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DANGEROUS TRANSITIONS: STUDY SHOWS DISCHARGE PLANNING RISKS

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Tomor Bardha, age 74, lives with his wife and near his son Peter and daughter-in-law, Diane. During his inpatient recovery following surgery for stomach cancer, his family felt the need to be present as much as possible to monitor his care. Bardha speaks fluent Albanian and Croatian, but communicates in English at only a rudimentary level. His translators were not readily available and hospital staff changed constantly. At one point, a nurse came to administer insulin; when his family asked why, she checked scribbled notes in the chart and said Bardha was diabetic. In fact, he needed insulin only temporarily because of his surgery. This and other miscommunications caused his family tremendous worry about his care. Of greatest concern was a problem he had developed with painful hiccuping. Despite repeated questions about this problem, Bardha's family members were told, "Hiccups are normal."

Two weeks after surgery, Peter learned in the evening that his father would be discharged the following morning. He and Diane were shocked because their father's condition still seemed acute. They were given no training or information about how to care for "Papa" at home. In the hours before discharge, Peter and Diane were given cursory training on a mechanical feeding tube they were told "would probably be different than the type delivered to the home." They felt very anxious about their ability to ensure Papa's safety while managing the feeding tube, monitoring blood sugar and administering insulin shots.

EXPERIENCES STUDIED

The Bardha family's (not their real names) experience was not rare, according to Health Research for Action (HRA) at the University of California, Berkeley, School of Public Health. To better understand the transitional care needs of older adults and their caregivers before, during and after a hospital stay, HRA analyzed the hospital-to-home transitional care needs of elders and their caregivers, assessed the services available to them in four San Francisco Bay Area counties, and examined the needs of selected vulnerable populations to identify potential interventions to improve transitional care. The study, titled *From Hospital to Home: Improving Transitional Care for Older Adults*, 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 elders.

In the Bardhas' case, one of the more striking failures of discharge planning that HRA researchers encountered, the family received no information about how to manage the complex care their father required and no one assessed either the family's ability or availability to provide care. The sole written discharge instruction was a sheet of paper with the word *Tylenol* scrawled across the bottom. Peter and Diane felt that Papa was in no shape to be discharged from the hospital, and they had tremendous fear about his care at home. They had no idea that they could have appealed the discharge decision.

Only six hours after coming home from the hospital, Tomor Bardha not only continued to experience violent hiccups, but also developed a fever and felt disoriented. Family members called their local hospital and were told to bring him to the emergency department. An X-ray determined that Bardha had pneumonia, and technicians reconnected him to feeding equipment to provide nourishment. They also

gave him an injection of Thorazine, which stopped the hiccups. However, Peter and Diane were stunned when told only hours later to take him home. Given the severity of his father's condition, Peter insisted that Bardha be kept in the emergency department overnight.

Although the Bardhas felt it very premature, they brought Papa home the next day after being reassured that a nurse was scheduled to visit. When the nurse examined Bardha and realized the severity of his condition, she immediately ordered his readmission to the hospital. It took him two more months to recover from pneumonia, as well as from a severe infection in the surgical site (the cause of his hiccups), before he could safely return home.

MULTIPLE RISKS

For Tomor Bardha and other elders, the proper return home can prevent problems or aid recovery from injury or illness. The patient's return home is also the first point at which many family members assume a significant caregiving role. Hospitalization can be a turning point for elders, whose physical and mental health often deteriorates after discharge. Many experience breakdowns in care during the transition home, placing them at increased risk.

Because caregivers are often unprepared for posthospital care, the often quick discharge of patients from hospitals places many family care providers at risk for physical and mental health problems associated with caregiving. Furthermore, although family members provide about three-quarters of home-care in the United States, they are seldom included in discharge planning.

Some older individuals 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 or other emotional problems, and poor general health.

The growing diversity of the older population in the United States raises additional posthospital care challenges. For example, non-English speakers, racial and ethnic minorities, and recent immigrants face cultural and communication barriers. Isolated elders have no one to advocate for them when they are ill or hospitalized, or to help with postdischarge care needs and coordination. Middle-income individuals often do not qualify for public programs and lack funds to purchase needed homecare, whereas low-income individuals may qualify for services but lack adequate health insurance or experience other barriers to care, such as lack of transportation. Quite simply, elders of all income levels have difficulty locating adequate services.

DEVASTATING BREAKDOWN

Transitional care is seldom coordinated. Despite the fact that patients commonly make several transitions after leaving the hospital—such as to a skilled nursing facility for rehabilitation—no single provider monitors patients across sites. The resulting poor communication among care sites causes mistakes in care and preventable returns to the hospital. Even when case management does occur, it is often initiated after a patient has returned home, and services may not start for days or weeks.

As healthcare costs have risen and hospital stays shortened during the past two decades, discharge planning has decreased in many hospitals. Discharge planners, usually nurses or social workers, are overwhelmed by large caseloads and do not have time to provide adequate services to patients. Moreover, they are not trained in effective discharge planning, transitional care and homecare, and most have inadequate knowledge about the services available in their communities. The result is a devastating breakdown in continuity of care: Patients and caregivers must fend for themselves after discharge.

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

The system of care for older Americans 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 allowed under Medicare or Medicaid. Further, lack of funding results in waiting lists, delayed care and other unmet needs.

A BETTER HOMECOMING

Tomor Bardha's family experienced major but preventable breakdowns in his care—breakdowns that resulted in his readmission to the hospital due to complications from his operation. He was lucky to have Peter and Diane living nearby; they were assertive and available to provide a high level of care in the

home. Only several months after his surgery was Bardha beginning to return to normal functioning, a recovery that his family considered miraculous given the many problems they experienced with his discharge from the hospital. Tragically, elders without caregivers fare much worse; Bardha might well have died without the critical care of his family.

To ensure that transitional care is safe and effective for all older adults, Health Research for Action has outlined a range of recommendations. If these changes are implemented, the future for all those moving from the hospital to home—and for their caregivers—will be transformed. ❖

Holly Brown-Williams is director of policy at Health Research for Action, University of California, Berkeley. PDF files of the 40-page summary report and other documents related to the hospital-to-home study are available online at www.uhealthaction.org/eldercare.html.

TRANSITIONAL CARE RECOMMENDATIONS

Following are key recommendations from the study *From Hospital to Home: Improving Transitional Care for Older Adults* by Health Research for Action at the University of California, Berkeley, School of Public Health. More detailed discussions are available at www.uhealthaction.org/eldercare.html.

- **Increase public awareness of transitional care issues for older people** by educating elders and their families about the risks of hospitalization and care transitions.

- **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.

- **Integrate risk and needs assessment for both patients and caregivers into discharge planning**, including medical, psychological, social and environmental factors.

- **Improve transitional care coordination** by assigning hospital staff or volunteers to follow up with patients after discharge to ensure that they are getting needed services.

- **Make transitional care a priority** of professional associations and health systems. Government agencies should prioritize oversight of transitional care to ensure consistency.

- **Develop materials for older adults and caregivers** to help them navigate the system of care during and after a hospital stay.

- **Create care support centers in hospitals**, where patients and caregivers can find educational programs and online resources,

connect with volunteers and get referrals to community-based services.

- **Develop professional training** on discharge planning and transitional care, and create opportunities for cross-disciplinary and cross-site education. Improve cultural and linguistic training, and develop new certification processes for paraprofessionals so they can perform some tasks that are currently limited to nurses or social workers.

- **Recognize caregivers** as part of the unit of care and integrate them into the care team.

- **Support and evaluate demonstration projects** in enhanced discharge planning and transitional care, including in-home services.

- **Simplify program eligibility** by expanding care integration efforts that create single points of access to determine eligibility and connect elders to multiple services.

- **Amend state and federal family leave laws** to give workers the right to more flexible schedules for providing eldercare while continuing to work.

- **Amend privacy and confidentiality policies** so that information can be shared across care settings with informed patient consent, and expand adoption of electronic health records.

- **Reward physicians and hospitals** that improve patient outcomes and reduce rehospitalization.

- **Promote policy and program changes to Medicare and Medicaid.**

- **Expand funding for public programs**, especially under the Older Americans Act.

FAMILY GUIDE

“A Family Caregiver’s Guide to Hospital Discharge Planning” is an excellent 20-page brochure that explains in clear language—English or Spanish—what discharge planning is, who does this job at hospitals, when it needs to be done, what insurance will pay for, and other information families should know.

Created by the National Alliance for Caregiving and the United Hospital Fund of New York, family members or practitioners working with them can download a PDF of the guide at <http://www.caregiving.org/pubs/brochures/familydischargeplanning.pdf>.