

## **Dangerous Transitions: Seniors and the Hospital-to-Home Experience**

Holly Brown-Williams

### **Seniors and Their Caregivers Are at Risk**

Lina Pappas, a 78-year-old woman who lives alone and has no children, was hospitalized for surgery for broken vertebrae. She felt that her hospital doctors were rushed and uncaring. The pain medication she was prescribed made her feel very tired and in a “stupor.” She felt that it also took away her appetite. When she asked her surgeon to speak to her heart doctor about her medication, the surgeon refused to help.



At discharge, many seniors are weakened and disoriented. For those without caregivers, the post-discharge risks are high.

When Miss Pappas came home from the hospital, she continued to be concerned about her medications and their interactions. The side effects of the pain medication continued, and she developed a gum infection that required antibiotics, a new swallowing problem, and a recurrence of sarcoidosis (an autoimmune lung disease). At first, she was bed-ridden and received nurse and physical therapy visits. A month after discharge, she had regained some mobility with the use of a walker, but she still needed help with personal care, especially bathing. At this time,

Medi-Cal (California’s Medicaid program) said that Miss Pappas no longer qualified for in-home services and cancelled her home health aide.

For Lina Pappas, as for many seniors, the hospital experience and the transition from hospital to home can prevent or facilitate the recovery from injury or illness. For some family members, it is the first point at which they assume a caregiving role, and this experience can set the stage for future caregiving.

As elders are released from the hospital after shorter stays and in weaker conditions, there is an even greater need for discharge planning and for post-discharge services at home. This need will grow rapidly in the years to come. People ages 65 and older are the fastest growing segment of the U.S. population, expected to more than double between 2000 and 2050, to 87 million. In California, by mid-century one in five people will be 65 or older. The greatest growth will be among seniors age 85 and up—this population is projected to increase by more than 300%.

Improving the transition experience for both seniors and caregivers should be a primary goal of health care planning.

***“After I came home from the hospital, I had a [home health aide] for a few weeks who helped me take a shower. Two weeks ago they cancelled her because they said my insurance didn’t cover it. I haven’t washed my hair in two weeks. Can you imagine?”***

*Isolated Senior*



*“Discharge planning is non-existent. It occurs in the last hour of the hospital stay. It’s not integrated and no time is spent on it in the hospital.”*

*Policymaker*

### The Hospital-to-Home Study

To better understand the transitional care needs of seniors and their caregivers before, during, and after discharge, Health Research for Action, a center at UC Berkeley’s School of Public Health, conducted a study to:

- Assess the services for seniors and caregivers in four San Francisco Bay Area counties: Alameda, San Francisco, San Mateo, and Santa Clara.
- Assess the hospital-to-home transitional care needs of seniors and caregivers.

### Problems in Transitional Care

The following findings were strongly reinforced by the literature and by informants, including seniors, caregivers, discharge planners and other hospital staff, home and community-based service providers, and policymakers.

**Hospitalization can be a turning point** for seniors, whose health, both physical and mental, often deteriorates after discharge. Many seniors experience breakdowns in care during the transition from hospital to home. Early discharge, often with inadequate information, puts them at even greater risk.



Rehospitalization is one of the poor outcomes frequently associated with inadequate discharge planning and support.

- Examine the needs of selected populations that are especially vulnerable during transitions.
- Identify potential interventions to improve transitional care.

The study included analyses of peer-reviewed studies and secondary data, focus groups with caregivers and providers, interviews with providers and policymakers, and case studies with families and isolated seniors.

**Caregivers are also at risk.** Caregivers reported being unprepared because their care recipient was discharged from the hospital too quickly. This puts the caregiver at risk for physical and mental health problems associated with caregiving.

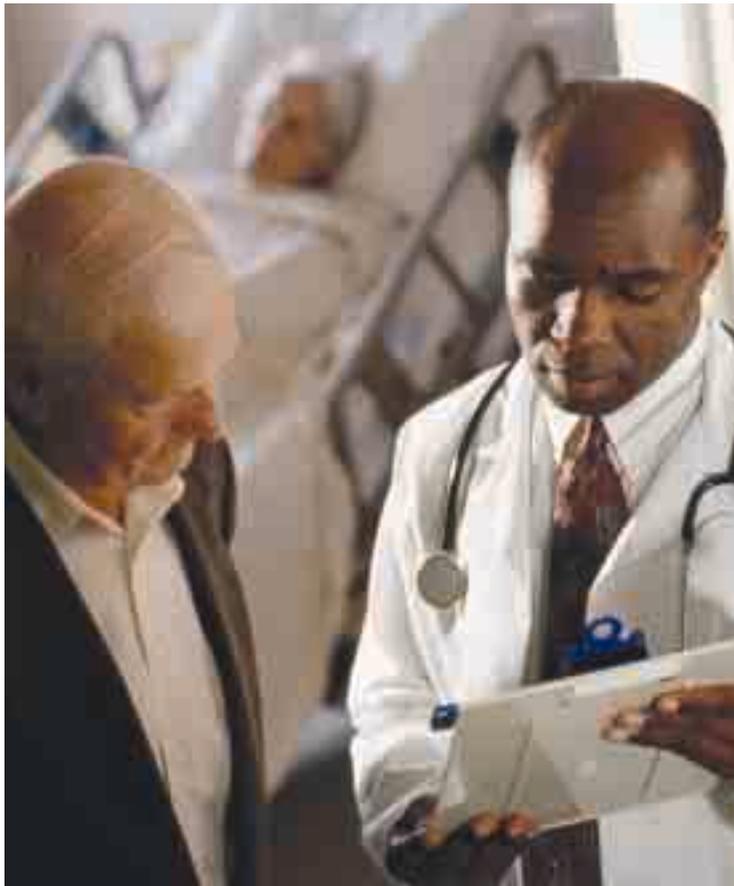
**Some seniors are at very high risk** for rehospitalization and increased morbidity and mortality after discharge, including those with multiple medical problems, functional deficits, cognitive impairment, depression and other

emotional problems, and poor general health.

**Our communities are diverse**—a one-size-fits-all approach to transitional care is simply not sufficient:

- Non-English speakers, racial and ethnic minorities, and recent immigrants face cultural and communication barriers.
- Isolated seniors have no one to advocate for them when they are ill or hospitalized, or to help with post-discharge care needs and coordination.
- Low-income seniors suffer the many hardships associated with living in poverty. They may qualify for public programs, but experience other barriers to care, such as lack of transportation and other social supports.
- Middle-income seniors often do not qualify for public programs, but may lack the money to purchase the care they need.
- High-income seniors are not immune to the impact of diseases with a high burden of caregiving, such as Alzheimer's. Having the money to pay for care does not eliminate the emotional impact of having a debilitating condition or being the caregiver for someone who does. Seniors of all incomes have difficulty locating adequate services.

**Transitional care is seldom coordinated.** Seniors often make several transitions after leaving the hospital—a patient may be discharged to a skilled nursing facility for rehabilitative care and then to home. Yet no single provider monitors the patient across sites. There is poor communication among care sites, resulting in mistakes in care and preventable returns to the hospital. Even when case management



occurs, it is often initiated after the patient has come home. Services may not start for days or weeks, particularly if programs have waiting lists.

**Hospital discharge planning is inadequate.**

As health care costs have risen and hospital stays have shortened, discharge planning has decreased in many hospitals. Discharge planners are overwhelmed by large caseloads and do not have time to provide adequate services to patients. The result is a devastating breakdown in continuity of care; patients and caregivers must fend for themselves after discharge.

Discharge planning should begin well before the patient leaves the hospital, and family caregivers, such as this husband, should be involved.

*“Information doesn’t follow the person in a timely way. . . . Orders like rehab can take a week. Services stop and start.*

*Policymaker*

*“Here is a real example: A husband with dementia who is resistant to care. The wife has macular degeneration and she has to give [him] shots because Medicare cut this back. Medicare says there is a caregiver and she can do it. What is the ability of the caregiver?”*

*Policy maker*

**Both patients and caregivers lack the information and training** to ensure safe recovery at home. They lack information on home care and condition-specific care, where to go for help, eligibility for services, how to arrange services, home modification, and caregiver self-care.

Caregivers said that the information the hospitals provided was inadequate, incomplete, or uncoordinated. Caregivers did not know what information to look for, and they found hospital staff unhelpful. These issues were intensified for non-English speaking patients and caregivers, and for those with low health literacy (the ability to understand basic health information in order to make appropriate decisions). Information that is linguistically and culturally appropriate is lacking or difficult to find.



Patients often leave the hospital with new prescriptions and inadequate instructions. There are potentially dangerous interactions with medications the patient is already taking.

**Professional training is inadequate.** Hospital staff responsible for preparing patients for discharge are not trained in effective discharge planning, transitional care, and home care. Most, whether nurses or social workers, do not know what services are available in their communities.

Physicians, nurses, social workers, and other providers need training to understand the needs of older patients and to better serve those from diverse backgrounds and those with limited English skills. Differences in language and culture can affect the quality and safety of care; disparities in health services and outcomes are associated with race, ethnicity, literacy and language.

**The medical and social service systems do not adequately support caregivers.** Although family members provide over two-thirds of home care, they are seldom acknowledged or included in discharge planning. As a result, their abilities, resources, and skills are often over-estimated, and they do not receive the information and training they need.

**The system of care for seniors is badly fragmented and outdated.** Home and community-based services are administered and funded by a patchwork of state and local agencies. The result is a confusing array of services with varying eligibility requirements. Many of the services that patients, caregivers, discharge planners, and providers identify as needed are unavailable or are not funded under Medicare or Medicaid. Further, lack of funding results in waiting lists, delayed care, and other unmet needs. The episodic, acute, and institutional focus of current long-term care policies and funding is outdated.

## Prescription for Change

The critical problems identified in our study are best addressed through concurrent action at many levels:

**1. Increase public awareness of transitional care issues for seniors**, with a campaign to educate seniors and their families about the risks of hospitalization and care transitions.

**2. Begin discharge planning before hospitalization** when possible. Review and update the plan at admission, before discharge, 72 hours after discharge, and at intervals up to six months after discharge.

**3. Integrate risk/needs assessment for both patients and caregivers** into discharge planning. Assess medical, psychological, social, and environmental factors. For caregivers, specifically, assess health status, ease of access to patient, and ability to provide care in the home. Integrate this into discharge planning at all stages.

**4. Improve transitional care coordination.** Create a consent mechanism for patients to approve sharing of information among providers (and volunteers) at inpatient, outpatient, and post-discharge care sites. Assign responsibility to hospital staff or volunteers to follow up with patients after discharge to ensure that they are getting needed services. Develop peer support programs that use seniors as volunteers helping hospitalized patients, especially for those who have no family caregivers.

**5. Make transitional care a priority** of professional associations, health systems, and government organizations. Recommend that government agencies include transitional care as a priority within their areas of oversight. Support and evaluate implementation of new Joint Commission on Accreditation of Healthcare Organizations (JCAHO) indicators on hospital discharge planning and transitional care as part of the hospital accreditation process.



**6. Develop materials for seniors and caregivers** to help them navigate the system of care during and after a hospital stay. Provide caregivers with information on obtaining home care, on providing condition-specific and direct care (e.g., bathing, lifting, and giving injections), and on self-care. Provide integrated, easy-to-use, and culturally appropriate resources in multiple formats suitable for all literacy levels. Partner with existing groups to distribute materials.

**7. Create care support centers in hospitals**, where patients and caregivers can watch educational videos/DVDs, find print and online resources, connect with volunteers, and be referred to community-based caregiver support programs and in-home services.

**8. Train health care providers.** Develop professional trainings on discharge planning and transitional care, and create opportunities for cross-disciplinary and cross-site education. Improve cultural and linguistic training, and increase the degree to which health care professionals interact with and learn about the communities they serve. Develop new certification processes and care standards for paraprofessionals such as In-Home Supportive Services workers so that they can perform some tasks now limited to nurses or social workers. Make information resources available to providers for use with patients and caregivers, and train providers on the use of these materials.

Improving the cultural competencies of the work force will help us reach diverse elders and their caregivers more effectively.

*“No, I wasn’t prepared. There weren’t any types of arrangements. We didn’t receive any kind of training. Just advice from the family, how to help her recuperate.”*

*Caregiver*

Assessment of the patient's—and the caregiver's—risks and needs should take place before discharge from the hospital.



**9. Acknowledge the vital role of caregivers and enhance caregiver support.** Promote family-centered care. Recognize caregivers as part of the unit of care and integrate them into the care team. Encourage the development and evaluation of innovative models in team caregiving, in which family, volunteer, and professional caregivers are partners. Expand the availability of support groups and other services to provide emotional aid and respite for caregivers.

**10. Change federal and state policies to improve transitional care.** Major policy shifts need to occur. To ensure continuity and coordination of care, we need integrated care delivery systems that incorporate medical and social services as well as caregiver assessment, training, and support. We also need a system that focuses on preventive care and chronic care management, not acute care.

Finally, we need to make in-home care a higher priority than more expensive institutional care. Specific actions needed include:

- Promote policy and program changes to Medicare, Medicaid, the Older Americans Act, and In-Home Supportive Services and increase funding for community services through these programs to support effective discharge planning and transitional care.
- Simplify program eligibility. Expand care integration models that create single points of access to determine eligibility and connect seniors to multiple services.
- Support and evaluate demonstration projects in enhanced discharge planning and transitional care, including in-home services.
- Develop new privacy/confidentiality policies so that information can be shared across care settings with informed patient consent.
- Reward physicians and hospitals that improve patient outcomes and reduce rehospitalization.

- Amend state and federal family leave laws to give workers the right to more flexible schedules so they can provide care while continuing to work.
- Undertake home assessments, and invest in home modifications and durable medical equipment, to ensure safe recovery in the home.
- Expand eligibility for public programs to meet the needs of the growing number of vulnerable seniors.

### A Better Homecoming

A month after being discharged from the hospital following surgery for broken vertebrae, Lina Pappas still felt that her doctors had been very lax about communicating with each other about her medications. She still had a great deal of anxiety about her medications: “Every time I put a pill in my mouth, I worry about what it is going to do with my other pills.”

Although she wanted to, she still could not correspond with friends. She said, “No. I just find myself feeling blah.” She felt too weak and tired to start writing letters again. She said that she felt depressed and lonely.

Miss Pappas was not destitute, but she did not have the money to pay for the services she needed. She received some help, but there were major breakdowns in her care. If the actions outlined above are implemented, the future for Lina Pappas and other seniors moving from the hospital to home—and for their caregivers—will be transformed.

*“The person going home and their family have no idea and understanding of what it takes to manage at home. . . . If they aren’t aware of services, they don’t know how to try to get them.”*

*Provider*



Services like physical therapy can help people recover at home. However, many public policies still favor institutional care.

### About the Author

Holly Brown-Williams is Director of Policy at Health Research for Action, University of California, Berkeley.

### To Learn More

Findings from this study are available in two reports on our website at [www.uchealthaction.org](http://www.uchealthaction.org). *From Hospital to Home: Improving Transitional Care for Older Adults* presents the key research findings and recommendations. *From Hospital to Home: A Strategic Assessment of Eldercare in the San Francisco Bay Area, Review of Literature* summarizes the results of other studies on the needs of seniors and their caregivers during the hospital-to-home transition.

### **About Health Research for Action**

Health Research for Action—formerly the Center for Community Wellness—is located in the UC Berkeley School of Public Health. Our mission is to conduct research and translate findings from that research into policies, products and programs that reduce health disparities and create healthier, more empowered communities. All of our work is conducted in partnership with the people living in these communities.

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