

The Standard of Caring: Why Do We Still Use Feeding Tubes in Patients With Advanced Dementia?

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A consensus among geriatricians, ethicists, and neurologists supports a palliative approach to the care of individuals with late-stage dementia. But ten years after the publication of the first large study demonstrating the lack of efficacy of percutaneous endoscopic gastrostomy (PEG) tubes in prolonging life for patients with advanced dementia, and seven years after the appearance of two articles in major medical journals arguing that tube feeding should no longer be the standard of care for individuals with advanced dementia, gastrostomy tubes remain commonplace in this population. One overlooked reason that many families and physicians continue to opt for artificial nutri-

tion is that the case for feeding tubes is a moral one and not a scientific one. What may be at issue for families is how best to demonstrate *caring*, and caring is not readily amenable to empirical study. A better approach to family members who want feeding tubes for the demented is to acknowledge the symbolic value of nutrition for them and to seek an alternative means of satisfying the need to feed. (*J Am Med Dir Assoc* 2008; 9: 364–367)

Keywords: *Dementia; feeding tubes; ethics; standard of care*

A consensus among geriatricians, ethicists, and neurologists supports a palliative approach to the care of individuals with late-stage dementia. Advanced dementia is increasingly recognized to be a terminal illness, with life expectancy of less than 1 year, and interventions such as attempted cardiopulmonary resuscitation, ventilators, or intensive care unit treatment are not recommended.¹ In addition, the development of difficulty swallowing or the lack of interest in eating is acknowledged to be part of the natural history of dementia.² As a result, guidelines such as those newly issued by the British Psychological Society and National Institute for Health and Clinical Excellence (NICE) state that “artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity.”³ These guidelines, along with earlier rec-

ommendations issued by the American Geriatrics Society,⁴ reflect the accumulated knowledge about the effectiveness of tube feeding in the setting of advanced dementia.

But 10 years after the publication of the first large study demonstrating the lack of efficacy of percutaneous endoscopic gastrostomy (PEG) tubes in prolonging life for patients with advanced dementia,⁵ and 7 years after the appearance of 2 articles in major medical journals arguing that tube feeding should no longer be the standard of care for individuals with advanced dementia,^{6,7} gastrostomy tubes remain commonplace in this population. As the speaker at a recent “Clinical Crossroads” asked, “with everything we know about [tube feeding in advanced dementia], why in the *world* would we be presenting tube-feeding as an option?”⁸

FACTORS PROMOTING TUBE-FEEDING

According to the most recent statistics available, the rate of feeding tube use among patients with advanced dementia living in nursing homes varies widely from state to state, ranging from a low of 7% in Maine to a high of 40% in Mississippi.⁹ It has fallen somewhat from the national average of 34% reported in 2003,¹⁰ although the decline is not found in minority populations.¹¹ A large literature has developed that seeks to explain the barriers to change. Several articles address patient factors: religion, socioeconomic status, or site of residence of the person with dementia.¹⁰ Other articles

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address institutional and regulatory factors, finding that nursing homes with in-house speech therapists have higher PEG use.¹² Still other articles have identified state statutes that limit the ability of health care proxies to authorize withholding of artificial nutrition as a potential contributor to prevailing practice.¹³ Finally, some investigators have examined the role of economic factors—the way PEG treatment is paid for—in the hope of explaining the dramatic regional variability in the use of feeding tubes in advanced dementia.¹⁴ Their conclusion is that states whose Medicaid programs provide markedly greater reimbursement to nursing homes for the care of tube-fed residents than hand-fed residents have higher rates of tube feeding. But all these factors, while clearly a crucial part of the story, do not fully account for the rate of PEG use in individuals with advanced dementia.

Another possible explanation for the continued use of PEGs is that the data that form the case against feeding tubes are not sufficiently compelling. The landmark 1997 article analyzing survival in 1386 nursing home residents with advanced dementia and feeding difficulties was an observational study, not a randomized trial. If our intuition tells us that feeding tubes ought to prolong life, even in individuals who are in the final stage of dementia, then surely we should demand rigorous proof, not merely a statistical analysis of government-mandated nursing home data.

But perhaps one overlooked reason that many loving families and caring physicians continue to opt for artificial nutrition is that the case for feeding tubes is a moral one and not a scientific one. Clinical experience suggests that family members who express concern about “starving” their relatives to death may not be asking for more data. They may not be interested in the relative merits of randomized versus observational studies. They are unlikely to be persuaded by claims that feeding tubes not only fail to prolong life but also are ineffective in preventing aspiration pneumonia or pressure ulcers.⁶ These medical outcomes, which can be scientifically measured, are of interest to physicians; it is not at all clear that they are important to families. From this perspective, families will derive little reassurance from a new, better designed study or a multipronged intervention that simultaneously addresses each of the factors that has a small but statistically significant effect on PEG usage.¹⁵ What may be at issue for families is how best to demonstrate *caring*, and caring is not readily amenable to empirical study.¹⁶

WHAT MATTERS TO PATIENTS AND FAMILIES NEAR THE END OF LIFE

What matters to patients near the end of life is not uniformly the same as what physicians identify as important. Patients want their symptoms to be controlled, they wish to remain in control, they are concerned about being a burden to their loved ones, and, what is most readily extrapolated to an individual with dementia, they wish to be treated respectfully.¹⁷ Cognitively intact dying patients are able to articulate that their dignity is upheld when health care providers affirm their personhood.¹⁸ Family members echo these concerns and often express disappointment with nursing home care precisely because they find that their relatives are not treated with respect.¹⁹

Determining how best to show respect to an individual with advanced dementia is difficult since patients cannot speak for themselves. Few studies have specifically addressed how families believe their demented relatives should be cared for. Specialists in Alzheimer's disease who recognize the importance of trying to enhance the well-being of people with dementia have focused principally on individuals with mild to moderate disease.²⁰

FEEDING TUBES AS CARING

Quantitative analysis can provide some help in determining a standard of caring. Investigators have designed instruments to measure pain in advanced dementia²¹ as well as scales to assess multiple dimensions of suffering.²² These tools can in principle help ascertain whether patients with advanced dementia suffer in the absence of artificial nutrition and hydration. One study of nursing home residents with severe cognitive impairment and pneumonia found that symptoms of discomfort diminished as death approached, even in the absence of artificial nutrition, but the study was small, uncontrolled, and restricted to individuals with pneumonia.²³ But studies purporting to measure suffering with and without a feeding tube are likely to be helpful to families only if they clearly show that withholding nutrition *increases* suffering. If tube feeding is not necessary to prevent suffering—as extrapolation from patients dying of cancer suggests²⁴—it could nonetheless demonstrate *caring* and preserve dignity.

Feeding has *symbolic* significance in our culture. For many families, arguing that the loss of the ability to swallow or of interest in food is part of the dying process is an insufficient reason for withdrawing or withholding artificial nutrition. Stating that the appropriate goal of care for the individual with advanced dementia is comfort rather than life-prolongation also misses the point: the family's goal in many instances is precisely to maximize comfort. The question is how best to achieve their goal, how to demonstrate caring, respect, and love. It is this question that cannot readily be answered by scientific studies.

The standard of caring is defined by social and cultural norms. In 21st century America, we assume that individuals with advanced dementia should be kept warm and clean, even though we have no data that demonstrate conclusively that people with profound cognitive impairment experience being cold as uncomfortable or are bothered by being unkempt or dirty. We take it for granted that those with dementia should be kept clothed and insist on covering individuals who repeatedly remove their clothes. We argue that an elderly person should remain dressed to preserve his dignity, even though patients with dementia often disrobe, presumably with no loss of dignity. When we claim to be showing respect for the person, we mean that being dressed is of *symbolic* significance.

Most families show their love for their demented relative—or for the person she once was—through physical affection: hugs, kisses, caresses. We do not expect the medical profession to perform studies purporting to show that Alzheimer's patients are, say, less susceptible to upper respiratory infections if they are hugged 3 times a day than if they are not. More-

over, if a carefully conducted study definitively demonstrated that hugging has no effect on the immune system, no daughter would stop hugging her demented mother.

Beyond these accepted norms—maintaining warmth and cleanliness and showing affection—the standard of caring is in flux. For some families, administering antibiotics in the setting of an infection is a sign of respect for it involves treating the person with Alzheimer's disease exactly as she would be treated if she did not have dementia. For others, pneumonia is truly the old man's friend, and combating it with medication is a burdensome way of prolonging a period of intolerable suffering. For some families, providing nutrition is an essential element of caring, even if it can only be administered artificially, via a gastrostomy tube. For others, use of a feeding tube in a person in the final stage of Alzheimer's disease is a burdensome technological intervention with little medical benefit.

Until we achieve a broader consensus on what constitutes the appropriate way to care for patients with dementia—and in a pluralistic society whose members have differing values and beliefs, such a consensus may never be achieved—some families (and physicians) will continue to advocate feeding this group. Ideally, an agreed upon standard of care will be developed, perhaps using the consensus conference approach successfully employed by the National Institutes of Health to evaluate a variety of types of treatment. Once a standard of care is adopted, implementation will require the Centers for Medicare and Medicaid Services to reimburse treatments only if they meet that standard. Surely tube feeding would not be regarded as “reasonable and necessary,” the statutory basis for Medicare coverage, if it were rejected by a consensus conference defining appropriate care for individuals with advanced dementia.

Until such a standard of care is established, and until reimbursement is tied to conformity with that standard, as already is the case for a procedure such as pacemaker insertion, we will need to find satisfactory ways to respond when a family requests a technical intervention that medical professionals regard as unjustified. Physicians typically argue that *medical* interventions should have measurable *medical* benefit. Tube feeding, as one commentator put it, has nothing to do with apple pie and motherhood. Tube feeding should be assessed physiologically, not culturally.²⁵ But is it true that we can so neatly separate the physiologic from the cultural, the technical from the symbolic? Rejecting tube feeding on the grounds that it does not work is just the latest instance of physicians attempting to invoke futility in place of moral argument. What we learned with the first generation of futility disputes is that physicians typically try to invoke futility in order to unilaterally refuse medical interventions they believed to be inappropriate: they hope to substitute a technical argument for a moral one, asserting the interventions were ineffective.^{26,27} In the best-known futility case, physicians attempted to remove the respirator from 88-year-old Helga Wanglie, who was in a persistent vegetative state, on the grounds that it was nonbeneficial. In fact, Wanglie's respirator was not “physiologically futile”; the problem was that Mrs. Wanglie's husband disagreed with her physicians about

whether the goal of treatment—maintaining her life in a persistent vegetative state—was reasonable.²⁸

A MORAL RESPONSE TO THE FEEDING DILEMMA

A better approach to family members who want feeding tubes for the demented is to acknowledge the symbolic value of nutrition for them and to seek an alternative means of satisfying the need to feed. Hand feeding is one strategy, and when the individual with dementia will eat if fed—albeit typically only very slowly, then this is the approach of choice. It is very labor-intensive and difficult to implement in the nursing home, where many individuals with advanced dementia live, but with a modified reimbursement system for nursing home care, it may be feasible. For those individuals who cannot be hand fed, either because they will not allow it or because their swallowing dysfunction is so profound, physicians will need to offer something else that meets the family's psychological need. We will need to create Ensure lollipops, for those who can use them, or sublingual high-calorie drops, for those who cannot swallow. This approach responds to the symbolic need for nutrition without subjecting an uncomprehending, frail individual near the end of life to an invasive technological procedure. It redefines palliative care for the individual with advanced dementia in a way that acknowledges that the trajectory toward death is different from that of the typical cancer patient or heart failure patient. It recognizes that determining the most humane form of care is extremely difficult in those who, precisely because they are demented, cannot describe their experience. And it accepts that good palliative care goes beyond the needs of the patient to encompass the concerns of the family.

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The Care Transitions Intervention: A Patient-Centered Approach to Ensuring Effective Transfers Between Sites of Geriatric Care

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ABSTRACT. During an episode of illness, older patients may receive care in multiple settings; often resulting in fragmented care and poorly-executed care transitions. The negative consequences of fragmented care include duplication of services; inappropriate or conflicting care recommendations, medication errors, patient/caregiver distress, and higher costs of care. Despite the critical need to reduce fragmented care in this

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older frail adults or the interests of health care personnel in various settings (Boling, 1999, p. 656). The current pressures and mis-aligned financial and organizational incentives set the stage for poorly managed transitions, which ultimately undermine the effectiveness of all involved parties and may result in additional costs for a given episode of care.

Providing cross-site interdisciplinary care has become even more challenging as these older patients receive care in multiple settings and for increasingly shorter lengths of stay. To compensate, interdisciplinary teams must become more dynamic, more complex, and make a greater effort to communicate. Broadly considered, interdisciplinary teams share goals for improving care; however, membership and roles are less well defined because they often do not work in the same setting, much less for the same organization. In order to adapt, teams must learn not to be constrained by the rigid boundaries of the location or program in which they work. Greater accountability is also needed for what happens in the interstices between programs or locations of care.

Effective intervention models are needed to improve geriatric interdisciplinary team care across settings. Transitional care is defined as a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location (Author, 2003). Transitional care, which encompasses both the sending and receiving aspects of the transfer, includes logistical arrangements, education of the patient and family, and coordination among health professionals involved in the transition (Coleman & Bout, 2003).

To improve care transitions, a shift must occur from institution-centered team care to patient-centered team care. Because older patients and their caregivers are the only common thread linking different providers and settings, it follows that any attempt to improve care transitions would, by necessity, have a patient-centered focus. This article describes an innovative patient-centered interdisciplinary team intervention (The Care Transitions Intervention), designed to improve transitions across sites of geriatric care by focusing on patient education and empowerment.

THE CARE TRANSITIONS INTERVENTION: BACKGROUND AND DESIGN

To manage the needs of chronically ill older adults within the context of an increasingly complex and decentralized health care system, the

population, few interventions have been developed to assist older patients and their family members in making smooth transitions. This article introduces a patient-centered interdisciplinary team intervention designed to improve transitions across sites of geriatric care. (Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2003 by The Haworth Press, Inc. All rights reserved.)

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INTRODUCTION

During an episode of illness, older patients may receive care in multiple settings; putting them at risk for fragmented care and poorly-executed care transitions. For instance, in the course of an episode of illness, a patient may interact with nurses, therapists, and physicians in a hospital, skilled nursing facility, in the home in conjunction with a home health agency and finally, in an ambulatory clinic setting. Care from these different sources is frequently not centralized or coordinated, which can result in care that is fragmented. The negative consequences of fragmented care may include the duplication of services, inappropriate or conflicting care recommendations, medication errors, patient and caregiver confusion and distress, and higher costs of care, due to rehospitalization and use of the emergency department that might have been prevented via the facilitation of a smooth transition from hospital to home.

Because of financial pressures to discharge patients quickly, hospital discharge planners often have limited time to arrange for transfer out of the hospital. Rarely do they receive feedback regarding the execution or outcomes of their proposed plans. Primary care physicians and home health nurses often maintain that they do not receive adequate information about what transpired in the hospital or skilled nursing facility that they require to effectively assume care of the patient. Finally, patient interaction with different providers across many settings often results in multiple medication prescribers. The lack of a single, accurate, and up-to-date medication list places the older patient at risk for medication and treatment errors.

Discontinuity is a major weakness in U.S. health care delivery, one that is perpetuated by funding mechanisms that do not align the needs of

authors have developed and implemented an innovative program to improve the efficiency and quality of care during the critical juncture of the transition from hospital to home. The focus of the Care Transitions Intervention was initially informed by the author's clinical observations of a need for assistance. From this starting point, the design of the intervention was shaped by the literature on interdisciplinary teams and care transitions, and empirical evidence gathered from focus groups with chronically ill older adults and their caregivers.

In the current context of an aging population, an increased prevalence of chronic illness and morbidity, and financial incentives to discharge patients as quickly as possible, older patients are frequently required to make multiple transitions across settings to meet their care needs (Kane et al., 1996; Ma, Coleman, Lin, & Kramer, 2002; Portner, Muse & Nystrom, 1996). These care needs do not necessarily conform to specific settings, nor do they end after discharge. As such, interdisciplinary team collaboration across sites is necessary to ensure that the plan of care is properly executed.

The majority of previous research on care transitions and interdisciplinary teams has been predominantly descriptive, and has not focused on or explicitly featured the role of the patient. Existing studies that focus more directly on care transitions have demonstrated the efficacy of intervention models utilizing advanced practice nurses who assume responsibility for overseeing care across health settings and disciplines to assure older patients' needs are met (Cefalu et al., 1997; Evans et al., 1995; Kane et al., 2001). Studies by Naylor et al. (1999) and Rich et al. (1995) support this finding and demonstrate that provision of comprehensive services in the weeks following discharge can reduce hospital re-admission in populations of older patients in general and those with congestive heart failure in particular, respectively. These studies and others like them suggest that in order to effectively address care continuity for older adults, a shift must be made from institution-centered care to patient-centered care.

The proposed intervention design was directly informed by data gathered in a series of six focus groups. The purpose of the focus groups was to understand the challenges faced by older adults receiving care in multiple settings (i.e., during care transitions). Each focus group was composed of 10-12 patients and their caregivers, all of whom were members of one of six targeted clinics in a large managed care health care organization. The study participants included 49 men and women, aged 65 and older, who had been hospitalized in the past six months and

received follow-up care from a skilled nursing facility or home health care agency. Participants represented an array of socioeconomic, educational, and ethnic backgrounds. Detailed information about the conduct and methods used in the focus groups is provided in Coleman et al. (2002).

The discussions explored patients' perspectives on the transition home, communication between providers, understanding of medications and discharge instructions, and patients' knowledge and ability to elicit answers to their questions from appropriate health care professionals. Participants were asked questions that addressed the extent to which patient's care needs were met after discharge, whether primary care providers were informed about the patients' hospitalization and subsequent care needs, the steps patients had or had not taken to gather information about self-management of their condition, and the family's level of preparation for the patient's return home.

Analysis of the focus group data revealed four primary domains: (1) information transfer; (2) patient and caregiver preparation; (3) self-management support; and (4) empowerment to assert preferences. The information transfer domain included patient reports of providers functioning independently within and between sites of care and poor inter-professional and inter-institutional communication. Patient comments about patient and caregiver preparation included reports of unrealistic expectations for care provision by family and caregivers. The self-management domain included demonstrations of patient confusion about what questions to ask their providers, and what medications they should take. Participants repeatedly commented on the inaccessibility of providers to answer questions. Finally, the empowerment domain served to stress the importance of patient advocacy and to illustrate patients' experiences of conflict between needing to take greater responsibility for their healthcare, but feeling unprepared and unsupported to do so by their health care providers.

The focus group data, in concert with existing research, provided the basis for the development and refinement of the intervention design presented below, with its emphasis on patient empowerment and fluid transfer of information. The results of the focus groups suggested that the intervention was most likely to be successful if it were patient-centered, individually-tailored, and attentive to the content and process issues highlighted in the four domains. Furthermore, because the patient is the only continuous component in a care transition (i.e., it is the patient who moves through the myriad settings and interacts with different service providers), the patient is an ideal target for the intervention. Just as patients are asked to self-manage their chronic conditions,

and need to be prepared to do so, patients can also be encouraged to self-manage their care needs across settings and with various practitioners, if given appropriate support and education. In addition, a higher level of receptivity to a new care model was anticipated in patient populations, as compared with providers. Moreover, systems-level interventions that require an additional layer of new health care professionals are likely to be viewed as unrealistic and too costly in today's healthcare market. Further, a patient-centered intervention may be more amenable to wide-scale adoption. Finally, the focus group analyses revealed that the ideal intervention would facilitate communication across venues of care by coaching patients (and their informal caregivers) to be their own advocates for ensuring that their needs were met across settings. This finding led to the adoption of a model that utilized a Transition Coach with the appropriate combination of clinical and interpersonal skills to foster communication and collaborative problem-solving, while providing support with medications and self-management.

Setting

The Care Transitions Intervention was designed in response to the need for a patient-centered, interdisciplinary intervention that addresses continuity of care across multiple settings and practitioners. The intervention is currently being implemented as part of a randomized controlled trial ($n = 1400$) in two nationally-recognized health care systems that respectively care for approximately 55,000 and 5,000 geriatric patients. The participating organizations were selected to demonstrate that this intervention could be implemented in different health care settings under different financing structures (group model managed care, Independent Practice Associates managed care, and traditional fee-for-service Medicare). Both organizations have a strong tradition for exploring and implementing new approaches to care for their older members locally and nationally.

Patient Population

The intervention is designed for use with persons with complex care needs who require ongoing management of both acute and chronic conditions. The target population for the current study of the intervention

includes patients aged 65 and older hospitalized with or for one or more of the following chronic conditions: Congestive heart failure, chronic pulmonary disease, diabetes, stroke, medical and surgical back conditions, hip fracture, peripheral vascular disease, cardiac arrhythmia, pulmonary embolism, or deep vein thrombosis. These conditions were selected because of their prevalence and the complex health care management needs that accompany them, and their association with use of post-acute care services (Gage, 1999, 103-126). Other eligibility criteria include being English-speaking, having a phone, and planned discharge to home or a skilled nursing facility (not to long-term care). Patients' cognitive ability and state are determined using a brief mental status screen. Those patients who fail the cognitive screen or who have a diagnosis of dementia noted in their medical record are eligible for the intervention provided that they have an able and willing caregiver available to act as a proxy.

Structure of the Care Transitions Intervention

The overriding goal of the intervention is to improve care transitions by providing patients with tools and support that promote knowledge and self-management of their condition as they move from hospital to home. The intervention focuses on four conceptual areas, referred to as pillars, based on the domains that emerged from the focus groups:

1. *Medication self-management:* Patient is knowledgeable about medications and has a medication management system.
2. *Use of a dynamic patient-centered record:* Patient understands and utilizes the Personal Health Record (PHR) to facilitate communication and ensure continuity of care plan across providers and settings. The PHR is managed by the patient or informal caregiver.
3. *Primary care and specialist follow-up:* Patient schedules and completes follow-up visit with the primary care physician or specialist physician and is empowered to be an active participant in these interactions.
4. *Knowledge of red flags:* Patient is knowledgeable about indications that their condition is worsening and how to respond.

The four pillars are operationalized through two mechanisms: (1) a Personal Health Record; and (2) a series of structured visits and phone calls with a nurse Transition Coach. Both of these mechanisms are designed

to empower and educate older patients to meet their health care needs and ensure continuity of care in the transition(s) following discharge.

The PHR is a dynamic record book consisting of the essential elements for facilitating productive interdisciplinary and patient-provider contacts during current and future care transitions. These elements include a record of the patient's medical history, medications and allergies, a list of red flags, or warning signs, a structured checklist of critical activities that need to take place prior to discharge (such as instructions and dates of follow-up appointments), and space for the patient to record questions and concerns. In contrast to hospital or physician-maintained medical records, the PHR is maintained and updated by the patient and, as necessary, by the Transition Coach. The intent behind the design of the PHR was that it needs to be simple and easily integrated into the paper or electronic medical record formats of practice settings.

The Transition Coach functions as a facilitator of interdisciplinary collaboration across the transition, coaching the older patient and caregiver to play a central and active role in the formation and execution of the plan of care. Aside from the Transition Coach, no new interdisciplinary team members are introduced: The interdisciplinary teams are already in place in the respective settings (i.e., hospital, skilled nursing facility, home care, and ambulatory care). Rather, the purpose of this model is to focus on the patient's needs during transition, thereby expanding the purview of the traditional team. The older patient, caregiver and Transition Coach work together to maximize the involvement of interdisciplinary expertise, ensuring that the appropriate professionals are involved, critical issues are addressed, treatment goals are understood, and the care plan is executed correctly. The primary role of the Transition Coach is to encourage self-management and direct communication between the patient/caregiver and primary care provider rather than to function as another health care provider per se. However, if necessary, the Transition Coach may make phone calls and facilitate connections when a critical need is present, coordinating communication with home health nurses, care managers, and primary care physicians involved with the patient's care.

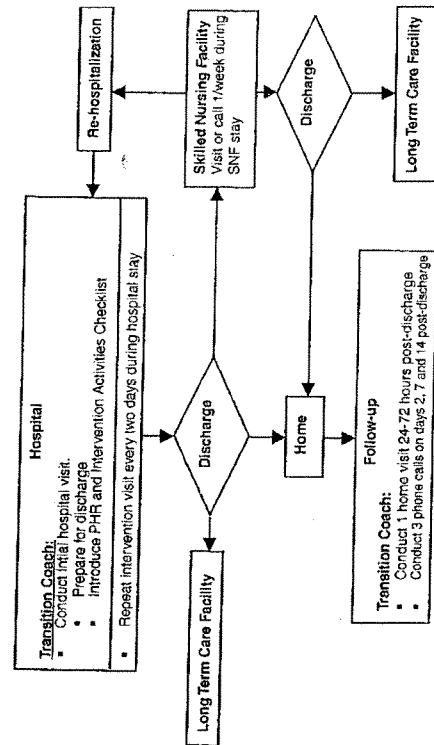
In this intervention, the professional background of the Transition Coach included a geriatric nurse practitioner and an RN skilled in education and advocacy with older adults. The Transition Coach first engages with the patient upon admission to the hospital. She works closely with patients and their caregivers to ensure a smooth transition from hospital to home following an acute episode requiring hospitalization. While the Transition Coach may interact with other service providers, the Transition

Coach's role is not that of a service broker or care manager. Rather, the Transition Coach is a source of information and support for the patient, assisting the patient in identifying key questions or concerns and empowering the patient to make contact with health care providers as necessary.

The structure of the intervention is outlined in Figure 1. Based on daily hospital census data and medical record review, the Transition Coach determines which patients are eligible for the intervention. Initial contact between the patient and Transition Coach is made in the hospital, and is followed by a home (or SNF) visit shortly after discharge, and three phone calls at 2, 7, and 14 days post-discharge. Ideally, the home visit takes place within 24-48 hours. However, the visits may be later in the case of scheduling difficulties or patient preference.

During the hospital visit, the Transition Coach introduces herself and the program to the patient and conducts the initial session aimed at imparting skills for greater self-management. The hospital visit is designed to help patients and their caregivers understand and use the PHR and Intervention Activities Checklist, and to prepare patients and caregivers for discharge. The follow-up visits in the skilled nursing facility and/or home, along with the accompanying phone calls, are designed to empower patients to play a more active and informed role in managing their care by expanding upon the information provided in the initial hospital visit and providing continuity across the transition.

FIGURE 1. Structure of the Care Transitions Intervention



While the four conceptual domains, or pillars, are reviewed during each contact, the intervention is tailored to the individual patient's needs, goals, and priorities at each stage of the transition. Thus, while the overall content of the pillars is revisited and reinforced at each contact between the patient and Transition Coach, the specific format and content of the pillars varies by patient and by visit. For example, during the home visit, the Transition Coach may discover that the patient has already scheduled a follow-up appointment and understands the red flags and warning signs that his or her condition is worsening, but may be confused about which medications and dosages to take. In this case, the primary focus of the visit would be medication management. Ultimately, the patient's readiness and ability to invest in the content of the pillars dictates the timing and focus on specific content. An abbreviated list of intervention activities is listed in Table 1.²

Beyond the activities listed in Table 1, the intervention addresses patient empowerment and self-management at a broader level by discussing the care plan with patients, reviewing possible transfer-related problems and creating prevention strategies in areas such as pain management, goal-setting, and lifestyle issues. The Transition Coach also assists patients in developing questions and role-playing interactions with providers. By modeling empowerment and providing patients with information, the intervention has the potential to alter the paradigm within which patients interact with the medical system, rendering them more responsible, aware, and savvy managers of their own health.

STRENGTHS AND BARRIERS

The Care Transitions Intervention has a number of strengths and advantages that make it unique and amenable to adoption in a variety of health care systems and settings.

First, the design of the intervention is consistent with recommendations provided in the recent IOM Chasm report, which advocates health care models that are patient-centered and collaborative, enhancing inter- and intra-team communication and coordination of care among health care professionals (Institute of Medicine, 2001). Second, the intervention is designed to impart skills that will be ideally sustained beyond the current episode and be applicable to subsequent acute health crises. Further, the cost of implementing the intervention is relatively modest; this intervention was explicitly designed not to create an entirely new layer of care, but rather to build upon the existing elements

TABLE 1. Care Transitions Intervention Activities by Pillar and Stage of Intervention

Pillar	Medication self-management	Dynamic patient-centered record	Follow-up	Red Flags
Goal	Patient is knowledgeable about medications and has a medication management system.	Patient understands and utilizes a Personal Health Record (PHR) to facilitate communication and ensure continuity of care plan across providers and settings. The patient manages the PHR.	Patient schedules and completes follow-up visit with Primary Care Provider/Specialist and is empowered to be an active participant in these interactions.	Patient is knowledgeable about medications that condition is worsening and how to respond.
Hospital Visit	Discuss importance of knowing medications and having a system in place.	Explain PHR.	Recommend Primary Care Provider follow-up visit.	Discuss symptoms and drug reactions.
Home Visit	Reconcile pre- and post-hospitalization medication lists, identify and correct any discrepancies.	Review and update PHR. Encourage patient to update PHR with Primary Care Provider and/or Specialist at follow-up visits.	Emphasize importance of the follow-up visit and need to provide Primary Care Provider with recent hospitalization information, practice and role-play questions for Primary Care Provider.	Assess condition. Discuss symptoms and side effects of medications.
Follow-Up Calls	Answer any remaining medication questions.	Remind patient to share PHR with Primary Care Provider/Specialist. Discuss outcome of visit with Primary Care Provider or Specialist.	Provide advocacy in getting appointment, if necessary.	Reinforce when/if Primary Care Provider should be called.

found in most geographic areas. The costs of the program include salary for the Transition Coach, reimbursement for travel/mileage and costs associated with equipment and supplies: Cellular phone, voicemail and pager services. Because the intervention is administered within existing structures, no administrative re-structuring is required, and additional costs are minimized. Finally, one of the greatest strengths of the intervention is the fact that the intervention design is standardized and replicable, but also flexible enough to allow responsiveness to patient's individual needs. Since the intervention is not disease-specific in its design, the model can easily be applied to patients with a variety of chronic illnesses. This design allows the intervention to be both patient-centered and also replicable, portable, and easily evaluated in numerous patient populations and healthcare settings. Although formal analyses are forthcoming, we predict that the intervention may prove effective in reducing rates of re-hospitalization, medication-related errors and improving patient satisfaction.

In addition to the strengths listed above, potential limitations of the intervention must be explored. The primary weakness of the intervention in-

volves attitudinal, organizational, and structural barriers to adoption. Currently, the health care system lacks financial incentives to improve the quality of transitional care, in part because of a lack of understanding of the role poor transitions play in medication errors, re-hospitalization, and overall poor care. Moreover, implementation of the intervention may face resistance from within health care settings if the role of the Transition Coach is perceived to overlap with discharge planning and home health nursing roles. One of the primary challenges to the success of the proposed intervention involves difficulties related to empowering of patients who are acutely ill to take charge of their health care needs. In cases where this is not possible, the intervention focuses on the informal caregiver (when available) as the target and primary recipient of the intervention. However, if the intervention is to succeed in reaching its objectives, it is also critical that health care providers be receptive to patients' new and emergent levels of activation and participation in meeting their health care needs and maintaining their own records.

NEXT STEPS: THE CARE TRANSITIONS INTERVENTION IN PRACTICE

As noted previously, the authors are currently collaborating with two nationally recognized health care delivery systems to test the intervention model. Since the inception of the study in May 2002, nearly 600 patients have participated in the intervention. The decision to study the proposed care model in two different delivery systems was governed by the need to directly address the question of external adoption. Demonstrating that an innovative care model improves outcomes of geriatric care is necessary but not sufficient for improving care to older adults. The true measure of success for an intervention is whether the approach is adopted and produces the desired change in a range of patient outcomes, delivery systems and populations. This goal of widespread adoption has guided the conceptualization and design of the intervention and the study. To facilitate implementation in both managed care and fee-for-service environments, the authors have considered the current incentives and pressures operating in these respective systems. The intervention model has been designed for adoption within a variety of payment structures. Furthermore, the role of the Transition Coach could be assumed by an existing health care professional, such as a home health nurse or care manager.

Although national efforts exist that call for greater integration of health care delivery and a more patient-centered focus in care, these changes are not imminent. In the meantime, it is critical that we prepare

patients, providers, and other members of health care teams to collaborate more closely, and thus improve care within existing structures. The proposed intervention design represents exactly this sort of interim step to bring our health care delivery into alignment with national goals.

CONCLUSION

This article introduces a patient-centered, interdisciplinary team intervention designed to improve care transitions and reduce fragmentation across sites of geriatric care. Based on the expressed needs of patients and caregivers with chronic illness, the intervention is designed to encourage patient self-management and enhance communication and collaboration between professionals across sites of care, potentially reducing medical errors, missed appointments, and dissatisfaction with care. Ultimately, improved transitions may lead to better health outcomes and reductions in unnecessary re-hospitalizations and health care costs. The intervention was also designed for ease of replication and implementation within existing structures, making it amenable to adoption in today's competitive health care market. Future research should seek to understand which patients will benefit most from this type of intervention, which components of the intervention are most critical, and how best to facilitate the adoption of programs such as the Care Transitions Intervention in various settings involving a myriad of providers and professionals.

NOTES

1. See Appendix A for a sample version of the Personal Health Record.
2. See Appendix B for an Intervention Activities Checklist, provided to patients prior to hospital discharge.

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APPENDIX A

The Personal Health Record of:

Personal Information

Address: _____

Home Phone #: _____

Alternate Phone #: _____

Birth Date: _____

Hospital ID #: _____

PCP Name: _____

Advance Directives?: _____

Hospitalization Information

Admitted: ___/___/___ Discharged: ___/___/___

Reason for Hospitalization: _____

Caregiver Information

Name: _____

Home Phone #: _____

Alternate Phone #: _____

Relation to Patient: _____

Personal Health Record

If you have questions or concerns,
Contact (Transition Coach)
at (303) 555-1234



REMEMBER
to take this Record with you
to all your doctor visits

APPENDIX A (continued)

Medical History

- Arthritis
 - Abnormal Heart Rhythm
 - Cancer
 - Diabetes
 - Hardening of the Arteries
 - Heart Disease
 - Heart Failure
 - High Blood Pressure
 - Hip Fracture
 - Lung Disease
 - Medical/Surgical Back Conditions
 - Pneumonia
 - Stroke
 - Other Diagnoses:
- To better manage my health and medications, I will...
- Take this Personal Health Record, with me to wherever I go, including ALL doctor visits and future hospitalizations.
 - Call my doctor if I have questions about my medications or if I want to change how I take my medications.
 - Tell my doctors about ALL medications I am taking, including over-the-counter drugs, vitamins and herbal formulas.
 - Update my Medication Record with any changes to my medications.
 - Know why I am taking each of my medications.
 - Know how much, when and for how long I am to take each medication.
 - Know possible medication side effects to watch out for and what to do if I notice any.

APPENDIX B

Intervention Activities Checklist

- | Before I leave the hospital... | After I leave the hospital... |
|--|--|
| <input type="checkbox"/> I know what to do to keep my health condition from getting worse. | <input type="checkbox"/> I will schedule and complete a follow-up appointment with my primary care physician (PCP). |
| <input type="checkbox"/> I know the symptoms to watch out for that mean my condition might be getting worse. | <input type="checkbox"/> I will write down questions I have about my condition. |
| <input type="checkbox"/> I know the name and phone number of who to call if I notice any of these symptoms. | <input type="checkbox"/> I will take all bottles of medicine I am using to each doctor visit. |
| <input type="checkbox"/> My family or someone close to me knows what I will need once I leave the hospital. | <input type="checkbox"/> I will call my Primary Care Provider (PCP) immediately at (303) 555-1234 if I experience any of the following: <ul style="list-style-type: none"> • Temperature above 101 ° F • Uncontrollable pain • Increased confusion • Increased redness or drainage around wound • Questions about which medications to take |
| <input type="checkbox"/> I know what medications to take, how to take them and their possible side effects. | |
| <input type="checkbox"/> I will have a clear and complete copy of my discharge instructions. | |

Medication Record

Name	Dose	Reason	New?
Azmacort MDI	4 puffs 2 times a day	Emphysema	<input type="checkbox"/>
Oxygen	2 liters per minute	Emphysema	<input type="checkbox"/>
Triam/HCZ	75/50-tablet; pill once per day	Leg swelling	<input checked="" type="checkbox"/>
Warfarin	5.0 mg once per day	Blood thinner	<input type="checkbox"/>
Atenolol	.25 mg once per day	Blood pressure	<input type="checkbox"/>
Atorvastatin	10 mg at bedtime	Cholesterol	<input type="checkbox"/>
Multi-vitamin	once per day		<input type="checkbox"/>

Allergies: Penicillin → Rash

Notes for My Primary Care Physician:

1. Do I need take the Triam/HCZ even when I do not have swelling?
2. How long will I receive home health care?
3. When is my next blood draw to check the Warfarin?