

National surveys of caregivers are relatively rare, and few focus explicitly on caregivers' experiences during care transitions and what types of support are most needed at that time. In addition, the measures traditionally used in LTSS research and policy focus on assistance with daily activities and "instrumental" daily activities, missing many other complex forms of help, including assistance with medical care, that family caregivers often provide.²⁴ Recently, however, researchers have developed new measures assessing difficulty of providing assistance with health care tasks, including taking medication, visiting health care providers, and managing medical bills.²⁵ They found that greater difficulty in assisting with health care tasks is associated with increased strain and depression among caregivers of chronically ill older adults. Caregiver "self-efficacy" (a person's belief about his or her ability and capacity to accomplish a task) was strongly associated with difficulty in providing this assistance.

Summarized below is evidence from surveys, focus groups, and ethnographic research pertinent to family caregivers' experiences providing transitional care.

Each bullet point below refers to a separate study, listed in chronological order by date of publication, unless otherwise noted.

1998 - The first national caregiver survey to demonstrate the prevalence of family caregivers' provision of medical care was conducted in 1998.²⁶ Over half of respondents (54%) reported that the person they cared for had been hospitalized overnight in the prior year. Of that group, 43% percent performed at least one of three medical tasks: (1) bandaging and wound care; (2) using pumps and machines at the bedside; and (3) administering medications. Substantial shares of family caregivers reported receiving no instruction or formal training with these tasks, and one in four said they were doing

this work because the care recipient had been sent home from the hospital too soon.

Being responsible for medical and nursing procedures like managing urinary catheters, skin care around a central line, gastrostomy tube feedings, and ventilators is anxiety provoking for the novice nursing student, but is becoming routine family care of persons with chronic illnesses living at home.

- [Reinhard, et.al. 2008²⁷]

- **2000** - Caregivers in the post-hospital period, surveyed in 2000, reported helping with a wide variety of tasks that were complex and demanding, as well as physically difficult. They were assisting with medical tasks that would be handled by a nurse or nurse's aide in the hospital, such as helping with prescription medicine (45%) and using medical equipment (38%), as well with as a range of "administrative tasks", such as handling the care recipient's finances, health insurance, and applying for government benefits.²⁸
- **2004** - Even within the period immediately following hospital discharge when stroke and traumatic brain injury patients were receiving home health services, families provided roughly 75 percent of total patient care hours.²⁹ None of the family caregivers participating in a 2004 survey in New York City had been referred by any health care professional in the hospital to community-based organizations for any type of support after their family member was discharged

from the hospital. These caregivers felt unprepared for the challenges ahead, including the expiration of any Medicare home health benefits, and experienced the transition as abrupt and unsettling.³⁰ (Medicare pays for home health care for eligible beneficiaries for only a short time, usually weeks, not months.)

- Studies reporting data from the National Long-Term Care Survey (1984-2004)** - Primary caregivers to frail older persons were significantly more likely to provide assistance with indoor mobility (such as transferring from bed to chair) and the administration of medications, including giving injections and changing bandages, in 1999 as compared with 1989. They were significantly less likely to be providing help with household tasks and shopping.³¹ Across the same time period, disability among care recipients increased significantly, while a higher proportion of primary caregivers had to “go it alone” without additional paid or unpaid assistance. Hence they tended to shift their focus to providing more intensive levels of care with greater frequency, with their average hours of help remaining at 30 hours per week.³² The trend toward declining formal (paid) support to supplement family caregiving continued between 1994 and 2004.³³ The decline in formal care may be explained in part by the changes in Medicare home health payment after passage of the Balanced Budget Act of 1997 (BBA), which reduced the availability of these benefits.³⁴
- 2007** - Family caregivers also provide frequent and intense assistance with end-of-life care, according to a survey of family caregivers for chronically ill older adults with disabilities living in the community in 2007. A total of 72.3 percent of chronically disabled older adults in the last year of life were receiving help from family or friends compared with 47% of their counterparts who survived the following year. End-of-life caregivers helped a mean of 43 hours per

week. They were spouses (41.5%), children (39%) and others (19.5%), who on average were 64 years old and tended to be female.³⁵

- 2009** - A 2009 survey of caregivers explored the link between (1) how able and confident they felt about managing their relative/friend's health and following through on medical treatments at home, and (2) their perceptions of the care recipients' transition following discharge from a health care facility. Those caregivers who felt least confident and capable were more likely to report a poor transition, i.e., that a relative or friend had unnecessary medical tests, conflicting information from providers, and problems with poor provider communication.³⁶
- 2009** - Qualitative data from diverse focus groups in 2009 on the needs of patients and family caregivers during the transition from hospital to home found that lack of training contributed to the emotional burden of caregiving among all groups, including English speakers and white caregivers.³⁷ In addition, family and friends, rather than health professionals, were the most important source of information for family caregivers about post-discharge care. Other unmet needs among ethnic minorities, recent immigrants, and seniors with limited English proficiency included: (1) lower levels of informal support than might be expected, leading to feelings of isolation during the transition; (2) lack of linguistically appropriate information and services, and (3) cultural and financial barriers to using LTSS. For example, filial piety, the cultural imperative of family care, emerged as a barrier to the use of formal services during times of transition among many of the study's ethnic groups. Low-income caregivers and older adults reported being unable to afford personal care services or housing. Although some qualified for Medicaid home care services, hours were often inadequate.

- 2010** - In a 2010 national survey of caregivers employed outside of the home, about one in five (21%) had “mixed” feelings about their communication with the health professionals about their relative’s care, and 6 percent said it was “poor.” Sources of family caregiver frustration included health professionals’ lack of time, lack of respect for relatives’ capacity to understand medical information (perceived as condescending by some), and lack of skill in conducting such conversations. When asked what their “one wish” would be for changes in the way doctors, nurses and others in the health care system support family caregivers, by far the most common wish was for better two-way communication with providers—that they take more time to explain things and listen to patients and their family caregivers.³⁸
- 2010** - Focus groups including caregivers and a national survey of adults 40 or older in 2010 by the National Partnership for Women and Families found that consumers want care focused on the “whole person.” Such care encompasses their life situation, caregiver status, home environment, and preferences.³⁹ Patients and caregivers wanted meaningful coordination and communication to enable smooth transitions between settings, free from the errors caused when multiple clinicians do not communicate effectively. They also wanted information so they know what to expect and links to community resources and other appropriate supports.
- 2012** - The desire for greater participation in the discharge process by family caregivers is illustrated by interviews with more than 150 relatives of patients consecutively admitted to an acute care stroke unit in Sweden. While more than half reported they did receive information about stroke as a disorder, fewer reported receiving any information about care, medication, rehabilitation, or support. Roughly 80% said that they had not participated at all in setting goals and identifying the needs of patients. Higher education, a longer stay at the hospital, and being female (as a patient or relative) were all associated with perceptions of higher participation in discharge planning.⁴⁰
- 2012** - Ethnographic research with hospitalized patients and caregivers, reported in 2012, found that “the work of transitioning occurs for patients and caregivers in the hours and days after they return home and is fraught with challenges.” The research, conducted in Kaiser Permanente’s Southern California, Colorado, and Hawaii regions, involved participant observation and in-depth video recorded interviews in the hospital the day of discharge, at post-discharge appointments, and in the home after discharge. Patients and caregivers expressed or demonstrated experiences in six domains: 1) translating knowledge into safe, health-promoting actions at home; 2) inclusion of caregivers at every step of the transition process; 3) having readily available problem-solving resources; 4) feeling connected to and trusting providers; 5) transitioning from illness-defined experience to “normal” life; and 6) anticipating needs after discharge and making arrangements to meet them.⁴¹

When asked what their “one wish” would be . . . by far the most common was for better two-way communication with providers —that they take more time to explain things and listen to patients and their family caregivers.

- [Galinsky, E. 2010³⁸].

“Even when a caregiver was present, hospital staff frequently directed teaching exclusively toward the patient. For example, a nurse and patient sat side-by-side to review instructions; the highly motivated caregiver, seated across the room due to lack of space, was unable to see the written material. The integral role of caregivers in helping patients at home contrasted with their often peripheral role in in-hospital transition processes.”

[Carol H. Cain, et al. 2012⁴²]

- **2012** - The first nationally representative population-based online survey of 1,677 family caregivers to determine what medical/nursing tasks they perform was released. This survey documents that almost half (46 percent) of family caregivers perform medical/nursing tasks for persons with multiple chronic conditions. These tasks include managing numerous medications, providing wound care, using monitors, managing incontinence, and operating specialized medical equipment. In addition, over half (53 percent) of family caregivers who performed medical/nursing tasks served as care coordinators.⁴³

Together, these findings demonstrate that family caregivers routinely provide medical care at home after discharge and do not get information and support from health care professionals that would help them do so. Family caregivers are

dissatisfied with the hospital discharge process and frustrated by the lack of two-way communication with professionals. The lack of support during and after discharge contributes to anxiety and feelings of emotional burden. Ethnic minorities and recent immigrants report even more barriers to communication and support from health care professionals, indicating a pressing need for culturally competent care during transitions.

How Health Care Providers View Family Caregiver's Roles

We could find very few representative surveys or other data on health care providers' views of the roles that family caregivers play. However, leaders in the health care community have long recognized the contributions of family caregivers to medical care, as well as to LTSS. Physician leaders gave timely advice on the role of family caregivers almost two decades ago, and we quote from the Journal of the American Medical Association (JAMA) in 1993:

“Primary care physicians need a strong and effective model to guide their relationships with family caregivers, key resources for the frail elderly...An effective relationship model would acknowledge the key linkage role of the primary care physician, recognize that caregivers and patients form interdependent units, and affirm a care partnership between the physician and caregiver. In this model, the physician conducts periodic assessments of the caregiver as well as the patient; uses a comprehensive home-based approach to care and services; provides training to caregivers, particularly in managing difficult behavior; validates the role of caregiver; and acts as case manager. Educational opportunities and reimbursement structures should be modified to encourage physicians to use the partnership model.”⁴⁴

Almost two decades later, in 2011, another physician leader wrote in JAMA that family caregivers and patients considering post-hospital care options are ill-prepared and in need of guidance:

*“They may not know the range of available options, the relative benefits of each, or have considered their therapeutic goals. Physicians should be informants, advocates, and facilitators of this big leap for their patients. Making a good long-term care decision requires information and structure, but such decisions are often made under great time pressure as part of a hospital discharge. Professional intervention and guidance by an informed but disinterested facilitator may be needed, but hospital discharge planners may not be well suited for this role because their mandate is a rapid discharge ... Physicians need at least a rudimentary knowledge of the array of options and the implications of each. Even if the physician cannot serve as the planning facilitator, the physician should ensure that this task is done well....”*⁴⁵

In 2007, nursing and social work leaders came together to launch a caregiving initiative—*Professional Partners Supporting Family Caregiving*—to address the need of family caregivers for support from health care professionals, in particular from nurses and social workers. The initiative included a historic collaboration among nurses, social workers, and family caregiving advocates that articulated best practices in family caregiving support and mapped out strategies for these professional groups to work together to reinforce and prepare family caregivers in all care settings. The symposium set the stage for the emergence of new models of “family-centered” care. Its findings appeared as special supplements to the American Journal of Nursing and the Journal of Social Work Education⁴⁶. (See: <http://www.nurcenter.com/library/static.asp?pageid=809507>)

A series of focus groups with family caregivers and with professionals (nurses and social workers), conducted as part of this caregiving initiative, indicated high agreement between the two groups on priorities describing the needs of family caregivers for help from professionals. Both groups set high priorities on family caregivers’ need for help managing stress/coping strategies; communicating with professionals, and information on disease and information about available services. Aside from stress management, none of the identified needs focused on the wellbeing of the caregivers.⁴⁷

The views of African American and Hispanic family caregivers, along with nurses and social workers who work with caregivers, primarily in hospital settings, also were explored as part of this initiative in a series of focus groups around the country in 2011. Both African American and Hispanic caregivers often felt invisible in the hospital, ignored by hospital staff, and unprepared to manage complex care at home, including managing medications. For Hispanic caregivers, language remains a major barrier. Nurses and social workers experience major challenges in responding to differing cultural preferences for care. When presented with possible solutions to improve collaboration, both the diverse family caregivers and the health care professionals shared common views, including the need for a 24-hour hotline to respond to caregiver questions once home and having a care coordinator available after discharge.⁴⁸

Recently, the Next Step in Care’s transitions in care quality improvement collaborative (TC-QuIC), an initiative of the United Hospital Fund, studied differences between providers and caregivers’ perceptions of communication. While two-thirds (67%) of the providers said the family caregivers were given an estimate of the patient’s length of stay “always or usually,” only 39% of the caregivers agreed. The biggest gap, however, was in the two groups’ perceptions of whether caregivers’ needs had been assessed: with 83% of the providers saying “always/usually” compared with 35% of the caregivers.⁴⁹

In 2009, The American College of Physicians (ACP) in conjunction with ten other professional societies offered ethical guidance to physicians in developing mutually supportive patient-physician-caregiver relationships. The document formally recognized the many roles family caregivers play: "Patients depend on family caregivers for assistance with daily activities, managing complex care, navigating the health care system, and communicating with health care professionals."⁵⁰

The ACP guidance also underscored the importance of partnerships between family caregivers, physicians, and other health care providers:

"Caregivers are valuable members of the health care team, helping patients manage and cope with illness. Patient information provided by the caregiver may be as pertinent and reliable as the medical record. Acknowledgement of the caregiver contribution is vital to ongoing trust and continued collaboration providing patient care. The degree to which family caregivers feel supported by the physician may influence the caregivers' burden attitude, and emotional health status. In turn, their ability to provide care affects patients' health, rates of hospitalization, and long-term care placement. Caregivers experience significantly less depression when the physician listens to their needs and concerns, and validates the importance of the caregiving role."

In addition to this guidance, the ACP also joined with four other clinical organizations and the American Geriatric Society to issue a consensus statement that recognized the "important role" that patients and their family or caregivers play in transitions of care. "Several observational and cross-sectional studies," the document observed, "have shown that patients and their caregivers and family express significant feelings of anxiety during care transitions. This anxiety can be caused by a lack of understanding and preparation

for their self-care role in the next care setting, confusion due to conflicting advice from different practitioners, a sense of abandonment attributable to the inability to contact an appropriate healthcare practitioner for guidance, and . . . an overall disregard for their preferences and input into the design of the care plan. Clearly there is room for improvement in all these areas of the inpatient and outpatient care transition."⁵¹

Family Caregiver Involvement and Patient Outcomes

Relatively few studies have been conducted on how family caregiver involvement affects patient outcomes.⁵² Some of the studies on how family caregiver involvement improves quality of care for the care recipients are summarized below.

Studies Involving Specific Patient Populations . . .

- Engaging families in patient care has been shown to improve outcomes for persons with dementia,⁵³ and for those with schizophrenia.⁵⁴
- A meta-analysis of 30 studies testing psychosocial interventions for caregivers for people with dementia revealed that interventions that were more intensive, adapted to individualized needs, and targeted both patients and their caregivers were more successful in preventing or delaying elders' institutionalization, reducing caregiver burden, and increasing their knowledge and skills.⁵⁵ A recent review also concluded that the literature gives "encouraging indications" that interventions with caregivers for persons with dementia will often have positive effects on the care recipients' behavior, function, and length of time remaining at home.⁵⁶

- Caregivers often play crucial roles in the hospitalization process of patients with Alzheimer's disease (AD). Persons with AD who are hospitalized are more likely to die than those who are not hospitalized, and those who survive hospitalization are more likely to require nursing facility care. Delirium in hospitalized AD patients further increases these risks. The authors conclude by encouraging caregivers to ask providers to carefully consider alternatives to hospitalization.⁵⁷
- Hospital palliative care programs have been shown to improve physical and psychological symptom management for cancer patients and family caregivers alike, as well as improving caregiver wellbeing. The hallmarks of these programs include their interdisciplinary focus, concern for quality of life of both patients and caregivers, and active involvement of caregivers in communication and medical decision-making.⁵⁸
- Training family caregivers of stroke patients in basic nursing skills in a stroke rehabilitation unit improved psychosocial outcomes for both patients and caregivers, while reducing patient rehabilitation costs.⁵⁹
- "Early supported discharge" for stroke patients, which includes caregiver follow-up and education, was shown in eight studies to reduce total hospital length of stay and improve patient satisfaction without adversely affecting survival, functional disability, or quality of life. Moreover, early supported discharge for this population may have reduced caregiver strain and improved some aspects of quality of life among patients as well as caregivers.⁶⁰
- A culturally sensitive Transitional Assistance Program (TAP) for stroke caregivers of veterans in Puerto Rico and Texas resulted in lower depression among caregivers and found that functioning in veterans was significantly linked to caregiver satisfaction with TAP. The TAP begins with a face-to-face meeting with caregivers in the hospital, followed by educational and supportive videophone interventions.⁶¹
- Providing web-based education and support for one year to caregivers of stroke patients discharged home from rehabilitation centers resulted in significant reductions in stroke patients' self-reported use of health care services, including emergency room visits and hospital readmissions. However, no differences between the intervention and control groups were found in the wellbeing of caregivers themselves.⁶²
- A Japanese study of frequent rehospitalizations of patients with congestive heart failure found that readmissions reflect the interplay between medical and social factors among patients and family caregivers. It concluded that adequate professional support of both patient and family during the hospitalization and discharge planning, as well as medical follow up, was needed. In addition, professional support in home care after discharge was found to be more effective in reducing readmissions than nonprofessional support by family caregivers alone.⁶³
- Video ethnography of the experiences of heart failure patients and their caregivers, part of an initiative to improve care transitions for older adults, contributed to major reductions in 30 day hospital readmission rates, helping to reduce readmissions at one medical center from 13.6 percent to nine percent in six months. Kaiser Permanente used the ethnographic

findings to identify patient-centered improvement opportunities, and communicate them effectively to clinical and administrative leaders and front-line staff.⁶⁴ These projects reflect the creative use of technology to both document and improve caregivers' efforts during and after patients' transition. But to succeed, as the authors emphasize, the clinicians and staff who conduct video ethnography "must suspend judgment and listen actively, which creates an environment in which a patient- and family-centered perspective emerges."

- Coordination between formal providers and family caregivers of patients undergoing knee replacement surgery improved caregiver preparation to provide care, which in turn was positively associated with patients' pain control, functional status, and mental health.⁶⁵
- The crucial contribution of caregivers to the successful rehabilitation of patients discharged after hip fracture was recognized in a recent guideline on the management of hip fracture in adults, although the guideline review found little published evidence on this topic. The guideline development group observed that "early discussion with carers of prognosis and discharge planning avoids misunderstanding of rehabilitation objectives", recommending more research on quality of life issues both for patients and carers.⁶⁶

Studies in Various Settings . . .

- Engaging family caregivers in the Guided Care program, a transitional care program in which nurses work with primary care physicians, improved the quality of care for patients.⁶⁷

- Accompanying and helping Medicare beneficiaries age 65 or older during routine physician office visits is a common role for family members, who actively engage in care processes by providing information about their relative's medical conditions, asking questions, and helping to record physician instructions. Four out of ten (39%) beneficiaries age 65 or older were accompanied to office visits, usually by spouses (53%) and adult children (32%). Beneficiaries' satisfaction with their physicians was related to the presence or functions assumed by their companions.⁶⁸
- Family companionship during physician visits also persists over time, and it is almost always the same person who is the companion. Many of the companions also provided assistance with the tasks of daily living to the older adults, who were older, less educated, and sicker than those who did not receive such assistance. These companions were more actively engaged in the physician visits. Over 40 percent of the older adults who received assistance with personal care from their companions were hospitalized during the calendar year, highlighting their relevance to the transitional care process.⁶⁹
- The need to bring family members or friends to medical appointments to help gather information was one of four overarching themes identified in focus groups of patients conducted in the San Francisco Bay area. These focus groups explored beliefs about communication behavior necessary for shared decision-making about treatment options with their physicians.⁷⁰
- A study examining readmissions within 30 days and transitions from hospital to home in two hospitals found that the broad array of providers involved often are not aware of patient and family readiness to assume the

responsibility of managing care in the home setting. Very few patients in this study received referrals for support services and few caregivers were included in the discharge planning process. The authors observe this result is consistent with other findings that have shown “the majority of older adults leave the hospital with unmet needs or are discharged without referrals, despite the need for home care and despite the risk of poor outcomes.”⁷¹

- Having a family caregiver increases the likelihood of discharge to the community after the transition from hospital to nursing home.⁷² Caregivers providing the greatest informal assistance (i.e., more than 35 hours of care per week) were most likely to discharge their loved ones from a nursing home. However, the literature linking family involvement in nursing homes to resident outcomes is sparse.⁷³

Despite these positive outcomes, some evidence also indicates that, without training, family members have difficulty handling the complicated regimens that chronically ill care recipients need.⁷⁴ For example, patients had negative outcomes when untrained informal caregivers managed their home enteral nutrition or tube feeding, including problems with tube displacement, infection, and dehydration.⁷⁵ Medication errors are one of the leading reasons for preventable hospitalizations, yet monitoring drug reactions and knowing when to report them to a health care professional is a skill that often requires training that caregivers do not receive.⁷⁶

In summary, evidence shows that family caregiver involvement has improved outcomes for persons with cognitive impairments, serious mental illness, cancer, stroke, congestive heart failure, and orthopedic conditions. In addition, family caregiver involvement as companions during physician office visits leads to greater patient satisfaction and contributes to continuity of care. Family caregiver

knowledge about the care recipient’s health and functional status, home environment, and care preferences can be highly valuable to physicians and other medical staff, and they can serve as allies with professionals in encouraging adherence to care plans and influencing health behaviors. However, some evidence also indicates that family caregivers are unprepared to provide complex medical care in the home, especially without training. A systematic review of evidence on patient safety and quality concluded that research still needs to determine what family caregivers do well, what they do not do well, and in what areas patient outcomes are most likely to be jeopardized if they do not receive effective training.⁷⁷

We now turn to an examination of the major transitional care programs, exploring if and how they engage family caregivers.

How Transitional Care Programs Compare with Other Chronic Care Programs

Comparison to other chronic care programs

Transitional care is only one approach to improving care for chronically ill individuals. Other closely related demonstration and pilot programs abound as the country seeks to improve coordination of care by reducing the fragmentation and complexity of the current health care system. These programs include care coordination, disease management, and “patient-centered medical homes,” all of which share some similar dimensions and features. Moreover, even within one model, programs vary widely due to being implemented in different settings, for different populations, and in different ways. It is not surprising that definitions of these programs themselves often do not have one consistent meaning. Some of their features overlap with those of transitional care. For example, while care coordination is a broader process than transitional care, all transitional care involves some coordination. Although most transitional care programs are implemented in hospital settings, they

are also being implemented in other settings, such as in “patient-centered medical homes.”

The current focus on improving transitional care in part reflects the results of evaluations of Medicare’s demonstration projects on disease management and care coordination, which showed little or no effect on hospital admissions or Medicare spending. The Congressional Budget Office recently cited several other lessons from the demonstrations as potentially helpful in reducing expenditures and improving quality, including focusing on transitions in care settings and targeting interventions toward high-risk enrollees.⁷⁸

specific focus on the movement of patients from one care setting to another and within settings, such as from different units in a hospital. It also is time limited and typically focuses on “at risk” older adults and others with severe disabilities.

Table 2 on the following page provides an overview of the key dimensions of “hospital-to-home” transitional care and several other chronic care programs. Transitional care is distinguished by its

Table 2: Comparison of Transitional Care Programs to Other Chronic Care Programs

Program Model:	Transitional Care—Hospital to Home	Care Coordination	Disease Management	“Patient-Centered” Medical Homes
Description/Definition:	A broad range of time-limited services designed to ensure health care continuity, avoid preventable poor outcomes among at-risk populations, and promote the safe and timely transfer of patients from one level of care to another or from one type of setting to another. (Naylor, et. al., 2011)	A person-centered, assessment-based, interdisciplinary approach to integrating health care and LTSS in which a care coordinator manages/monitors an individual’s needs, goals, and preferences based on a comprehensive plan, (Berenson and Howell, N3C)	Programs to slow the progression of chronic illness by providing health information and engaging (“activating”) patients to assume an active role in managing their conditions. (IoM, Retooling)	Reorganization of the way primary care practices provide care through (1) a patient-centered orientation;(2) comprehensive, team based care; (3) coordinated care (4) superb access to care; (5) a system-based approach to quality and safety. (Rich et. al., Agency for Healthcare Research and Quality [AHRQ] Decisionmaker Brief)
Target Group:	High risk chronically ill older adults	Varies by program, usually chronically ill individuals or persons with disabilities	Patients with one or more chronic diseases, such as diabetes, hypertension, congestive heart failure	Full range of patients, may include those with complex needs
Setting:	Hospital to home or post-acute care; usually includes one or more home visits & phone visits	Across medical & LTSS settings	Community-based; usually via telephone. May include telemonitoring.	Primary care practice (PCP); team approach
Coordinator:	Usually APN, RN, or social worker	Care coordinators are usually nurses or social workers	Often RNs under physician guidance; can include trained lay persons (IoM)	PCPs, often assisted by care managers, typically nurses or social workers.
Duration:	Time-limited	Ongoing	Ongoing	Ongoing
Scope of Services:	Usually medical, focusing on post-acute	Can span medical and LTSS	Medical	Medical; may coordinate w/ social & mental health services
Caregiver Engagement:	In some Programs	In some Programs	None or limited	Limited except in a few Programs.

Sources: Adapted from Naylor, M.D., and J. A. Sochalski. *Scaling Up: Bringing the Transitional Care Model into the Mainstream. Issue Brief. The Commonwealth Fund.* November 2010. Table 2.

Berenson, R, and J. Howell. *Structuring, Financing, and Paying for Effective Care Coordination. A report commissioned by the National Coalition on Care Coordination (N3C).* July 2009. Note that this definition is broader than that used in the Medicare demonstration evaluations.

Institute of Medicine. *Retooling for an Aging America: Building the Health Care Workforce.* Washington, DC: The National Academies Press; 2008.

Naylor et al. *The Importance of Transitional Care in Achieving Health Reform. Health Affairs*, April 2011 vol. 30, no. 4 (746-754.)

Rich D, E. Rich, J. Libersky and M. Parchman. *Ensuring That Patient-Centered Medical Homes Effectively Serve Patients with Complex Health Needs. Prepared by Mathematica Policy Research. AHRQ Publication No. 11-0109. October 2011.*

Key Features and Outcomes of Transitional Care Programs

Table 3a on the following pages summarizes key features of selected **“hospital to home”** transitional care programs, including whether they engage family caregivers in transitional care processes. These programs were selected because they all have been identified as evidence-based transition interventions by the Centers for Medicare and Medicaid Services (CMS) and the Administration for Community Living (ACL) Aging and Disability Resource Center Initiative. Outcomes for patients and/or providers, as well those for readmissions and cost, are also summarized briefly for all of the programs in *Table 3b*, on the subsequent page.

Table 3a: Key Features of Hospital-to-Home Transitional Care Programs

Care Model: >>	<u>Coleman - CTI[®]</u>	<u>Naylor - TCM[®]</u>	<u>BOOST</u>	<u>RED</u>	<u>Bridge</u>
Short Description:	Transition Coaches focus on skill transfer for common transition related challenges through goals setting, simulation, and developing a single “gold standard” medication list	Transition Care nurses provide comprehensive discharge planning, care coordination, and home follow-up	Hospitalist model, with standardized discharge process and implementation guides. <i>(NOTE: A hospitalist is a doctor who receives special training to take care of acutely ill persons in hospitals)</i>	Hospital to home model with discharge advocate. Special focus on medication management	Social workers provide care coordination from a biopsychosocial perspective to facilitate safe transitions to the community and link hospital & aging network services.
Target Population:	65+ in community. Includes those w/dementia or depression if caregiver willing and able.	65+ with risk factors such as multiple chronic conditions and recent hospitalization. Currently being tested with cognitively impaired persons and family caregivers	High risk, especially older adults	All adult patients	Adults 60+ (and caregivers) identified as at high risk for post-discharge complications
Setting:	Hospital to home and skilled nursing facility to home	Hospital to home	Hospital to home	Hospital to home	Hospital to home and SNF
Coordinator: Caseloads: Training:	Transition Coaches (nurses, social worker). One care coordinator per 40 patients; 1.5 days of training	Master’s prepared nurses. One care coordinator per 39 patients; one month of training on average	Multidisciplinary team/ no specific coordinator. Team leaders often include both a physician and a non-physician. For a care transition improvement team, team leaders may be a hospitalist or other physician and a nursing leader.	Nurse discharge advocate; clinical pharmacist	Master’s level social workers; 1 care coordinator per 45 patients. 1 day training
Duration After Hospitalization:	One month	1-3 months	72 hours post-discharge	Short-term	Up to one month
Scope of Services:	Medical, focus on post-acute; primary focus is on skill transfer for how to handle common transition related challenges	Focus on post-acute. However, services can extend to patients who would be ineligible for care under the Medicare home health benefit and provide for greater	Medical, focus on post-acute	Medical, focus on post-acute	Medical to LTSS

Care Model: >>	<u>Coleman - CTI</u> [®]	<u>Naylor - TCM</u> [®]	<u>BOOST</u>	<u>RED</u>	<u>Bridge</u>
		frequency, duration, and intensity of services after hospitalization.			
Patient Follow-up after Discharge:	Home visit and 3 follow-up phone calls	Home visit within 24 hours, then regular home visits and 7 –day per week phone support	Telephone follow-up 72 hours after discharge	Clinical pharmacist calls 3-4 days after discharge	Phone assessment 2 days after discharge. The social worker intervenes for an average of 6 days to address identified needs.
Interaction w/ PCP or Specialists After Discharge:	All interactions with other health professionals occur through the patient and family	Yes, nurse accompanies patient to first primary care visits & later if needed	Yes	Makes follow-up appt. with physician	Yes. Schedules visits, facilitates inter-provider communication and arranges transportation
Referrals to Community Supports:	Yes	Yes	No	No	Yes
Self-Management/ Patient Education:	Yes	Yes	Yes	Yes	Yes
Medication Review/ Mngmnt:	Yes	Yes	Yes	Yes	Identifies any confusion over medications
Special Tools:	Variety of materials available at no cost, including Patient Activation Assessment, Medication Discrepancy Tool, and quality measure, Care Transitions Measure (CTM)	Comprehensive geriatric assessment including standardized instruments for depression, delirium, cognitive status, activities of daily living, quality of life, and experience with care. Standardized instruments are all available in the public domain	Geriatric Evaluation Tool for Transition	RED checklist with 11 components. Virtual patient advocate who can do “teach back” is being tested.	Comprehensive Social Work Assessment; Dedicated hospital space for Aging Resource Center
Family Caregiver Involvement:	Yes. See Table 6	Yes, when present and available. Required when patients have cognitive impairment See Table 6.	Mentions “patient/ caregiver” in tools. Absence of caregiver to assist with discharge & home care is considered a risk factor for readmission	Limited. Assessing patient understanding of discharge plan “may require contacting caregivers “	Yes. See Table 6

Table 3b. Key Outcomes of Hospital-to-Home Transitional Care Programs

Care Model:	Coleman - CTI®	Naylor - TCM®	BOOST	RED	Bridge
Patient/Provider Outcomes:	Initial results found patients reported high levels of self-identified goal achievement, confidence in obtaining information to manage their condition, communicating with the healthcare team, and understanding their medications. (Coleman 2004)	Three randomized controlled trials (RCTs) consistently demonstrated improved health outcomes, including in quality of care. A recent quasi-experimental study also showed improvements in all health status and quality of life measures. (Naylor et. al. 2011)	Pilot sites indicate that BOOST tools are well received by health care teams and patients as it improved communication and collaboration across functions within the hospital and out-patient physicians. Patients reported a very positive response to what they perceive was an increased level of service and medical attention. (BOOST Fact Sheet)	RCT showed PCP follow-up rate increased, and effects of low literacy on readmission were mitigated. However, the studies that show support for Project RED had the discharge advocate only see two patients per day. (Wagonhurst, 2012).	Rush RCT* shows significant increase in access to community services, understanding of discharge instructions and medication regimens, and lower mortality
Cost and Resource Use:	RCT demonstrated reductions in hospital readmissions within 30 days by 30% in an integrated health system. Anticipated cost savings for 350 chronically ill hospitalized adults was \$295,594 (Coleman 2006) Also significantly reduced readmission rates in fee-for-service settings. (Voss, et. al. 2011 and Parry, et. al. 2009)	RCTs demonstrated reductions in hospital re-admissions and total health care costs, with mean savings of nearly \$5,000 per older adult (Naylor, 2004). A quasi-experimental model found per member savings in a Medicare Advantage plan of \$2,170 at one year. (Naylor et. al., 2011.) In 2011, the TCM was one of a few program models identified by the nonprofit, nonpartisan Coalition for Evidence-Based Policy as meeting the Congressionally-based standards for Top-Tier Evidence. (Coalition, 2011).	Project BOOST mentor sites are in various stages of planning implementation and data reporting. Aggregate findings for sites with an intervention in place for one year will be available in 2012. Early data from six sites that implemented Project BOOST reveals a reduction in their 30 day readmission rates from 14.2% before BOOST to 11.2% after implementation; the data also showed a 21% reduction in 30 day all-cause readmission rates. (Source: Boost website)	RCT showed reductions in ER visits and readmissions versus controls. Saved \$412 per RED participant. (Jack, et .al., 2009)	Rush RCT* showed reductions in hospital readmissions. (Golden 2011; AHRQ 2012). *Note: Bridge Model is an adaptation of the Enhanced Discharge Planning Program, an evidence-based model developed & evaluated at Rush Medical Center
Website:	http://www.caretransitions.org/	http://www.transitionalcare.info/	http://www.hospitalmedicine.org/ResourceRoomRedesign/RR_CareTransitions/CT_Home.cfm	https://www.bu.edu/fammed/projectred/index.html	http://www.transitionalcare.org/the-bridge-model/

Care Model:	Coleman - CTI©	Naylor - TCM©	BOOST	RED	Bridge
<p>SOURCES:</p> <p>Adapted from AoA, [http://www.aoa.gov], and California HealthCare Foundation, <i>Navigating Care Transitions in California: Two Models for Change</i>. CHCF Issue Brief, September 2008.</p> <p>Sources for specific programs include their websites, and the following:</p> <p>AHRQ Innovations Exchange Innovation Profile.. Hospital-Based Social Workers Follow Up with Recently Discharged Older Adults to Resolve Transition Problems, Reducing Readmissions and Deaths. Detailed description of BRIDGE and its evidence base. http://www.innovations.ahrq.gov/content.aspx?id=33442012</p> <p>Coleman, E.A., Smith, J.D., Frank, J.C., Min, S., Parry, C., Kramer, A.M. (2004). Preparing Patients and Caregivers to Participate in Care Delivered Across Settings: The Care Transitions Intervention. <i>Journal of the American Geriatrics Society</i>.</p> <p>Coleman, E.A., Parry, C., Chalmers S., Min, S.J. The Care Transitions Intervention: Results of a Randomized Controlled Trial <i>Archives of Internal Medicine</i>. 2006;166:1822-8</p> <p>Coalition for Evidence-Based Policy: Top Tier Evidence. Transitional Care Model. Available at: http://toptierevidence.org/wordpress/?page_id=582#respond. Accessibility verified: May 9, 2011.</p> <p>Golden, Robyn. <i>Frontline Provider Perspective (on the Bridge model)</i>. Presentation at the NPP Patient Safety Webinar, 07/06/11.</p> <p>Jack, B.W. et al. A Reengineered Hospital Discharge Program to Decrease Rehospitalization: A Randomized Trial. <i>Ann Intern Med</i>. 2009; 150:178-187. Wagonhurst, P. Tools to Successfully Apply for the Centers for Medicare & Medicaid's (CMS) Community-Based Care Transitions Program (CCTP): An Opportunity to Develop Community Programs to Avoid Unnecessary Hospitalizations for Older Adults. <i>The Scan Foundation</i>, April 2012.</p> <p>Naylor, M.D., et al, Transitional care of older adults hospitalized with heart failure: a randomized, controlled trial. <i>J Am Geriatr Soc</i>. 2004;52:675-684.</p> <p>Naylor, M.D. et al. High-value transitional care: translation of research into practice. <i>Journal of Evaluation in Clinical Practice</i>. 10.1111/j.1365-2753</p> <p>Parry, C., Min, S., Chugh, A., Chalmers, S., Coleman, E.A. Further Application of The Care Transitions Intervention: Results of a Randomized Controlled Trial Conducted in a Fee-For-Service Setting. <i>Home Health Care Services Quarterly</i>. 2009;28:84-99.</p> <p>Voss, et al. The Care Transitions Intervention: Translating From Efficacy to Effectiveness, <i>Archives of Internal Medicine</i>. 2011; 171(14):1232-1237.</p>					

A systematic review and summary of 21 randomized clinical trials of transitional care interventions targeting chronically ill adults was recently conducted by Mary D. Naylor and colleagues. It found nine interventions that demonstrated positive effects on measures related to hospital readmissions.⁷⁹ The interventions were diverse in their nature, the settings in which they were conducted, the populations studied, and where patients went when discharged from the hospital, i.e., to home, skilled nursing facility, rehabilitation, or nursing home. All of these interventions relied on nurses as the clinical leader or care manager. They averaged six and a half weeks after discharge, although the three more effective interventions, which demonstrated reductions in readmissions through six or nine months, averaged more than nine weeks after discharge. In-home visits and patient self-management were also included in successful interventions.

As shown in *Table 3a*, hospital-to-home programs all share some common characteristics:

- Interaction with a designated staff person prior to and following discharge (phone, in-person)
- Enhanced discharge planning
- Medication reconciliation

- Coordination with PCP so that follow-up visit is arranged
- Improved provider to provider communication
- Patient and caregiver education
- Referrals to community resources

However, as shown in *Table 4* all of these features vary in their intensity, duration, and scope. For example, medication management can range from simply checking for adverse interactions between the medications the patient was taking previously with those newly prescribed in the hospital to finding out if the patient anticipates any problems getting their prescriptions filled, e.g., due to cost or transportation problems. Engagement of family caregivers can range from token, such as making sure they will be the patient's ride home, to being integrated as full partners in shared decision-making with patients and professionals.

In addition, each of the different programs has unique features, as discussed below.

TRANSITIONAL CARE MODEL (TCM)® –“NAYLOR MODEL”

- In the Transitional Care Model (TCM)®, the “Naylor model,” care is delivered and coordinated over an entire episode of acute

illness by the same master's prepared advanced practice nurse (APN), starting in the hospital and transitioning the patient to home, including stays in a skilled nursing facility (SNF). Social supports are assessed at patient engagement and family caregivers involved to maximize the patients understanding and adherence with the plan of care. Care is available seven days a week and interactions occur within 24 hours of any change in site of care delivery (within the hospital, hospital to community, hospital to SNF, and the like). The focus is on longer-term outcomes and achieving maximal self-management of their complex health needs.⁸⁰

CARE TRANSITIONS INTERVENTION®—"COLEMAN MODEL"

- In the Care Transitions Intervention® (CTI), the "Coleman model," a Transitions Coach focuses intensely on training patients and family caregivers to assert more active roles in care that will last until the "next time" an acute episode occurs. By proactively engaging patients and family caregivers, it is a "To coach, not to do" model rather than a care management model. For example, patients are encouraged to achieve their own personal goals, such as symptom management and functional recovery.⁸¹ Dr. Coleman is currently developing an enhanced Care Transitions Intervention specifically for family caregivers, as well as a measure of family caregiver activation and experience.

THE BRIDGE PROGRAM

- The BRIDGE program is the only social worker model among the transitional care programs. It focuses more directly on linkages to LTSS and use of resources in the aging network than do the other programs. BRIDGE works with overburdened caregivers to provide support, connect them to available services, and evaluate the impact the stressed caregiver has on the patient's recovery.

PROJECT RED

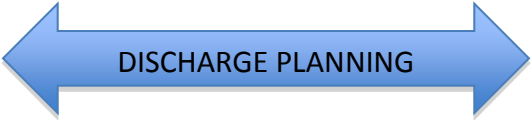



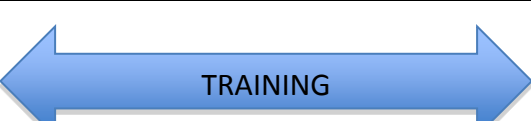
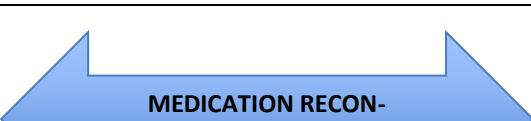
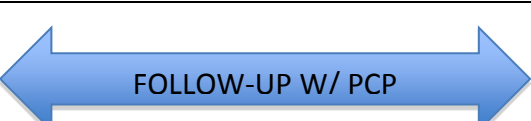
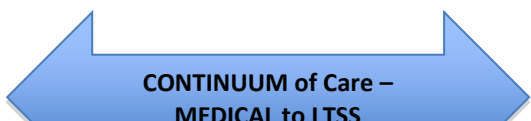
- Project RED re-engineers the hospital workflow process and improves patient safety by using a nurse discharge advocate who follows specific steps shown to improve the discharge process and decrease hospital readmissions. The project is testing "virtual patient advocates," animated interactive characters that educate patients prior to discharge from the hospital.

PROJECT BOOST

- Project BOOST is distinguished by being a hospitalist model. It is being implemented in a growing number of hospitals around the country. It offers technical assistance to hospital teams that involves face-to-face training and a year of expert mentoring and coaching to implement BOOST interventions, which aim to build a culture that supports safe and complete transitions.

Some of the programs above have these key features: (1) use of highly educated and experienced nurses or social workers as care coordinators; (2) having face-to-face contact with patients (and, as needed, their caregivers) and with physicians; (3) educating patients and caregivers; (4) having the care coordinator serve as a communications hub; and (5) managing medications with the help of pharmacists or physicians. Notably, these are the features found to reduce hospitalizations in the latest evaluation of the Medicare Coordinated Care demonstration. In addition, the availability of social work resources was found to be critical for some patients.⁸² Assigning a nurse as the clinical manager, as well as including in-person home visits to discharged patients, were two of the key features in the successful interventions discussed by Naylor et. al.⁸³

Table 4: Variation in Comprehensiveness of Transitional Care Features

Low	Transitional Care Feature	High
Gives patient/family Rx instruction list	 DISCHARGE PLANNING	Conducts thorough assessment of patient and family needs. Jointly set goals. Discusses range of options after discharge.
One phone call	 FOLLOW-UP AFTER DISCHARGE	Frequent home visits.
Reads discharge plan. Asks patient if he/she understands and will sign	 ENGAGING PATIENTS	Uses “teach back” technique to empower patients. Engages patient & family in setting goals and sharing in decision-making
None, unless patient is cognitively impaired	 ENGAGING FAMILY CAREGIVERS	Primary caregiver is identified, their needs are assessed and addressed, and they are involved in decision-making
Lay person receives brief training	 TRAINING	Advanced-practice nurse provides ongoing training
Hospital medications are not reconciled with what patient was taking before	 MEDICATION RECONCILIATION/MONITORING	Pharmacist or physician is involved. Nurse explains why they are needed to patient and family and how to monitor for reactions. Provides personalized Rx record at discharge.
Sends copy of discharge plan to PCP	 FOLLOW-UP W/ PCP	Care coordinator accompanies patient to first PCP visit; shared electronic medical records
Gives patient list of post-acute providers	 CONTINUUM of Care – MEDICAL to LTSS	Arranges post-acute and LTSS services, if needed; has network of collaborating post-acute and LTSS providers

Many transitional care programs, along with other innovative chronic care programs, make some type of referral to home and community-based services but only a few work actively to help set up services after discharge, which can be quite time consuming. Nonetheless, help with tasks such as bathing, dressing, and transferring from bed to chair, which receive only limited Medicare home health coverage, are essential to recovery. Moreover, unmet need for help with activities of daily living (ADL) has been associated with increased risk for hospital readmission. Those who report unmet need for new ADL disabilities after they return home are especially at risk.⁸⁴

Although patients with severe functional limitations are the most likely to have family caregiver support, some family caregivers cannot manage without additional help with what is considered “unskilled” care. These caregivers may need training not only in nursing care but also with tasks such as lifting properly and preventing falls. Other family caregivers may not be able to assist with such tasks because they are working or ill themselves, do not feel competent in doing them, or live too far away, in which case paid (formal) home care services are essential. It should not be automatically assumed—as it generally is—that families will somehow

manage to do it all without help or that they can afford to hire someone to help. They should be asked in the discharge process exactly what they can and cannot do, with and without training.

Table 5a shows the key features of two **physician practice-based coordination programs** with specific transitional care components (Guided Care and GRACE). These two programs are designed to improve coordination and access to services across the full continuum of care, from medical to LTSS. They are longer-term interventions than “hospital to- home” programs. For example, in the Geriatric Resources for Assessment and Care of Elders intervention (GRACE), the length of contact with the patient in one evaluation was two years.⁸⁵

Both Guided Care and GRACE are interdisciplinary team programs, but have different patient populations and team structures. Unlike Guided Care, GRACE focuses on low- income older adults (with incomes less than 200% of the federal poverty level) and was tested in a large primary care practice.⁸⁶ Guided Care was tested in eight primary care practices of varying sizes. Both programs have been tested in randomized controlled trials (RCTs), with promising results.

Table 5a: Key Features of Physician Practice- based Transitional Care Programs++

Care Model: >>	Guided Care++	GRACE++
Short description:	Care coordinator located in primary care practices. Also considered a “patient-centered medical home.” Guided care nurse performs home assessment; works with 3-4 physicians to manage all aspects of care & support caregivers	Care coordinator located in primary care practices. Also considered a “patient-centered medical home.” Home-based geriatric care provided through a multidisciplinary team, including a nurse practitioner, social worker, led by a geriatrician and supported by a pharmacist, physical therapist, and community resource specialist.
Target Population:	65+ at high risk of heavy use of health care services. Being expanded to other populations with complex needs.	Low income, high-risk older adults. Expanded to other populations with complex needs.
Setting:	Primary care physician office	Primary care physician office
Coordinator Caseloads Training	RN who completed 6 week training and earns certificate. Coordinates care for 50-60 patients.	Nurse practitioner and social worker complete a 12 session program. Coordinates care for 125 patients with support of multidisciplinary team.
Duration after Hospitalization	Long-term; indefinite	Long-term; averaged 2 years in evaluation
Scope of Services:	Medical and referrals to LTSS	Medical and referrals to LTSS
Patient Follow-up After Hospital Discharge:	Initial home assessment, monthly phone contact; home visit after ER or hospital stay	Initial home assessment and home visits at least once a month; also after any ER or hospital visit
Interaction w/ PCP or Specialists After Discharge	Yes	Yes
Referrals to community supports:	Yes. Facilitates access to community resources.	Yes. Integrated program is affiliated with pharmacy, mental health, home health and HCBS.
Self-Management/ Patient Education:	Yes	
Medication Review/Management:	Yes	Yes
Special tools:	Customized electronic health record	Protocols for the treatment of 12 targeted geriatric conditions; electronic medical record
Family Caregiver Involvement:	Yes. Caregiver assessment. See Grid 5	Assessment of caregiver burden. Also mentions proactive support of caregivers

Table 5b: Outcomes of Physician Practice- based Transitional Care Programs

Care Model: >>	Guided Care++	GRACE++
Patient/ Provider Outcomes	A randomized controlled trial (RCT) showed Guided Care improves patient and caregiver perceptions of quality and produces high satisfaction among physicians. (AHRQ Innovations Exchange).	RCTs found Program improved the provision of evidence-based care; led to significant improvements in measures of general health, vitality, social functioning, and mental health; reduced emergency department visits and hospital admissions; and generated high levels of physician and patient satisfaction.” (AHRQ Innovations Exchange)
Cost & Resource Use	May lower costs and utilization. Preliminary findings showed net savings of >\$1,300 per patient and \$75,000 per guided care nurse, mostly due to decrease in hospital use . However, one recent analysis found that cost savings were not statistically significant. (Peikes et al.2012) After 20 months, Guided Care patients experienced significantly fewer home health episodes. (AHRQ Innovations Exchange)_	RCT reduced hospital use and resulted in savings for high-risk Medicare subgroups only. (Peikes et al. 2012) A recent analysis found that the program was cost neutral for high-risk patients in the first 2 years, and yielded savings by year three. (AHRQ Innovations Exchange.)
Website	http://www.guidedcare.org	http://medicine.iupui.edu/IUCAR/research/grace.aspx
<p>++ Physician practice-based care coordination programs with transition elements Adapted from AoA, Naylor, and CHCF Sources: program websites, AoA technical assistance grid, and the following: AHRQ Innovations Exchange. Innovation Profile: Team-Developed Care Plan and Ongoing Care Management by Social Workers and Nurse Practitioners Result in Better Outcomes and Fewer Emergency Department Visits for Low-Income Seniors. Detailed description of GRACE and its evidence base. AHRQ Innovations Exchange. Innovation Profile: Onsite Nurses Manage Care Across Settings to Increase Satisfaction and Reduce Cost for Chronically Ill Seniors. Detailed description of Guided Care and its evidence base. Peikes, D. et. al., Early Evaluations of the Medical Home: Building on a Promising Start. Am J Manag Care. 2012;18(2): 105-116</p>		

Interventions in Transitional Care Programs to Support Family Caregivers

While some of the transitional care programs actively involve family caregivers as partners in care, their roles in others are much more limited.⁸⁷
The four programs that specify multiple steps to

engage family caregivers are described in *Table 6* and in more detail below. In addition, the Next Steps in Care program of the United Hospital Fund in New York, which focuses on family caregivers during transitions and could be integrated into any transitional care model, is briefly described.

Table 6: Family Caregiver Involvement in Transitional Care Programs

Care Model: >>	Coleman	Naylor	Guided Care	Bridge
Goals Reference Family Caregivers:	Teach patients & caregivers skills to ensure their needs are met through use of specific tools and work with a Transition Coach	Prepare patients & caregivers to more actively manage changes in health. Enhance patient & family experience with care	Provide continuing education, resources and support for family caregivers.	Reduce caregiver burden and stress. Educate about resources. Increase older adult and caregiver activation.
Key Elements Reference Family Caregivers:	Proactive approach to engaging patients and family caregivers during transitions ("To coach, not to do" model). Caregivers are central to the model. Encouraging Patients and Family Caregivers to Assert a More Active Role During Care Hand-Offs: The Care Transitions Intervention SM	Follow-up includes actively engaging patients and family caregivers to meet their goals: Facilitate communication among patients, caregivers, and professionals	The Guided Care Program for Families and Friends (GCPFF) is one component of the broader "Guided Care model.	Builds from aging network services. Integrates assessment of caregiver burden and stress. Refers families for caregiver support
Articles About Model Reference Family Caregivers in Title or Findings	Yes. Coleman et. al. (2004) conclude that "Supporting patients and caregivers to take a more active role during care transitions appears promising for reducing rates of subsequent hospitalization." Findings of Coleman et. al. (2006) in a RCT suggest that encouraging patients and their caregivers to assert a more active role in care transitions results in reduced rehospitalization rates. Coleman (2011) calls for fostering greater engagement of patients and family caregivers and elevating their status as essential members of the care team.	Yes. Naylor et al. (2007) explored the need for improved transitional care for older adults with dementia or delirium and their caregivers. Bradway et. al. (2012) described the barriers and facilitators to implementing a transitional care intervention for cognitively impaired older adults and their caregivers lead by advanced practice nurses (APNs). M. Naylor and S. Keating (2008) reviewed the state of the science related to transitional care programs for older adults and the role of caregivers in these programs.	Yes. As described in Wolff et. al. (2009), the GCPFF melds support for family caregivers with the delivery of coordinated and comprehensive chronic care and seeks to improve the health and well-being of both patients and their family caregivers.	Yes. See Altfeld et. al. (in press, 2012), Fabbre et al.,(2011), and AHRQ Innovations Exchange (2012).
Tools Specifically for Family Caregivers:	Yes. Works in collaboration with Next Steps in Care by United Hospital Fund, New York	Assessment of caregiver burden, health related quality of life, and experience/satisfaction with care.	An individualized "Action Plan" is developed collaboratively with patient and caregiver based on home	

Care Model: >>	Coleman	Naylor	Guided Care	Bridge
Outcomes for Caregivers Have Been Assessed:	A project is underway to enhance the CTI to more explicitly meet the needs of family caregivers. Results are expected to be ready in 2013. In the process, a new tool to gauge family caregiver activation (FCAT) will be created.	Yes, in ongoing studies. The goal is to lessen burden among caregivers. Currently testing a range of interventions to enhance the care management of elders with cognitive impairment and their caregivers throughout episodes of acute illnesses.	assessment. Yes. The Guided Care group caregivers reported significantly better quality of care for patients. No significant differences were found in caregiver depression, strain, or work productivity at 18 months. After 18 months, employed caregivers reported increased work productivity. See Wolff et. al (2010).	Yes, The Bridge program includes caregiver assessment. The Rush RCT found less stress among patients and caregivers. Sources: Frontline Provider Perspective at NPP Patient Safety Webinar 7/06/11. Also AHRQ Innovations Exchange, April 2012.
<p>Sources:</p> <p>AHRQ Innovations Exchange Innovation Profile. (2012). <i>Hospital –Based Social Workers Follow Up with Recently Discharged Older Adults to Resolve Transition Problems, Reducing Readmissions and Deaths</i>. April 2012. Detailed description of BRIDGE and its evidence base. http://www.innovations.ahrq.gov/content.aspx?id=33442012.</p> <p>Altfeld, S.J., PhD, Gayle E. Shier, MSW, Madeleine Rooney, LCSW, Tricia J. Johnson, PhD, Robyn L. Golden, LCSW, Kelly Karavolos, MA, Elizabeth Avery, MS, Vijay Nandi, MPH and Anthony J. Perry, MD <i>Effects of an Enhanced Discharge Planning Intervention for Hospitalized Older Adults: A Randomized Trial</i>. (2012). <i>The Gerontologist</i> (in press)</p> <p>Bradway, C. et. al. (2012) <i>A Qualitative Analysis of an Advanced Practice Nurse-Directed Transitional Care Model Intervention with Cognitively Impaired Older Adults and Their Caregivers</i>. <i>The Gerontologist</i> (2012) 52 (3): 394-407. http://www.ncbi.nlm.nih.gov/pubmed/21908805</p> <p>Coleman EA, Smith JD, Frank JC, Min S, Parry C, Kramer AM. (2004). Preparing Patients and Caregivers to Participate in Care Delivered Across Settings: The Care Transitions Intervention. <i>Journal of the American Geriatrics Society</i>.</p> <p>Coleman EA, Parry C, Chalmers S, Min. (2006). <i>SJ. The Care Transitions Intervention: Results of a Randomized Controlled Trial</i>. <i>Archives of Internal Medicine</i>. 2006;166:1822-8.</p> <p>Fabbre V.D., Buffington A.S., Altfeld S.J., Shier G.E., and Golden R.L. <i>Social work and transitions of care: observations from an intervention for older adults</i>. (2011), <i>J Gerontol Soc Work</i>. 2011;54(6):615-626.</p> <p>Coleman, E.A. (2011). <i>What Will It Take to Ensure High Quality Transitional Care?</i> http://www.caretransitions.org/What_will_it_take.asp</p> <p>Naylor, M.D. et. al. (2007) <i>Care Coordination for Cognitively Impaired Older Adults and Their Caregivers</i>. <i>Home Health Care Serv Q</i>. 2007 ; 26(4): 57–78.</p> <p>Naylor, M. and S. Keating. (2008) “Transitional Care,” <i>American Journal of Nursing</i>, Sept. 2008. Volume 108, Number 9—supplement: <i>State of the Science: Professional Partners Supporting Family Caregivers</i>. http://journals.lww.com/ajnonline/Fulltext/2008/09001/Transitional_Care.23.aspx</p> <p>Wolff JL, Giovannetti ER, Boyd CM, Reider L, Palmer S, Scharfstein DO, Marsteller J, Wegener ST, Frey K, Leff B, Frick KD, Boulton C. (2010). Effects of Guided Care on Family Caregivers. <i>Gerontologist</i> 2010;50(4):459-470. PMID: PMC2908533.</p> <p>Wolff JL, Giovannetti ER, Palmer S, Wegener S, Reider L, Frey K, Scharfstein DO, Boulton C. (2009). Caregiving and Chronic Care: The Guided Care Program for Families and Friends. <i>J Gerontol Med Sci</i> 2009; 64A(7):785-791. PMID: PMC2844134.</p>				

The Coleman CTI model helps older adults and family caregivers become more comfortable and competent in participating in their care during care transitions. It focuses on transferring a core set of self-care skills to help patients and family caregivers ensure that their needs are met during transitions. Studies of the model have shown that most patients and family caregivers are able to become engaged and do considerably more for themselves than some might expect. Five months after the Transition Coach signed off, these patients continued to remain out of the hospital, showing a sustained effect from investing in a self-care approach.⁸⁸ The CTI, which is relatively inexpensive to put in place, has been implemented in hundreds of organizations around the country.⁸⁹

Mary Naylor and colleagues at the University of Pennsylvania are testing a TCM intervention with cognitively impaired older adults and their caregivers. APNs provide the link between hospital and home (or rehabilitation), using patient and caregiver education about diagnoses, symptom management, and accessing equipment, and services, such as respite care. They focus on care coordination, advocacy, and education through home visits and phone contact, and demonstrate advocacy behavior for caregivers.⁹⁰ The APNs needed to develop individualized approaches for both older adults and caregivers, and “do whatever was necessary to prevent negative outcomes”.⁹¹ This finding will resonate with family caregivers, who also will typically say that they are “just doing whatever is needed” to care for their spouse, partner, or parent. Initial findings indicate that the time to first readmission was lower for older adults who were TCM participants than those in a comparison group not participating in the TCM.⁹² Despite the evidence establishing the linkage between TCM and enhanced value, a number of organizational, regulatory, financial and cultural barriers have prevented the model’s adoption. In response to these challenges and with the support of a number of foundations, the Penn team formed partnerships with leaders of major health insurers to translate and integrate the TCM for use in everyday practice and

promote widespread adoption of the model by demonstrating its effectiveness among at-risk, chronically ill older adults.⁹³

The Guided Care Program for Families and Friends (GCPFF) is one component of Guided Care (GC), a model of primary care for chronically ill older adults that is facilitated by a registered nurse who has completed a supplemental educational curriculum (described in *Table 5*). The GCPFF melds support for family caregivers with the delivery of coordinated and comprehensive chronic care and seeks to improve the health and wellbeing of both patients and their family caregivers. It encompasses (a) an initial meeting between the nurse and the patient's primary caregiver, (b) education and referral to community resources, (c) ongoing “coaching,” (d) a six-session group Caregiver Workshop, and (e) monthly Support Group meetings, all facilitated by the patient's GC nurse.⁹⁴ The Guided Care nurses and primary care physicians work collaboratively with the patient and caregiver to design a patient-friendly plan of care.

Assessment of family caregiver needs as individuals (not just as “resources”) in the hospital is essential to developing discharge care plans that are realistic and appropriate to the “real world” environment in which discharged patients will receive care.⁹⁵ Both “patient-centered medical home” programs, Guided Care and the GRACE, are said to include assessment of family caregivers needs⁹⁶, which seems to occur infrequently in the hospital-based programs. In Guided Care, program leaders developed a tool for caregiver assessment. GRACE uses a measure of caregiver burden.

In the Enhanced Discharge Planning Program (BRIDGE), the social worker follows up after hospital discharge with the patient or the patient's caregiver if the patient cannot communicate. The social worker attempts to verify their understanding and ability to adhere to discharge recommendations and determine if that patient is receiving appropriate

health and HCBS. In more than 80 percent of cases, problems that need to be addressed are identified. The three most common are difficulty coping with change, caregiver stress, and problems managing medical care (including medications).⁹⁷

Next Step in Care, an initiative of the United Hospital Fund, is a campaign that attempts to change practice so that family caregivers are routinely involved in planning, decision-making, and coordinating care, particularly during transitions in care settings. (Note that it is not included in this paper as a “transitional care program” because it is a framework rather than a specific intervention.) Its website observes that most of the existing programs that attempt to address problems in transitional care focus on provider-to-provider communication, basically excluding caregivers. The Next Step in Care has developed 23 user-friendly guides and checklists for family caregivers and providers in English, Spanish, Chinese, and Russian. (See Appendix.) The program also works with community agencies to train staff to use the materials with family caregivers.

In 2010, the Next Step in Care program formed a learning collaborative focused on family caregivers that involves multiple providers—not only hospitals but also nursing home rehabilitation programs, home care agencies, and hospice. This program, Transitions in Care-Quality Improvement Collaborative, or TC-QuIC, is being conducted in several phases. An early evaluation found that many providers viewed the program positively although some aspects did not work as well, such as establishing partnerships with other organizations, and serve as lessons for the future.⁹⁸ In 2012, the participants in the first round were interviewed again by an outside evaluator, who found that many of the improvements first implemented, such as establishing a system for identifying family caregivers and charting that information, had been sustained and spread. The second round, which ended in June 2012, is currently being evaluated.

Transitional Care Interventions and Outcomes for Family Caregivers

As shown in *Table 6*, the only two transitional care programs that have reported outcomes for family caregivers are BRIDGE and Guided Care. The BRIDGE program enhanced caregivers' knowledge and ability to manage at home, and reduced stress. Although Guided Care did not improve caregiver strain or depression at 18 months, family caregivers did report a significantly better quality of care for patients. The authors observe that it is noteworthy that GC caregivers did not experience increases in strain or burden relative to caregivers receiving usual care, a distinct possibility given the medical complexity and challenging care needs of study participants.⁹⁹

Mary Naylor and colleagues' work assessing outcomes for family caregivers of cognitively impaired older adults is ongoing. Results from Dr. Eric Coleman's work to enhance the CTI to more explicitly address the needs of family caregivers should be available in 2013.

A Canadian study of “early supported discharge” (ESD) for stroke patients found that caregivers in the ESD group scored consistently, but not significantly, lower on a burden index than caregivers with usual care, even caregivers for persons with major functional limitations.¹⁰⁰

The paucity of information available on outcomes for family caregivers in transitional care programs indicates a need for more systematic documentation of family care involvement in these programs. Outcome measures of how these programs affect families also need to be developed and tested. As Gitlin and Wolff observe, most current transitional care programs report reductions in readmission rates for patients, “but do not measure at what cost for family members (psychosocial, financial, and health) this may be achieved.”¹⁰¹

How Technological Advances Can Assist Family Caregivers as Partners in Care

Information technologies need to be integrated into daily patient care, as suggested by a study that found huge gaps in patient-physician communication about diagnoses, medications, and discharge plans during hospital stays.¹⁰² Multiple forms of communication appear to be needed, and perhaps the most important is communication with family caregivers.

Hospitalized patients are often too ill or too heavily medicated to be able to absorb and retain medical information. Technology-based approaches are ways “to help caregivers get the right information and support at the right time and in the right place.”¹⁰³

Using pictures or videos has been shown to improve communication, especially among persons with low levels of health literacy. The series of podcasts for family caregivers and health care providers on medication management developed by Next Step in Care, in collaboration with CMS, is an example of the types of technologies that could be available in hospitals, as well as other health care settings, using closed circuit television. (See:

http://nextstepincare.org/Caregiver_Home/Medication_Management_Guide/videos_about_medication/)

Imagine a future in which a patient admitted to the hospital and accompanying caregiver(s) receive immediate information and assistance through access to a Patient Information Center outfitted with computers, closed-circuit video guides, loanable handheld communication devices, along with professional staff to facilitate their use.

In a survey of 1,000 family caregivers who currently used some type of technology, caregivers were most receptive to technologies that would help them deliver, monitor, track, or coordinate their loved one’s medical care.¹⁰⁴ A growing repository of counseling and teaching programs, guides and checklists is becoming available to assist both patients and family caregivers during transitions

between settings. The challenge now is to make these materials easily usable and available when needed, especially at the point of care. The exponential growth of the use of personal technologies, such as the iPhone® or iPad® and their links to interactive Internet websites presents opportunities to empower patients and family caregivers in making health care decisions. These digital tools include: (1) voice enabled phone query systems that provide instant responses to queries (Siri®); (2) interactive internet sites that facilitate the sharing of caregiving information among family and friends (see www.caringbridge.org); and (3) digital treatment and monitoring systems that divert suitable patients in the ER or outpatient settings to their homes rather than the hospital, and give caregivers the tools to assist in a successful transfer (See <http://www.hospitalathome.org>)

Barriers to Greater Engagement of Family Caregivers as Care Partners

Financial and Resource Barriers

On the one hand, financial pressures to reduce the length of stay in hospitals may make discharge planners’ and other hospital staff’s highest priority getting patients out quickly. On the other hand, the growing emphasis on preventable 30-day readmissions offers incentives for hospitals to improve transitional care and reduce such readmissions, at least for patients with the three conditions targeted by CMS, i.e., congestive heart failure, pneumonia, and acute myocardial infarction. However, a recent data synthesis and taxonomy of 43 studies to reduce rehospitalization within 30 days made no explicit mention of family caregivers.¹⁰⁵

Another concern about limiting the focus to patients with these three conditions is that the most frail and vulnerable older adults typically have multiple comorbidities, often including cognitive impairments, which affect outcomes. It is not clear if or how payment for these coexisting conditions will

be treated in the incentive payments. It is also not clear if post-acute providers or LTSS providers—including family caregivers—will be engaged in accompanying quality improvement efforts. Moreover, other diagnoses that can result in rehospitalizations, and in which family caregiver engagement has been shown to improve outcomes, such as stroke and hip fracture, are not targeted. As summed up by Mary Naylor and colleagues¹⁰⁶, reductions in rehospitalizations may be difficult to achieve without better integration of services “to meet both the health and LTSS needs of frail older adults and alignment of Medicare policies across all of the currently siloed providers.”

Barriers to Provider Support

The amount of time and hospital resources available to prepare patients and family caregivers prior to discharge has not significantly changed commensurate with the increasing complexity of discharge instructions due to higher patient acuity and shorter lengths of stay.¹⁰⁷ Other barriers to provider support of patient and family engagement are professional norms and experiences, fear of litigation, and perceived level of effort.¹⁰⁸ In addition, some clinicians still equate families with trouble, in part due to differing perceptions of the roles families should play in and how they should play them.¹⁰⁹

Lack of Professional Training

Lack of professional training about the role that families play in good transitional care is another barrier. A recent review found a growing but still modest number (25) of brief curricular interventions to teach best practices in transitional care to physician-trainees and physicians. The authors recommend that allied health professionals, all of whom are necessary to assure effective care transitions, be involved in developing medical curricula.¹¹⁰ The input of family caregivers as well would be desirable. Additionally, provider accountability would be significantly improved by including measures related to family experiences

with care in transitional care measurement.

Reluctance of Patients to Ask Questions

The reluctance of patients to ask questions or be more assertive with their physicians remains a major obstacle to shared decision-making. As Sherri Kaplan famously observed during an AARP roundtable on patient-centered approaches to quality assurance more than twenty years ago, “It’s hard to be assertive when you’re naked. The doctor is not only going to have clothes on but is going to do and say things that are going to impair recall and compromise one’s ability to make rational decisions.”¹¹¹ Today, patients (very likely their family caregivers too) still fear the consequences of speaking up, such as being labeled as “difficult.”¹¹² Evidence suggests that while some patients do not want to be involved in shared decision-making, many do. AHRQ is working with the Ad Council on a “Questions are the Answer” campaign to help individuals understand that one of the best ways to communicate with their doctor and health care team is to ask questions. (See: <http://www.ahrq.gov/questions/>)

Education/Language Difficulty

Patient education materials (PEMS) that many patients and caregivers are not able to understand contribute to communication problems. The average US resident reads at or below an 8th grade level, and the average Medicare beneficiary reads at a 5th grade level. However, the majority of PEMS available through the National Library of Medicine and a popular electronic health record vendor are written at considerably higher reading levels.¹¹³ The ability to access digital information via the visually and orally enabled devices used by increasing numbers of individuals eventually may serve to break through some of the barriers written materials pose.

Awareness of Rights

Patients and families are still rarely aware of their rights during transitions. For example, Medicare

beneficiaries have the right to appeal discharge decisions if they think they are being discharged too soon. They can talk with hospital staff and their doctor about these concerns. They also can contact their state Quality Improvement Organization (QIO) no later than the planned discharge date and before they leave the hospital to request an appeal. By law, hospital staff must give them the phone number for the QIO and a short guide to the appeal process. If they do this, they do not have to pay for services received during the appeal (except for charges like copays and deductibles). If they lose the appeal, however, they are responsible for the charges. Organizations representing family caregivers and older adults can help their constituencies learn what rights they have during hospitalizations, as well as in appealing discharges from hospitals, home health care, and skilled nursing care.

professionals can share medical information with family caregivers and others directly involved with a patient's care. "The only time this cannot happen is when the patient says he or she does not want his information shared with others."¹¹⁶ Even then, staff should explore the reasons. Often they have more to do with not wishing to be a burden to family than concerns about privacy.

Hospital Use of "observation status"

In an effort to cut down on hospital admissions and readmissions, hospitals are increasing the use of "observation status" for Medicare patients. These patients may be held in the hospital one, two, three, or more days without being formally admitted.¹¹⁴ As a result, they are financially responsible for "outpatient," i.e., Medicare Part B, charges for the episode, rather than complete coverage after a deductible under Part A. At the same time, this "limbo" status most likely makes a casualty of comprehensive discharge planning and opportunities for family involvement in the process. Furthermore, Medicare will not cover a rehabilitation program in a skilled nursing facility unless the patient has spent three days as an inpatient. Information about the observation status issue is available, but very few patients and caregivers know about the problem until it happens to them.¹¹⁵

Patient Awareness of HIPAA Rights

Considerable confusion also surrounds family caregiver rights in the Health Insurance Portability and Accountability Act (HIPAA). Many people still do not know that physicians and other health care

Conclusion & Recommendations

Summary of Key Findings

Relatively little research has been conducted on how family caregivers perceive their own roles and needs during transitions across settings. However, the evidence available indicates they do not receive adequate recognition or support during the discharge process from health care professionals.

The evidence base on how family caregiver involvement affects the quality of health care remains sparse but is expanding. It shows that their involvement has improved out-comes for persons with physical, mental, and cognitive disorders, contributes to greater patient satisfaction, and improves continuity of care. However, evidence suggests that family caregivers should not be expected to provide complex medical care in the home, especially without training or in-home support from professionals.

Very little research has been conducted on health care professionals' perceptions of family caregivers roles and needs or on their communication with them. However, leading physician, nursing, social work organizations have affirmed family caregivers' contributions and the need to work in partnership with them. Together with family caregiving organizations, work is underway to overcome the large gap between the vision and the reality.

Some of the transitional care programs offer specific steps to actively engage family caregivers as partners, but in others they are viewed more passively. In the latter, mention of family caregivers focuses on how they can help patients adhere to discharge instructions or medication regimens, not on how their expertise can be tapped to improve transitional care or how their needs as individuals should be assessed and addressed (both during discharge and for their caregiving role afterward) as part of effective discharge planning.

Few of these programs seem to place sufficient emphasis on coordinating care with LTSS after

release from the hospital. This part of the care continuum is essential for most of the "high risk" older adults on which the programs focus, and it is the part in which family caregivers play starring roles.

While there are good programs of engaging family caregivers in transitional care, they are not yet being used widely.

Public and Private Initiatives

Wide consensus exists that transitional care policies need to be improved. Many leading governmental and non-governmental entities involved in health care policy have recommended ways to improve quality across transitional care setting. These include Center for Medicare and Medicaid Services (CMS) and its partnering Quality Improvement Organizations,¹¹⁷ AHRQ, MEDPAC, the Joint Commission, the Institute of Medicine, American Hospital Association, National Quality Forum, the National Transition of Care Coalition, and the Long-Term Care Quality Alliance.

Consensus is also beginning to emerge among health policy experts that ensuring high quality and cost-effective care will require a much closer focus on the subgroup of "high risk" patients most likely to need expensive care due to multiple chronic illnesses. Moreover, the definition of "high risk" needs to encompass persons with functional limitations *in addition* to chronic illnesses. Medicare beneficiaries who have chronic illnesses and functional limitations account for even higher Medicare spending than those with multiple chronic illnesses only.¹¹⁸ For example, average spending per person on hospital services was nearly double for enrollees with chronic conditions and functional limitations, compared to those with 3 or more chronic conditions only—\$4,600 compared with \$2,500 in 2006. A corollary to expanding the focus to include older adults with functional limitations is to meaningfully engage family caregivers in transitions across settings, which have been described as "critical pathways" to LTSS.

Both the CMS and the Administration for Community Living/Administration on Aging have encouraged pilot programs to improve transitional care over the last five years. These initiatives have informed the development of the Community Care Transitions Program included in the Affordable Care Act, discussed later in the paper.

CMS has recognized the importance of Aging and Disability Resource Center (ADRC) roles as care coordinators in encouraging community living by Medicaid beneficiaries after hospitalization. ADRCs can streamline access to public benefits, link individuals with community-based services and supports, and counsel individuals and their families on service options. In 2008–'09, CMS awarded a total of \$12.4 million in Real Choice Systems Change grants for "Person-Centered Hospital Discharge Programs" to ten states. They are expected to complete activities by the end of September, 2012.

CMS also began a pilot program called "Care Transitions" in April 2009, funding sites in 14 states in order to reduce avoidable readmissions and the fragmentation in care. Each of the Care Transitions pilot communities was led by a state Quality Improvement Organization (QIO). The projects continued through summer 2011. Each QIO worked with partners to design (a) hospital and community-system wide interventions; (b) interventions that target specific conditions or diseases; and (c) interventions that target specific reasons for admission. From August 2008 through July 2011, the 14 participating communities reduced admissions per 1,000 beneficiaries by 5.6%, compared to a 3.4% reduction in 52 peer communities.

Moving forward, QIOs will bring together hospitals, nursing homes, patient advocacy organizations and other stakeholders in communities with high hospital readmission rates. The QIOs' most recent three- year contract cycle includes features and programs that are of interest to organizations seeking to improve care transitions. In particular, QIOs will be under contract to recruit communities and to provide

Medicare claims analyses and assistance in coalition organizing so that many communities can improve transitions. All communities will be welcomed into the QIO's statewide Care Transitions Learning Network. In addition, the QIOs can pick a small number of communities in which to work much more closely. These contracts, started in August 2011, must focus on improvements that yield reductions in readmissions, admissions, and costs for fee-for-service Medicare beneficiaries.

In 2010, ACL funded the ADRC Evidence-Based Care Transitions program, which is intended to fill some of the gaps in care that occur during transitions. This program supports state efforts to significantly strengthen the role of Aging and Disability Resource Centers (ADRCs) in implementing evidence-based transitional care programs that "meaningfully engage older adults and individuals with disabilities (and their informal caregivers)." ¹¹⁹

In 2010, ACL issued awards to 16 states implementing six different evidence-based care transition programs, in which ADRCs support individuals and their caregivers during transitions through the creation of partnerships between health care and community systems. The majority of these states (11 of 16) reference family caregivers in their one-page project summaries. The majority (11 of 16) is implementing the Coleman CTI model. The BOOST, BRIDGE, GRACE, Guided Care, and TCM programs are also being used in one state each. The projects will be completed by the end of September, 2012.

Other federal care transitions initiatives include:

- 2011 ACL Systems Integration grants that have a care transitions component, and
- 2012 CMS/ACL/VA Options Counseling program announcement that specifically highlights role of Options Counseling during times of transition. (See: <http://www.adrc-tae.org/tiki-index.php?page=SysInt>)

Recommendations

Recommendations for Quality Improvement, Research, and Public Policy

Increasing emphasis is being placed on “person and family-centered” care as a way to improve quality and care outcomes. A “person- and family-centered” approach respects and meaningfully involves the older adult’s family caregivers, as appropriate, in the planning and delivery of health care and supportive services.¹²⁰ However, engaging individuals and families in health care, including transitional care, is still far from common. Indeed, the voices of both individuals and families need greater emphasis in “person- and family-centered” care.

Following are recommendations focused on making “person and family-centered care” the rule rather than the exception in transitional care.

1. Adopt a patient and family-centered framework for transitional care

Framework for Patient and Family-Centered Care During Transitions Across Settings*

- A. Patients & families are integral partners in care
 - i. Are identified as partners in care. Primary caregiver (s) may not be the person who accompanies an older adult at admission
 - ii. Work with hospital team to set the goals for care, in the hospital and after discharge
 - iii. Ensure that interpretation services are offered and available when needed, especially when planning for discharge and at discharge
 - iv. Have family caregiver needs assessed and addressed in the plan of care, including those for training and education, ranging from teaching family caregivers how to prepare meals to how to monitor for “red flag” symptoms
 - v. Participate in discharge planning, identifying what family caregivers can and cannot do, and anything in the home environment that could prevent a

- successful recovery, such as stairs or no downstairs bathroom.
 - vi. Identify barriers to obtaining prescriptions or accessing formal services after discharge, such as language barriers or not being able to afford expensive medications or home care.
 - vii. Participate actively in medication management discussions.
 - viii. Are aware of the rights of beneficiaries to appeal Medicare discharge decisions if they think they are being discharged too soon.
 - ix. Share in informed decision-making about discharge options, e.g., to home without home care services; home with home care services; to a skilled nursing facility for rehabilitation. Have this discussion well before discharge so that services can be arranged in a timely way.
 - x. Are given adequate time to discuss, question (if necessary), and sign the plan of care provided at discharge
- B. Patients and families are engaged in improving transitional care practices by routinely examining the patient and the family caregiver’s experience of care
 - i. Participate in patient/family councils or other regular meetings
 - ii. Respond to surveys about their experiences of care
 - C. Patients and families are engaged in policy and research
 - i. Have a seat at the table where policy decisions are made
 - ii. Help design transitional care programs
 - iii. Help design surveys of care experiences and focus groups
 - iv. Give input on developing medical curricula on transitional care

* Adapted by authors from Framework for Patient and Family Engagement in the Medical Home, Sarah Scholle, et. al. AHRQ.121

2. *Focus more attention on the needs of patients and family caregivers of diverse cultures, ethnicities and races.*

Develop networks among hospitals, other providers, and HCBS organizations, including those that serve vulnerable populations. Examples are grassroots language or cultural specific organizations, refugee organizations, and faith-based services.

3. *Fund the development of quality measures focused on family caregivers in transitional care.*

These measures have been identified as a major gap in current transitional care quality measurement.¹²² Include measures of family caregivers' experiences with transitional care, including the extent of burden, levels of support, and experiences with assessment, monitoring, and care coordination. As the Long-Term Care Quality Alliance has observed, "optimal care outcomes should be in accord with person-and family determined goals for care." Hence there is a need to study what quality of life values individual patients and caregivers place on different mobility, independence, and residence outcomes. In addition, a recent Patient-Centered Outcomes Research Institute (PCORI) funding announcement noted that most research on doctor-patient communication has focused on the doctor-patient dyad. Little is known about the role of the patient's family members or significant others in shaping the decision-making process.¹²³

4. *Enroll family caregivers in studies on transitional care that include measures of their needs and the outcomes they experience.*

The lack of data and information on family caregivers of diverse cultures, races, and ethnicities is especially pronounced.

5. *Conduct more research on attitudes of healthcare professionals toward family caregivers and barriers they encounter while trying to improve transitional care processes and engage family caregivers.*

These healthcare professionals include physicians, nurses, social workers, discharge planners, and other hospital staff. Also, conduct more research on whether transitional coaches or care managers should be based in hospitals, primary care physician offices, or other community settings.

6. *Require primary care practices to demonstrate active engagement of patients and families in transitional care and quality improvement activities in order to qualify as a medical home.*¹²⁴

7. *Include information about family caregivers in the electronic medical record that transfers across settings*

This should include not only name and contact information but information from caregiver assessments. Also give families access to medical records in ways that are HIPAA compliant. Explore whether a note could be made in medical records transferrable across providers that the patient has (or has not) given permission to speak with a family caregiver.

8. *Seek meaningful responses by hospitals to the Medicare Conditions of Participation (COP)*

Providers must meet these requirements in order to qualify for reimbursement; in certain circumstances, they require family caregivers' involvement in discharge planning.¹²⁵ Urge greater attention to the role of family caregivers in the development of transitional care policy and programs by the Joint Commission, other accreditation bodies, and provider organizations and institutions.

9. *Change payment to support the engagement of patients and families.*

The key components of good transitional care and good care coordination generally rely upon services not typically covered by fee-for-service (FFS) Medicare. It is not realistic to expect that patient and family-centered care requiring considerable time by a professional can be provided without payment. Examples of payment approaches include additional FFS payments and bundled payments that include LTSS and incentives to coordinate care across health and LTSS. In addition, dedicated investments should be made in training health care professionals in how to engage and support families during transitions.

10. *Expand family caregiver engagement in new programs in the Affordable Care Act*

Advocate for adequate funding for programs that support family caregiver engagement in transitional care.¹²⁶ In particular, focus on:

- ***The Community-based Care Transitions Program (CCTP)*** provides \$500 million in funding to test programs for improving care transitions for high-risk Medicare beneficiaries over a five year period. Hospitals with high readmission rates that partner with community-based organizations (CBOs) or CBOs that provide transition services are eligible for the program. CMS is particularly encouraging Area Agencies on Aging and ADRCs, or acute care hospitals that partner with CBOs, to apply. The CCTP is part of the Partnership for Patients, a national patient safety initiative through which the Administration is supporting broad-based efforts to reduce harm causes to patients in hospitals and improve care transitions. The CCTP builds upon evidence-based transitional care programs by pairing an ongoing payment mechanism with them to reduce readmissions in hospitals with high readmission rates, while maintaining or improving quality of care.¹²⁷

Approximately 30 awards have been made since the funding opportunity was announced in April 2011. CMS will accept applications, approve and enroll participants on a rolling basis as funding permits. The program will run through 2015.¹²⁸ The authors' review of the brief summaries of these programs on the CCTP website showed that only a few specifically mention family caregivers, perhaps because there was little mention of family caregivers in the letter of solicitation. Nonetheless, most of the programs are adopting the CTI intervention, which actively engages family caregivers, and a few have adopted the TCM and BRIDGE program, which do so as well. For any new awards going forward, we recommend that the language in the solicitation be more explicit, and that applicants better address how family caregivers will be engaged in their programs.

- ***Medicaid Health Homes for the Chronically Ill.*** As of 2011, all states will have opportunities to receive 90 percent Federal funding to develop Medicaid health homes for persons with chronic conditions. Many states have already adopted medical health homes, and this option is viewed as an opportunity "to integrate and coordinate primary, acute, behavioral health, and LTSS for persons with chronic illness across the lifespan."¹²⁹ Eligibility for being a provider as a Medicaid health home includes providing person-and family-centered services, transitional care with appropriate follow-up from inpatient to other settings, coordinating and providing access to family supports and LTSS, and having the capacity to use health information technology to facilitate communication between the health team and family caregivers.¹³⁰
- ***Independence at Home Demonstration Program.*** This program will pay physicians, nurse practitioners, and other providers (such as social workers) to deliver primary care

services in the homes of high-need Medicare beneficiaries. The three-year demonstration, beginning in January 2012, will test whether the model improves health outcomes and reduces expenditures for Medicare beneficiaries with multiple chronic conditions. It includes multiple performance measures, many of which are tied to incentive payments, such hospital admissions for ambulatory-sensitive conditions, and contact with beneficiaries within 48 hours upon admission to the hospital and discharge from the hospital and/or ED. It also will test whether the model achieves both consumer and family caregiver satisfaction and reduces caregiver stress.¹³¹

Conclusion

As the U.S. continues its pressing search for ways to contain healthcare costs and improve quality, the one group whose role has been largely ignored is the nation's 42 million family caregivers.¹³²

Transitions between care settings have been identified as points where preventable breakdowns in communication and care processes result in poor outcomes for patients and unnecessary costs. Family caregivers are a critical missing link in improving transitional care for frail older adults with disabilities—with few exceptions, they are the ones who will provide and/or coordinate most of the care received after discharge home. It makes little sense to overlook both their contributions and their needs for support.

Appendix

Resources for Consumers

Next Step in Care

http://www.nextstepincare.org/Caregiver_Home/

Website provides 23 guides and checklists for family caregivers and providers, in English, Spanish, Chinese, and Russian. The topics span admission, planning for discharge, and discharge in three settings (hospital, rehabilitation programs, and home care agencies), as well as other topics such as HIPAA, hospice and palliative care, hospitalist care, urgent care centers, and LGBT caregivers.

Family Caregiver Alliance's Hospital Discharge Planning: A Guide for Families and Caregivers

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2312

Resources from QIOs for Patients

http://www.cfmc.org/integratingcare/patient_resources.htm

CMS discharge list

http://www.medicareadvocacy.org/InfoByTopic/DischargePlanning/Discharge_09_12.03.Checklist.ThinkThroughNeeds.htm

AMA Caregiver Self-Assessment

<http://www.ama-assn.org/ama/pub/physician-resources/public-health/promoting-healthy-lifestyles/geriatric-health/caregiver-health/caregiver-self-assessment.page>

National Transitions in Care Coalition's Patient's Bill of Rights

<http://www.ntocc.org/Portals/0/PDF/Resources/PatientBillOfRights.pdf>

National Stroke Association's webpage of resources for Caregivers & Families

<http://www.stroke.org/site/PageServer?pagename=CARE>

Family Caregiver Alliance

<http://www.caregiver.org>

Website provides information for care planning, increasing shared care within families, legal and financial concerns, resources for family caregivers, direct care videos and tip sheets and an online support group.

Resources for Providers

Links to all of the transitional care programs described in this report can be found in the Tables. Almost all of these websites have tools for providers. In addition, see:

American Journal of Nursing's Professional Partners Supporting Diverse Family Caregivers across Settings

A three-part article-video series in AJN, "Professional Partners Supporting Diverse Family Caregivers across Settings", is designed to help nurses help caregivers. This series is part of the Professional Partners Supporting Family Caregivers project described above. Each article has an accompanying video.

<http://journals.lww.com/ajnonline/pages/collectiondetails.aspx?TopicalCollectionId=16>

Needed: Nursing and Social Work Leadership

Carol Levine writes on the hospital nurse's assessment of family caregiver needs. The article provides advice about how health care professionals can examine their personal attitudes toward caregivers, identify who the primary caregiver(s) are, and communicate effectively with them. It also lists a number of useful assessment tools.

http://www.nursingcenter.com/library/journalarticleprint.asp?Article_ID=815774.

What Do I Need as a Family Caregiver?

A tool developed by UHF's Next Step in Care Program, which is brief, to the point, and allows healthcare professionals to gather information from caregivers in order to develop a care plan, is "What Do I Need as a Caregiver?" available at:

http://www.nextstepincare.org/uploads/File/What_Do_I_Need_as_a_Family_Caregiver.pdf

Teaching Essential Skills to Family Caregivers

Cynthia Nigolian writes on teaching essential skills to family caregivers. Nurses can use "teachable moments" to help the transition from hospital to home. The article provides suggestions and resources to overcome barriers to communication, including cultural and language differences, functional and health care literacy, sensory limitations, and cognitive status. It also describes the key principles of "teach back", a technique use in a number of transitional care programs.

http://www.nursingcenter.com/prodev/ce_article.asp?tid=1259046

Supporting Family Caregivers: Communicating with Family Caregivers

Mary K. Walton writes on fostering partnerships with patients and families during acute care hospitalizations. The article identifies structures and processes that can be used to promote nurse-family caregiver partnership, including admission assessment, change-of-shift reports, bedside rounds, family meetings, discharge planning, and patient and family education. Printer friendly:

http://www.nursingcenter.com/prodev/ce_article.asp?tid=1271946

Community Care Transitions Project:

ACL has developed a toolkit for organizations that will be involved in care transition activities:

http://www.aoa.gov/AoA_programs/HCLTC/ADRC_CareTransitions/Toolkit/index.aspx

Transforming Care at the Bedside

(TCAB)

<http://www.ihl.org/IHI/Programs/StrategicInitiatives/TransformingCareAtTheBedside.htm>

Always Events

The Picker Institute has funded several transitional care "always events."

<http://alwaysevents.pickerinstitute.org/>

Institute for Patient- and Family-Centered Care's Free Downloads: Reports/Roadmaps

With the AHA, the IPFCC published "A Resource Guide for Hospitals on Advancing the Practice of Patient and Family Centered Care." This includes a "Patient and Family-Centered Hospital Self-Assessment Inventory (2004). Visit the IPFCC downloads page:

<http://www.ipfcc.org/tools/downloads.html>

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