

# A Qualitative Analysis of an Advanced Practice Nurse–Directed Transitional Care Model Intervention

Christine Bradway, PhD, RN, GNP-BC,<sup>1,\*</sup> Rebecca Trotta, PhD, RN,<sup>1</sup>  
M. Brian Bixby, MSN, CRNP,<sup>1</sup> Ellen McPartland, MSN, CNS, ANP/GNP-BC,<sup>2</sup>  
M. Catherine Wollman, DNP, RN,<sup>3</sup> Heidi Kapustka, MSN, CRNP,<sup>1,4</sup>  
Kathleen McCauley, PhD, ACNS-BC, FAAN, FAHA, RN,<sup>1</sup> and  
Mary D. Naylor, PhD, FAAN, RN<sup>1</sup>

<sup>1</sup>University of Pennsylvania School of Nursing, Philadelphia.

<sup>2</sup>Pennsylvania Hospital, Philadelphia, Pennsylvania.

<sup>3</sup>Neumann University, Aston, Pennsylvania.

<sup>4</sup>Philadelphia VA Medical Center-Long Term Care, Pennsylvania.

\*Address correspondence to Christine Bradway, PhD, RN, University of Pennsylvania School of Nursing, Department of Biobehavioral Health Sciences, 418 Curie Boulevard, Fagin Hall, Philadelphia, PA 19104-6096. E-mail: [cwb@nursing.upenn.edu](mailto:cwb@nursing.upenn.edu)

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**Purpose:** The purpose of this study was to describe barriers and facilitators to implementing a transitional care intervention for cognitively impaired older adults and their caregivers lead by advanced practice nurses (APNs). **Design and Methods:** APNs implemented an evidence-based protocol to optimize transitions from hospital to home. An exploratory, qualitative directed content analysis examined 15 narrative case summaries written by APNs and fieldnotes from biweekly case conferences. **Results:** Three central themes emerged: patients and caregivers having the necessary information and knowledge, care coordination, and the caregiver experience. An additional category was also identified, APNs going above and beyond. **Implications:** APNs implemented individualized approaches and provided care that exceeds the type of care typically staffed and reimbursed in the American health care system by applying a Transitional Care Model, advanced clinical judgment, and doing whatever was necessary to prevent negative outcomes. Reimbursement reform as well as more formalized support systems and resources are necessary for APNs to

consistently provide such care to patients and their caregivers during this vulnerable time of transition.

*Key Words:* Care coordination, Continuum of care, Nursing studies, Qualitative research methods

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Close to 50% of adults over age 65 years have three or more chronic illnesses and over 20% live with more than five chronic conditions (G. Anderson & Horvath, 2002). Comorbidity is associated with numerous adverse effects including poor quality of life, polypharmacy and increased adverse drug events, increased use of health care resources, increased mortality, and caregiver (CG) burden (Boyd et al., 2007; Gijzen et al., 2001; McGlynn et al., 2003). The posthospitalization period is an extremely vulnerable time for these individuals.

Cognitive impairment (defined in this study as a diagnosis of dementia or delirium or as deficits in orientation, recall, or executive function) is one of the most common comorbidities seen in an older

adult population, and its presence compounds the management as well as the complications associated with multiple illnesses, including a greater risk for morbidity, preventable rehospitalizations, and decreased survival (Feil, Marmon, & Unuizer, 2003; Zuccala et al., 2003). Research has also demonstrated that chronic cognitive impairment typically worsens during hospitalization for a variety of reasons, that delirium is also highly prevalent in hospitalized elderly individuals, and that preexisting cognitive impairment can increase hospitalized patients' level of vulnerability to adverse events as well as CG burden and CG stress post-hospitalization (Bell, Araki, & Neumann, 2001; Inouye, 2006).

To address the issues surrounding an increasingly elderly population and test strategies for reducing the adverse effects of hospitalization for cognitively impaired older adults, we conducted a study of an advanced practice nurse (APN)-led Transitional Care Model (TCM; M. Naylor et al., 1994; M. D. Naylor et al., 1999, 2004) intervention. The TCM has been tested with cognitively intact older adults in previous research (M. Naylor et al., 1994; M. D. Naylor et al., 1999, 2004); in this article, we report the findings of an exploratory, qualitative descriptive content analysis focused on the barriers and facilitators associated with implementing this model in a population of cognitively impaired older adults and their family CGs.

## Literature Review

### *Transitional Care*

Transitional care is a successful model of care (MOC) that encompasses a broad range of services, is focused on preparing and implementing safe and timely passage from one environment to another, and is typically delivered by nurses or APNs (Boult et al., 2009; Liggins, Prylor, & Bernard, 2010; Naylor & Keating, 2008). In one study, the Acute Care for Elders MOC, targeted to optimize older patients' transitions within an acute care hospital setting, has demonstrated shorter lengths of stay, improved function, and decreased costs compared with patients receiving "usual care" (Panno, Kolcaba, & Holder, 2000). Other studies have focused on interventions aimed at easing the transition for older adult patients as they move between hospital and home settings, using APNs as a "transitions coach" (Coleman, Parry, Chalmers, & Min, 2006) or testing an APN-directed TCM (M. Naylor et al., 1994; M. D. Naylor et al., 1999, 2004). Study

subjects have included some of the most vulnerable elders, including those with complex comorbid conditions, and in a recent, randomized controlled trial, elders with cognitive impairment and their CGs, whose experiences were used for the analysis described in this article (M. D. Naylor et al., 2010). Findings from studies examining the APN-directed TCM and collaboration and consultation with national policy leaders have demonstrated that although the TCM consistently results in improved patient outcomes and reduced health care costs, greater clarity is needed about the specific factors and interventions that produce or inhibit quality outcomes (Bixby, Konick-McMahan, & McKenna, 2000; Brooten et al., 2002; Konick-McMahan, Bixby, & McKenna, 2003; McCauley, Bixby, & Naylor, 2006; M. D. Naylor, Hirschman, et al., 2007; M. D. Naylor, Stephens, Bowles, & Bixby, 2005). A critical component of successful translation of this research and areas that have been identified as in need of further study include an improved understanding of the most effective APN interventions, individual or system-wide factors that help or hinder efforts to design and deliver transitional care, and a focus on how transitional care interventions affect CG outcomes (Naylor & Keating, 2008).

### *Barriers and Facilitators to Providing Care*

Existing literature provides some clarity related to factors affecting care of patients and CGs coping with chronic disease and during times of transition. For CGs of stroke patients, the transition home has been described as "very difficult" (Lutz, Chumber, & Roland, 2007, p. 40). In another study, lay CGs for post-stroke patients identified that the intensity of the caregiving role and its impact on the CG, the lack of adequate community support, and lack of collaboration with the health care team were primary barriers to undertaking and continuing the CG role (White et al., 2007). Peek and colleagues (2009), in their study of patients diagnosed with diabetes, also found that poor collaboration with the health care team was a factor negatively impacting shared decision making between patients and their physicians, that it was grounded in the patient-provider power imbalance, and in some instances, exacerbated by racial differences.

Interactions with health care providers have been described by CGs as both barriers and facilitators to care depending on how the provider

meets patients' educational needs, confirms patients' experiences, uses interpersonal skills effectively, and is knowledgeable and available (Peek et al., 2009). For families of stroke patients, the caregiving experience is facilitated by adequate care coordination, skill in the caregiving role, a helpful social environment, accessible community resources, and "progress of the patient towards normalcy" (White et al., 2007, p. 9). A recent study explored restorative care for nursing home residents, all diagnosed with moderate to severe cognitive impairment, from the perspective of the nursing assistants providing daily care (Galik, Resnick, & Pretzer-Aboff, 2009). Two dominant themes relevant to facilitators of care were identified from focus group data: (a) knowing the resident's past and "what makes them tick" (p. 50) and (b) working as a team and utilizing resources (Galik et al., 2009).

Inadequate information from hospital discharge planners and inadequate CG training at hospital discharge are two factors that have been identified by patients and CGs as barriers affecting the transition from hospital to home (Graham, Ivey, & Neuhauser, 2009). Literature specific to the TCM includes findings from a pilot study of transitional care for older adults with cognitive impairment (M. D. Naylor, Hirschman, et al., 2007). In this study, factors facilitating APN-directed care provided via the TCM included sufficient income, adequate insurance with a prescription plan, access to specialty and primary care, supportive home environment, community support, and good quality home health care support (M. D. Naylor, Hirschman, et al., 2007). In particular, cognitively impaired older adults benefited from access to expert geriatricians and geropsychiatric physicians and nurses and memory clinics (M. D. Naylor, Hirschman, et al., 2007). Similar facilitators have been identified in providing high-quality care service to high-risk cognitively intact younger adults (aged 55 years or younger without cognitive impairment) with severe physical disabilities, such as spinal cord injury and multiple sclerosis (M. D. Naylor, Hill-Milbourne, et al., 2007). M. D. Naylor and colleagues (2009) have also identified system-wide barriers and facilitators to implementing the TCM in a "real-world" non-research setting. Findings suggest that some of the essential factors that facilitate integration of the TCM model include the presence of strong champions, clear communication, and organizational commitment.

In summary, despite what is known about barriers and facilitators affecting transitions for patients

**Table 1. Exclusion Criteria for Parent Study Enrollment**

End-stage disease (<6 months prognosis)
Cancer diagnosis currently undergoing active treatment
End-stage renal disease
Current drug and/or alcohol abuse
Neurological impairment (other than cognitive impairment)
Current nursing home resident or plan for long-term placement on discharge

and their CGs, a better understanding is needed of how APNs, providing transitional care, and in the case of our study, implementing the TCM with cognitively impaired older adults and their lay caregivers, can overcome individual and system-related challenges and maximize facilitators to improve quality of care and prevent negative outcomes.

### Description of the Parent Study and APN Protocol

The overall design of the parent study has been described in a previous publication (M. D. Naylor, Hirschman, et al., 2007); final results of the completed study are pending. Briefly, patients were screened for eligibility if they were admitted to any of the University of Pennsylvania Health System (UPHS) hospitals. Research assistants were provided with census sheets for all currently admitted English-speaking patients aged 65 years or older at each hospital on a daily basis. Additional eligibility criteria included (a) cognitive impairment as evidenced by a score of  $\leq 4$  on the six-item screen (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002; Wilber, Carpenter, & Hustey, 2008) or  $\leq 10$  on the CLOX1 (Royall, Cordes, & Polk, 1998); (b) residing within 30 miles of the admitting hospital; and (c) the presence of a primary CG who would provide support following discharge, was reachable by telephone, and agreed to work with the APN during the course of the study. Exclusion criteria are described in Table 1.

After obtaining informed consent, the TCM intervention was implemented using an evidence-based APN-directed protocol ([www.transitionalcare.info](http://www.transitionalcare.info), last accessed July 26, 2011) adapted for the study population (see Table 2). Findings from pilot work (M. D. Naylor et al., 2005) informed the development of a proposed APN schedule of visits; however, APNs were encouraged and supported to use their clinical judgment to identify the need for additional visits and the specific focus of each visit in the hospital, at home, or in a skilled nursing facility (SNF) if the patient was discharged to an

Table 2. Key Components of the Transitional Care Model Intervention Protocol

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1. Schedule of Advanced Practice Nurse (APN) visits<sup>a</sup>:
    - Patient–caregiver (CG) dyad visited within 24 hr of study enrollment
    - At least daily throughout hospitalization
    - Within 24 hr of skilled nursing facility (SNF) admission or discharge to home
    - At least weekly during first month postdischarge from hospital to SNF or home
    - At last semi-monthly throughout the duration of the intervention
  2. Hospital component/primary goals:
    - Establish trusting relationships with patient and CG
    - Implement targeted risk reduction strategies to prevent/minimize the effects of cognitive impairment
    - Develop individualized care plans in collaboration with patient, CG, and patient’s health care providers
    - Begin to implement plans
  3. Home Component: begins immediately posthospital discharge to home or SNF.
  4. Discharging the patient–CG dyad<sup>b</sup>:
    - APNs use clinical judgment to determine length of intervention. Termination guided by:
      - Patient is medically stable
      - Patient–CG goals
      - CG able to identify early symptoms that require intervention and strategies for preventing poor outcomes
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<sup>a</sup>Note: While the proposed schedule defines minimal expectations, APNs use clinical judgment to determine frequency (number) and intensity (length) of patient–CG visits and telephone contacts.

<sup>b</sup>For a dyad to be considered having “received the intervention” a minimum of four home visits (SNF and/or home) must have occurred.

SNF prior to going home. APNs made every effort to schedule all visits at times mutually agreeable to patients and CGs; when this was not feasible, the APN made contact with the CG via telephone. The protocol directed APNs to make a visit to the acute hospital setting within 24 hr of study enrollment. During this visit, the APN performed a comprehensive assessment of the patient’s health status; worked with the patient, CG, and inpatient team to define priority goals and services; and collaborated with other health care team members to streamline and coordinate plans for inpatient and postdischarge care based on the comprehensive assessment and mutually developed goals.

Patients and CGs knew the APN caring for them was available 7 days per week (8 a.m.–8 p.m.). Home visits (or visits to an SNF) occurred within 24 hr of discharge from the hospital; during this visit, the APN, patient, and the CG developed an explicit personalized plan for emergency care during those hours when the APN was unavailable. Throughout the study, the protocol directed APNs to visit at least once per week during the first month posthospital discharge and then bimonthly until the patient and CG were discharged from the study. APNs also made telephone contact with patients and CGs as needed and, at a minimum, at least once per week when a home visit was not scheduled. APNs also accompanied the patient (and in many instances, the CG also attended this visit) on their first (and in some cases, subsequent)

postdischarge visit with their primary care or specialist health care provider. Prior to the visit, the APN worked with the patient and CG to generate a list of questions to be addressed during the visit. During this visit, the APN focused on facilitating excellent communication related to the plan of care between hospital and out-of-hospital providers, fostering mutually acceptable goals of care, advocating for the patient and CG as they navigated transitions or any health issues that occurred during the intervention, and assisting patients and CGs in understanding the provider’s instructions and need for additional follow-up.

Throughout the study, APNs worked with the patients and CGs to develop goals, identify teaching–learning needs, and address any other issues impacting care. APNs had access to all team members at any time, either by electronic mail, telephone, or in-person. APNs also had access to a multidisciplinary team of local experts who were known to the team and were willing to provide support and advice including a geropsychiatric nurse specialist, neurologist, pharmacologist, nutritionist, and nurses expert in culturally sensitive care and educational and behavioral strategies targeted to older adults. Access to any of these experts was implemented on a case-by-case basis; for example, if the APN determined that a nutritionist might be helpful in achieving goals, the APN worked with the patient and CG to arrange for specialist input.

## Purpose and Specific Aims

The overall aim of the parent study was to measure outcomes for chronically ill cognitively impaired older adults and their family CGs after they received a transitional care intervention delivered by an APN. In the parent study, APNs had the latitude to enlist whatever resources they felt necessary, spend as much time with patients and CGs as they felt necessary, and provide individualized care to meet their patients' and CGs' needs. The purpose of the analysis presented in this article is to further understand what took place over the course of the parent study to ensure successful delivery of the TCM intervention and specifically to examine barriers and facilitators to delivering an APN-directed TCM intervention.

## Ethical Considerations

The parent study was approved by the University of Pennsylvania Institutional Review Board and additionally granted approval by the Medical and Nursing Directors at each UPHS facility.

## Methods

An exploratory qualitative design was used to examine barriers and facilitators associated with providing transitional care to cognitively impaired elders and their CGs.

## Data Sources

Two types of data were used to meet the aims of this analysis. Individual case summaries written by APNs for each enrolled patient–CG dyad were used as the primary source of data. Fieldnotes written by two of the study coinvestigators during the case conferences served as a secondary data source.

1. *Individual case summaries written by APNs for each enrolled patient–CG dyad:* Three APNs provided the transitional care for the patients and CGs in this study. Each patient–CG dyad was followed by one APN over the entire study period. At study discharge, each APN completed a detailed narrative case summary describing his or her delivery of the study intervention and the outcomes of the intervention. More specifically, the case summaries included (a) a summary of the salient clinical or social events that occurred over the course of the study, (b) a chronology of the APN's

individualized interventions and outcomes of those interventions, (c) a summary of the patient's clinical condition and any additional information about the patient–CG dyad's relationship at study discharge, and (d) a summary of the APN's experience in working with the patient–CG dyad. No direct feedback from the patient–CG dyad was included or solicited for completion of the narrative case summaries.

2. *Fieldnotes from biweekly APN case conferences:* Biweekly case conferences were held from the beginning of patient–CG dyad enrollment (February 23, 2006) until discharge of the last patient–CG dyad (March 31, 2010). Each conference was facilitated by two of the study coinvestigators; one who had expertise in gerontology and cognitive impairment (C. Bradway) and one who was an expert in the TCM (K. McCauley). Each conference lasted an average of 1.5 hr. During the conference, the three APNs and two coinvestigators reviewed each patient–CG dyad currently enrolled in the study. Conferences were semi-structured in that the same topics were covered for each patient–CG dyad, yet individual concerns and specific situations were also included in the discussion as they arose. Discussion topics included any issues regarding adherence to the research protocol of the parent study, clinical issues, and unique individual issues the APNs were managing. Fieldnotes provide a descriptive and focused account of a social situation (Speziale & Carpenter, 2003). During these conferences, two of the study coinvestigators kept hand-written fieldnotes detailing their thoughts and impressions of the study intervention, as well as any salient points voiced by the APNs.

## Patient and Caregiver Characteristics

An exploratory, qualitative directed content analysis examined 15 narrative case summaries written by APNs and fieldnotes from biweekly case conferences. Demographic characteristics of the 15 patients and their CGs are found in Table 3. In addition, patients' mean Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) score was 20.4 (range = 6–30), their mean number of comorbid conditions was 5.4 (range = 2–10), and 5 of the 15 patients (33.3%) lived alone. Most of the patients' CGs were either a spouse or adult daughter (60%;  $n = 9$ ); other CGs included sons ( $n = 4$ ), a friend ( $n = 1$ ), and a nephew ( $n = 1$ ).

**Table 3. Demographic Characteristics of Patients and Caregivers**

	Patients (N = 15)	Caregivers (N = 15)
Age: M (SD)	80.2 (±7.7)	61.7 (±12.9)
Male sex: n (%)	6 (40)	4 (27)
Education: mean number of years (SD)	12.7 (±3.2)	13.4 (±2.4)
Race: % White	40	40

### Data Analysis

A directed content analysis was conducted to identify major themes related to barriers and facilitators to the APN intervention. These content categories of “barriers” and “facilitators” were predetermined in accordance with the specific aims of this analysis. Directed content analysis allows for a structured deductive approach to qualitative data. It is most useful in extending or validating existing knowledge about a particular phenomenon (Hsieh & Shannon, 2005). The APN case summaries as well as the coinvestigators’ fieldnotes recorded during the APN case conferences served as the units of analysis (Graneheim & Lundman, 2003). Fieldnotes were considered as a secondary source and were used to augment and support findings from analysis of the case summaries. The predetermined content categories “barriers” and “facilitators” were not used to guide data collection; rather, they were only applied during the analytic process as described below. Both data sources were transcribed into a Microsoft Word document, reviewed by one of the coinvestigators and compared with the original documents for accuracy. The Word documents were then uploaded to NVivo (©QSR International, Version 8, 2009) for analysis.

Directed content analysis occurs via coding, data reduction, and identification of themes in relation to predetermined content categories (Graneheim & Lundman, 2003). Prior to coding, data were reviewed to get a sense of the barriers and facilitators with regard to implementation of the TCM intervention. This review aided in the development of operational definitions for these predetermined categories. Next, the authors began coding, which involved line-by-line extraction of key phrases, termed meaning units, from the raw data. Next, meaning units were grouped based on underlying similarity and reduced to subthemes (Graneheim & Lundman, 2003). Operational definitions were created for these subthemes to ensure systematic

organization of individual meaning units within subthemes. As subthemes emerged, they were tentatively categorized as either a barrier or a facilitator to delivery of the TCM intervention.

During the process of reducing meaning units into subthemes, the authors had two critical insights. First, the predetermined category of barriers and its operational definition did not seem to adequately represent the data; rather, “challenges” was chosen as a more appropriate descriptor. The second insight occurred with regard to the “facilitators” category. As meaning units were reduced to subthemes and identified as facilitators, evidence of several subthemes that exceeded our conceptual definition of “facilitators” emerged. Based on this discovery, we added a third category to our content analysis structure: “above and beyond.” Finally, subthemes were then grouped into themes, based on interpretation and meaning of the subthemes.

We first coded nine APN case summaries (three randomly selected summaries from each of the study APNs), examined emerging subthemes and patterns, and then coded an additional six APN case summaries (two randomly selected summaries from each of the three APNs), aiming for saturation. After coding a total of 15 case summaries, continual analysis failed to yield new information, indicating that saturation was reached (Speziale & Carpenter, 2003). None of the APNs were involved in analysis of the case summary data. The coinvestigator’s fieldnotes were also analyzed as part of the data and used to support findings that emerged from analysis of the APN case summaries.

Several measures were instituted to ensure trustworthiness (Walsh & Downe, 2006). First, the authors strictly adhered to systematic implementation of directed content analysis methodology. Second, to minimize the potential for bias, the analysts bracketed their knowledge of the TCM. Bracketing ensures, to the extent possible, that conclusions are data driven and not influenced by the analysts’ prior knowledge or experience (Gearing, 2004). In addition, one of the authors primarily responsible for conducting the data analysis had only cursory knowledge of the TCM, had no prior involvement with the APNs, never attended any of the case conferences, and was not informed of the specifics of the TCM protocol until after data analysis was completed. This added to the trustworthiness of the findings in that it limited the potential for prior knowledge and experience to influence the analysis. Third, the analysts

maintained an audit trail (Guba, 1981) throughout the analytic process. The audit trail was developed and updated by one of the coinvestigators (C. Bradway) and reviewed by another one of the manuscript authors (R. Trotta) for credibility. Credibility refers to the fit between the raw data and the conclusions drawn through data analysis (Tobin & Begley, 2004). Regular meetings were held to review the audit trail and discuss analytic decisions and interpretations until credibility was established.

## Findings

This section describes each of the three central themes in detail with respect to the (a) challenges, (b) facilitators, and (c) above and beyond. Excerpts from the data are included to illuminate the findings.

### *Having the Necessary Information and Knowledge*

**Challenges.**—Three challenges related to having the necessary information and knowledge impeded optimal delivery of the TCM intervention. First, some patients and CGs lacked baseline knowledge about posthospital care needs or their chronic illnesses. Second, although aware of their chronic illnesses, some patients and CGs tended not to acknowledge the severity of their illnesses or the implications of their symptoms. For example, one APN wrote “[the patient] was reluctant to acknowledge that his symptoms of coughing and fatigue were due to his heart, stating that he usually gets colds like this during the fall.” This challenge is related to the first in that the APNs identified they spent considerable time acknowledging the patient and CGs’ perceptions and then teaching patients and CGs about the health-related aspects of their chronic conditions and setting up workable management plans. Third, despite the APN’s best efforts, patients and CGs did not consistently follow mutually developed plans of care, hospital discharge instructions, or ongoing suggestions from the APN. For instance, one APN “provided the patient with a medication planner to assist her with medication administration, but she declined to use it.”

Patients and CGs not having and using the necessary information were compounded by the patient’s cognitive impairment. In some instances, these were patients with a preexisting cognitive impairment; in other cases, APNs were working with patients and CGs as an acute episode of delirium

was in the process of resolving, but for all patients, some type or degree of cognitive impairment existed. APNs needed to quickly assess the learning capacity and abilities of the patients and CGs before they could continue with the study intervention. APNs needed to gauge the CG’s knowledge of cognitive impairment and understanding of its impact and the patient’s underlying health problems. For some of the patients with chronic cognitive impairment, the degree to which CGs understood it as a chronic and progressive disease influenced the success of the intervention. For example, one APN wrote, “The intervention also included some [patient and CG] teaching around the cognitive impairment that the patient had been experiencing over the past few years.”

Moreover, in situations where the CG did not understand the cognitive limitations of the patient, it was difficult for APNs to maximize the potential of the intervention. In one case, a patient’s cognitive impairment was interfering with her ability to self-administer insulin. Ultimately, “The APN worked to help [the CG] become more involved in insulin administration, stressing her mother’s unreliable memory of prior insulin doses and confusion about current dosing.”

**Facilitators.**—Fortunately, APNs were able to identify challenges related to information and knowledge quickly and institute measures to facilitate the success of the intervention. They identified specific gaps in knowledge and educational needs among patients and CGs. This allowed them to tailor information and individualize approaches to learning. For example, one APN discovered that a CG could care for the patient if verbal instructions were supplemented with written materials. As a result she “. . . provided the caregiver with an intervention folder that included a calendar to record health-related information to assist in self-disease management, daily blood glucose results, weight, bowel movements, and physical activity. The folder also included highlighted information about how to contact the APN, information about cognitive impairment [e.g., the National Institutes of Health handbook on dementia], contact information for the PCP [primary care provider] and other providers, signs and symptoms of disease exacerbation and an emergency protocol for exacerbation of disease”. With this individualized written information, the CG was able to intervene appropriately and better manage the patient’s care.

In addition, the APN shared the idea of using an intervention folder with the other APNs during one of the biweekly case conferences, and APNs were then able to use this strategy if needed with their own patient–CG dyads.

APNs systematically reinforced the information they provided; helped patients and CGs set up systems to support record keeping of vital information (e.g., symptoms, blood glucose levels, blood pressure recordings, upcoming health care appointments); and fostered patient and CG independence in assessment, decision making, and problem solving. The following excerpt is a continuation of the case of the patient with heart failure portrayed above under “challenges.” “The APN worked with [the patient] to identify his symptoms of exacerbating heart failure and the benefits of the medications he takes. By the end of the intervention [the patient] was able to describe how fatigue and [shortness of breath] and difficulty lying flat were signs of heart failure and steps to take to modify his drug regime including an extra dose of Lasix and contacting his cardiologist.” This patient’s receptiveness to the APN’s teaching facilitated the APN’s delivery of the intervention.

*Above and Beyond.*—APNs ensured patient and CG well-being by getting to know them personally over the course of the intervention and thereby uncovering obstacles related to lack of knowledge and essential information that may not have been evident to other health care providers. The near constant availability of the APN and encouragement to call with questions at any time allowed APNs to intervene before situations escalated to the point of requiring hospitalization. In one situation, the APN guided an extremely frail 90-year-old patient, whose CG was a distant relative and minimally involved, in managing an accidental calcium channel blocker drug overdose caused by a new method of medication delivery from the pharmacy; the use of blister packs. “[the patient] called the APN complaining of tremors and headache, the APN was able to visit within 30 minutes and evaluated his blister pack which had double his meds in the box. The APN found the patient with a slightly elevated blood pressure, and fasciculations of hands. The patient refused [to go to the emergency room with the APN, so] the APN stayed with the patient until his headache resolved and the tremors subsided. The APN discussed appropriate use of the blister pack—one bubble per

day. After this incident the patient used the blister pack appropriately. The APN also communicated the plan to the patient’s primary care office and the cardiologist . . . ” In this exemplar, as a direct result of this APN’s availability and personal relationship with the patient, a potentially poor outcome was avoided.

### *Care Coordination*

*Challenges.*—As APNs engaged with patients and CGs, several challenges associated with coordination of care were evident. First, some patients and CGs had difficulty scheduling medical appointments, managing specialist care, and arranging transportation to appointments. In one instance, despite the APN’s offer of assistance, the patient “was unable to get to any follow up physician appointments for approximately 1 week post SNF discharge due transportation problems.” A second challenge was that some patients and CGs ultimately refused the APN’s services for care coordination. For example, in more than one instance, the patient–CG dyad declined the APNs’ assistance in coordinating care and reported that they would make the necessary arrangements on their own. One APN noted that “over the course of the intervention the patient did see her PCP, but did not want the APN to make a joint visit with her.”

Finally, although some CGs allowed the APN to accompany the dyad to medical appointments, they themselves were not well coordinated, ultimately leading to a suboptimal encounter for the patient. This is evident in the following excerpt: “An additional barrier to coordination and medical follow up was that neither [daughter A] nor [daughter B] attended the initial follow-up visit. Rather a friend who had provided supervision in the past for [the patient] and [the patient’s] grandson, who is involved in her care but not a primary caregiver, [accompanied her to the appointment]. There was confusion about which behavioral problems were currently most bothersome at the appointment because recent events over the past two days were very different than reports [the APN] received from [daughter A and daughter B] in the weeks prior.”

*Facilitators.*—APNs’ skills in advanced physical assessment, insights into patient’s problems and needs and CG capability, and knowledge of chronic illness and cognitive impairment management facilitated communication with the patient’s PCPs

and specialists. Moreover, APNs were able to identify complex needs, collaborate on effective interventions, and persevere to ensure that the needs were met. In one instance, “the APN called the PCP to discuss whether he still felt a referral was indicated [to hospice] and he [said yes, and] asked that the APN make the referral. The APN contacted [hospice] who initiated services within 3 days.” In another example, “The APN discussed how [the patient’s] cognitive decline, frequent hospitalizations and weight loss could signal a slow decline of her health status and that hospice services could improve the resources available in the home to meet [the patient and CGs’] goal of avoiding hospitalization.” This example demonstrates the APNs ability to employ advanced clinical judgment in her recommendation to help the patient and CG dyad meet their goals.

*Above and Beyond.*—Data analysis further revealed that APNs were extremely successful in aligning the necessary services for patient–CG dyads and ensuring that patients’ other health care providers had the necessary information to make appropriate care decisions. APNs worked tirelessly to ensure well-coordinated care, which included frequent phone calls and meticulous follow-up. One APN reported that he made, “five hospital visits, seven home visits, one joint visit with the patient to the PCP office, and made 17 phone calls during the intervention.” They went “above and beyond” by seeing what was necessary and ensuring that the necessary action happened. Their unique relationships with patients and CGs allowed them to understand all that was needed, and from there, they intervened with authority and advocated on behalf of both the patients and their CGs.

In the following data exemplar, the APN made herself personally available to a patient and her CGs 24 hr a day, seven days a week, in case they needed her at times other than the 8 a.m. to 8 p.m. specified by the APN protocol: “The APN discussed a plan for urgent care with all [of the patient’s] caregivers including contacting the APN and attempting to manage mild symptoms at home before calling 911.” This example demonstrates the lengths to which the APNs went to ensure patients received appropriate individualized care, even beyond the APN protocol, and provides an example of advanced clinical judgment and care employed by the APN to avoid escalation of a clinical situation.

## Caregiver Experience

*Challenges.*—Implementation of the parent study intervention required active CG participation; evidence of the caregiving experience was found throughout the APN case summaries. In actively working with CGs, the APNs uncovered challenges that underscore the complexity of caring for frail cognitively impaired older adults. A common challenge was helping family members deal with CG burden. One APN wrote, “Caregiver burden was a significant issue for [the CG] who was the enrolled and primary caregiver for [the patient]. [The CG] had few resources either financial or otherwise to utilize to provide respite for herself or to help with maintaining her own house and affairs. In addition, the relationship between [the patient] and [CG] was strained at times.” APNs identified CGs’ unique needs and promptly instituted supportive interventions; however, CGs did not always welcome the support, making it difficult for APNs to provide optimal patient care. This can be seen in one APNs account: “[The CG] was clearly overwhelmed by her responsibilities at times, yet refused to accept or seek further assistance.”

For some patient–CG dyads, the data revealed poor coordination among multiple CGs. Although it may seem that an adequate number of CGs existed, the following excerpt involving a patient with severe cognitive impairment reveals the complexity of administering a home-based care intervention that requires the participation of CGs.

“[The patient] lives with her granddaughter who is power of attorney for health care but not her overall power of attorney. [The patient] has a son who is estranged from the family but lives [nearby] and is peripherally involved with his mother’s care. From [the APN] conversations, the son provides no financial or other direct assistance to his mother. [The granddaughter] works full time and during the day [the patient] is cared for by her ex-daughter-in-law. When [the ex-daughter-in-law] is not available during the day [the patient] is cared for by other family members including the patient’s grandson and great-grandson.”

These situations provide insight into the challenges APNs face in actively engaging CGs and also the experiences CGs have that, in a typical home care system, may go undetected in the posthospitalization period. At times, these challenges required APNs to make multiple revisions to management plans to optimize the CGs’ abilities and resources.

*Facilitators.*—Despite the challenges, the CG experience also facilitated APNs' delivery of the intervention. Caregivers often reached out to the APNs by telephone and engaged the APN for problem solving during home visits. Evidence of these interactions was found repeatedly in the coinvestigator's fieldnotes, for example, one CG "was active in the APN intervention, making frequent telephone calls to the APN to collaborate and discuss needs." Another CG "assumed this role [of CG] and worked closely with the APN, [who was] in a coaching role, to make her family's need known."

Staying in close contact with the APNs allowed CGs to fulfill their caregiving obligations by receiving support for themselves and coaching in care management. One APN noted: "The caregiver was active in the APN intervention and present for all visits. She assisted in safety assessment and reinforced the plan of care—especially activity/exercises—between APN visits." In another case, an APN's involvement with the patient and the CG led to a successful outcome: "During the intervention the APN worked closely with the patient and her caregiver to start a new insulin regimen of prandial and sliding scale insulin three times a day. At the end of the intervention, through coaching from the APN, [the CG] was managing her mother's medications more closely, especially her sliding scale insulin doses."

*Above and Beyond.*—APNs also went above and beyond as they interacted with CGs. APNs acknowledged the hard work CGs were doing and made sure CGs had resources to take care of themselves. Similar to their actions with regard to patient care coordination, APNs exhausted all avenues to obtain maximum support services for CGs. APNs' frequent contact with CGs and efforts to establish a mutually trusting relationship resulted in a shared goal of CGs learning to function as independently and confidently as possible. For example, one APN wrote that she was "making multiple home visits and calls"; and "caregiver is stressed. APN talked with caregiver in hospital, called multiple times when patient arrived home, caregiver also called [the APN], caregiver starting to trust [the APN] and connect with her. [Caregiver] starting to listen to [APN suggestions.]"

This next example illuminates the APN's persistence in going above and beyond to obtain support for both the patient and her CGs in a circumstance where several CGs, providing varying levels of care

to the patient, were involved. "The APN referred [the patient] to [the Area Agency on Aging] and [the local Program for All-Inclusive Care for the Elderly (PACE)], and while her caregivers were interested in exploring options for adult day services they were not able to complete the application process because this required the involvement of [the patient's] son. The APN did contact the son by phone on multiple occasions to discuss the services available and the application process; while he seemed interested, he did not follow through on providing the information necessary to complete an application. The APN mailed [the patient's] son more information on initiating referrals and services himself, in particular for the [PACE] program which would be the best option to provide coordinated services and respite to [the patient's] caregivers."

### Limitations

The results of this study reveal important information about APN delivery of transitional care to cognitively impaired older adults and their CGs; however, the data are confounded in ways that deserve mention. First, although the three APNs followed the same TCM protocol, each APN implemented his or her own style when determining the content of the case summaries. In addition, APNs were not directed to specifically note barriers or facilitators to implementing the study intervention. Second, the coinvestigator fieldnotes were originally intended to track details of the APNs' caseloads. We chose to incorporate them as data for this analysis because of their richness and ability to contribute to the findings.

Although we are confident that we achieved saturation in our themes and that our results are trustworthy, our analysis was based on a randomly selected small subset of a larger study sample. Had we chosen an entirely different subset, it is possible that we would not have drawn the same conclusions. Therefore, the results and subsequent conclusions reported here are representative of the sample from which they emerged but cannot be generalized to other situations or populations.

### Discussion

This study adds to our knowledge of challenges and facilitators faced by APNs in delivering a TCM intervention and documents some of the difficulties health care professionals have in relating to and

addressing the day-to-day challenges that patients and CGs have to cope with in order to manage their chronic illnesses. APNs in our study needed to overcome significant gaps in knowledge and skills among both patients and CGs in managing posthospital care and complex chronic health problems and build skills among these patient–CG dyads in coordinating their own care. In addition, the experience of caring for a frail and cognitively impaired elder was found to be fraught with challenges that some CGs were able to handle with support; however, other CGs were poorly prepared for the increased demands placed on them. To address this, the APNs rapidly identified challenges, worked tirelessly to provide high-quality individualized care, and see the “big picture.” In this study, the big picture was a vulnerable patient with an average of more than five comorbid conditions, compounded by cognitive impairment, and in many cases, a stressed CG who lacked information, skill, or the physical or emotional stamina to provide optimal care and navigate an extremely complex health system. This type of situation is fraught with the potential for poor outcomes (Bynum et al., 2004; Sands et al., 2002); yet the APNs in our study were able to direct the patient’s transition with careful insight and planning and were able to prioritize so that they maximized the capabilities of the patient–CG dyad and marshaled additional support as needed.

The first theme, *having the necessary information and knowledge*, focused on how the APNs in our study rapidly identified knowledge deficits and individual needs, used multiple strategies to ensure learning, and were flexible in how information was delivered (e.g., telephone, folders, in-person). Moreover, although both patients and CGs in our study had, on average, educational levels of 12 or more years, findings also identified that cognitive impairment reduced patients’ abilities to engage in problem solving and further complicated care. A model, such as the one employed in this study, that reinforces the importance of providing timely, culturally appropriate information and training for patients and CGs has been identified in other studies as essential to meeting the care needs of vulnerable older adults (K. Anderson, 2010; Graham et al., 2009; White et al., 2007). An essential component of delivering information and knowledge was based on APNs in our study developing deep relationships, allowed coaching, and focused on a person-centered care approach that supported getting to know patients and their CGs as individuals (Galik

et al., 2009). These components are also consistent with those identified in a study of stroke CGs as being potentially helpful in assisting families in the caregiving role including a specific focus on the CG’s needs, coaching in problem solving, CG respite, and individualized attention to CG needs (White et al., 2007).

Study findings further support previous research which suggests that the complexity of patient needs and challenges associated with caring for cognitively impaired older adults posthospitalization, coupled with fragmentation engendered by our current health care system, results in the need for highly sophisticated *care coordination* processes (Golden, Tewary, Dang, & Roos, 2010; Institute of Medicine, 2008; Naylor & Keating, 2008). Our findings further solidify the APN intervention described here as one type of intervention that can thoughtfully and systematically meet challenges associated with transitional care, and future research should compare outcomes of the APN intervention described here with other strategies. An extensive body of literature supports the importance and contributions of APNs in providing complex care to chronically ill older adults (Dellasage & Zerbe, 2000; Kane et al., 1989; Ryden et al., 2000); however, limitations of published studies have also been described, including the inability of quantitative findings to showcase vital APN skills such as “communicating, relating, and contextual thinking” (Bourbonniere & Evans, 2002, p. 2074). Examining the APN case summaries and coinvestigator fieldnotes using a directed content analysis makes a significant contribution by providing specific examples of care coordination and highlighting some of these vital, yet oftentimes, invisible skills.

The third theme, *caregiver experience* is important to highlight because limited evidence exists regarding how TCMs affect family CGs (Naylor & Keating, 2008). It was essential that the APNs in our study connect with CGs from the very start of the intervention. They acknowledged CGs needs, recognized them as integral partners, helped arrange respite and other support services, coached and advocated for the patient–CG dyads, and were persistent in staying in contact, even when faced with multiple challenges. These partnerships and “therapeutic relationships” (Rosenbloom-Brunton, Henneman, & Inouye, 2010, p. 29) have been identified in a previous study of hospitalized older adults with delirium, and in our study, also were found to be facilitators to the transitional care of a challenging and vulnerable population.

One of the most important and compelling findings from our study suggests that what the APNs did was above and beyond what is typically expected and reimbursed in our current health care system, yet sorely needed as a model for economic and clinical reform (Bauer, 2010). The APNs had the resources to go above and beyond because this intervention was delivered as part of a research protocol. In a non-research setting financial, incentives do not exist for the number and intensity of services our APNs were able to provide, for example, in the case of one of our patient–CG dyads, where the APN made 5 hospital visits, 7 home visits, 1 joint visit with the patient to the primary care office, and 17 telephone calls during the course of the intervention. Frail cognitively impaired patients and their CGs enrolled in our study were identified by the APNs as in need of this level of care and support, yet current Medicare regulations promote a system of fragmented, separate, provider-based care that does not include the high level of care coordination and collaboration necessary for cost-effective high-quality care (Bauer, 2010; Boling, 2009; Naylor & Keating, 2008). Our findings support arguments that policy changes must occur to meet the challenges and provide the level of care necessary as frail cognitively impaired older adults transition across and within health care systems.

Finally, study findings have important implications for clinical practice, future research, and health policy. First, care of cognitively impaired older adults and their CGs during times of transition should focus on providing individualized knowledge and information, helping coordinate and navigate care needs, and placing a high priority on partnerships between health care providers and patient–CG dyads. Second, future research should explore patient and CG perceptions of the challenges and facilitators to transitional care and then compare those findings with the findings reported in this study. Listening to the voices of patients and CGs has been recognized as an important component of care during various phases of the stroke-recovery trajectory and during the transitional time posthospital discharge (Lutz & Young, 2010; Reiley et al., 1996) and would add an essential piece to existing literature. Additional research may also be warranted regarding how or if self-efficacy, CG distance and level of involvement, health literacy, and learning capacity impact the transitional care of cognitively impaired patient–CG dyads. Finally, study findings emphasize how the APNs in our study were able to direct and implement

an evidence-based TCM intervention to go above and beyond, not what APNs are capable of or ought to be doing, but rather the type of care typically reimbursed within our current health care system (Bauer, 2010; Liggins et al., 2010). This has significant implications for future policy discussions and development, particularly by redefining what is “usual care” to coincide with both what is needed and with what is cost-effective and to address how APNs might be most effectively used in a reformed health care system. Additional questions beyond the scope of our study, yet important to consider in the future include: In the ideal situation, who would APNs work for (e.g., health care systems, a community agency, the families themselves)?; Are there some situations/patients/families for which a transitional care intervention is not enough?; Are there potentially quantifiable limits to which patients can be realistically maintained at home, or what additional resources are essential if the patient is to successfully remain at home?

## Conclusions

In summary, findings from this qualitative study highlight some of the factors facilitating transitional care for cognitively impaired older adults and their CGs, challenges faced, and the myriad of strategies employed by APNs to ensure the highest quality of care. The three major themes that emerged during data analysis summarize the key elements APNs encountered in the study. These themes reveal the importance of assuring that patients and CGs have the necessary information and knowledge and the critical nature of care coordination and collaboration, as well as the skill APNs possess in directing and implementing transitional care for an extremely vulnerable population of cognitively impaired older adults and their family CGs.

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