

# Enhancing the Care Transitions Intervention Protocol to Better Address the Needs of Family Caregivers

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**Background:** Family caregivers play a central role in ensuring the execution of the discharge care plan.

**Objective:** To enhance an evidence-based model—the Care Transitions Intervention (CTI)—and to make it more responsive to the needs of family caregivers and determine its impact on a measure of activation.

**Methods:** Prospective cohort of 83 patient–family caregiver partnerships discharged from hospital. The domains of the CTI were modified to incorporate those areas that family caregivers identified as wanting to feel better prepared and more confident.

**Results:** Family caregivers experienced a mean improvement in activation of 6 points on a 0–10 scale ( $p < .0001$ ). Sixty-four percent (95% confidence interval [CI], 52–75%) of family caregivers met or exceeded self-identified goals. Transitions Coaches identified 71% (95% CI, 60–80%) of patients as having medication discrepancies or errors after hospital discharge and coached family caregivers on how to respond. The mean 3-item Care Transitions Measure score on a 0–100 scale was 80.89 (95% CI, 76.62–85.16). Almost all (99%) (95% CI, 92–100%) participants would recommend the model to a friend or family member.

**Discussion:** The enhanced family caregiver CTI significantly improved activation, quality, goal achievement, satisfaction, and medication safety. The enhanced family caregiver CTI may have application in improving the hospital discharge experience.

The project team conducted a previous qualitative study to explore the facilitators and barriers that family caregivers experience during transitions in care settings experienced by a loved one. Five central themes emerged from the analysis: (1) family caregivers' contributions to the care of their loved one unfold along on a spectrum where the readiness, willingness, and ability of both parties are often dynamic, (2) family caregivers have unique and potentially incongruent goals from those of the patient, (3) family caregivers feel unprepared for postdischarge medication management, (4) family caregivers need encouragement to assert their role and identity, (5) family caregivers often assume the responsibility for sequencing of post-hospital care plan tasks and anticipating next steps (Coleman and Roman, 2014). The purpose of this study was to incorporate the learning from the previous qualitative study into the CTI and then test the enhanced model.

## Literature Review

The project team reviewed the relevant published literature that addresses the confluence of family caregiving, care transitions, and skill transfer to support self-care. Although this article does not intend to offer a comprehensive review of the literature, we conducted a search of MEDLINE using the following terms: family, family caregiver, discharge planning, hospital discharge, patient transfer, patient discharge, care transitions, and care coordination. Overall, we were struck by a relative paucity of articles that address the experiences of family caregivers during this important time. In studies that have analyzed older adult and family caregiver dyads

**Keywords**  
family caregiver  
care transitions  
care coordination

## Purpose

Family caregivers frequently play an instrumental role in the care of patients at the time of transition out of the hospital (Fuji et al., 2013; Hesselink et al., 2012). Despite the importance of this role, no evidence-based intervention has been explicitly developed to impart a core set of skills to promote their ability to implement the posthospital care plan. This project addresses this gap by creating a family caregiver enhancement to the evidence-based Care Transitions Intervention (CTI) (Coleman et al., 2013).

during transitions from acute care settings, the focus is primarily on caregiver burden and satisfaction rather than activation or empowerment, goal-directed care, or patient outcomes. The identified literature does have strengths in the areas of qualitative studies and an emerging emphasis on the use of technology to improve communication. Thus although we retrieved 376 articles, we found that most of these did not have direct relevance to the intervention reported herein, either because the study was performed outside the U.S. healthcare system or because the focus of the article was on a single condition. What follows is our assessment of the most relevant literature.

Although the field is underexamined, existing literature suggests that family caregivers are frequently dissatisfied with the amount of information they receive during the discharge process (vom Eigen et al., 1999) and many feel ill-prepared to manage the complex care needs of chronically ill older adults in the home setting (Bull et al., 2000; Given et al., 2008; Grimmer et al., 2000).

Reinhard and colleagues revealed that 46% of family caregivers perform medical/nursing tasks, 78% of family caregivers manage medications, and 53% of family caregivers serve as care coordinators. Most family caregivers reported receiving no specific training for these roles (Reinhard et al., 2012).

An evidence review determined that to have a positive effect, discharge planning interventions for frail older patients should address family inclusion and education, communication between healthcare workers and family caregivers, ongoing support after the patient's discharge, and should commence well before discharge (Bauer et al., 2009).

Weinberg and colleagues (Weinberg et al. (2007) found that better coordination between health professionals and family caregivers improves family caregiver preparation to provide care and was positively associated with patients' pain control, functional status, and mental health.

Foust and colleagues (Foust et al. (2012) explored transition-related challenges in the context of patients and families who

received skilled home healthcare services. Family caregivers struggled to get answers to basic questions such as when their loved one was to be discharged. Many family caregivers found the information they received was often lacking in important details, particularly regarding medication instructions. Unless they took the initiative, family caregivers were infrequently included when discharge instructions were provided.

An Agency for Healthcare Research and Quality (2012) review identified hospital-level strategies to increase patient and family engagement include supporting patients and families in care coordination, establishing systems for patients and family members to track medications and health records after discharge, communicating with physicians, and providing access to health information.

Extending beyond a transition-specific focus, Rosland and Piette reviewed programs that aimed to increase effective family caregiver support for chronic illness management and self-care for adult patients without significant physical or cognitive disabilities. They identified programs that produce three primary findings: (1) programs that guide family members in setting goals for supporting patient self-care behaviors have led to improved implementation of family support roles, but have mixed success improving patient outcomes, (2) programs that train family in supportive communication techniques, such as prompting patient coping techniques or use of autonomy supportive statements, have successfully improved patient symptom management and health behaviors, (3) programs that give families tools and infrastructure to assist in monitoring clinical symptoms and medications are being conducted, with no evidence to date on their impact on patient outcomes (Rosland and Piette, 2010).

## Study Design and Methods

### Study Setting

The study hospital was a 253-bed non-profit acute care hospital serving a relatively geographically isolated community

of 82,000 people and a surrounding rural population of 120,000 people. Patients were recruited from the cardiovascular unit, the general medical-surgical unit, and the orthopedics unit.

### ***Study Population and Eligibility***

The project team defined “family caregiver” as any family member, partner, friend, or neighbor who provides or manages the care of someone who is ill, disabled, or frail. The sample included 83 consented patient–family caregiver partnerships. Patients were Medicare recipients aged 65 years and older admitted to the study hospital between May 1, 2012, and March 31, 2013. Patients were asked to identify their family caregiver. Patients were eligible if they and their family caregiver spoke English, they were not enrolled in hospice, both the patient and family caregiver had telephones, the patient and family caregiver lived no more than 30 miles apart, and the patient lived no further than 30 miles from the study hospital.

### ***The Original Care Transitions Intervention***

The CTI is an evidence-based intervention that prepares patients for a successful hospital discharge and postacute recovery through an explicit focus on skill transfer and self-management. A detailed description of the CTI is available at [www.caretransitions.org](http://www.caretransitions.org) and in previous publications (Coleman et al., 2004, 2006, 2013; Parry et al., 2003, 2006, 2009). Through the CTI, patients are prepared for how to respond to common transition challenges. “Transitions Coaches,” typically Registered Nurses and Social Workers, are trained in how to transfer these self-care skills during a single home visit and three follow-up phone calls. Transitions Coaches do not provide skilled services. To date, Transitions Coaches have routinely offered the core elements of the patient-oriented CTI to family caregivers although without any specific modifications to address their particular needs.

The project team conducted a qualitative study designed to better understand the unique challenges family caregivers

face during transitions and explore potential adaptations that could be incorporated into an enhanced family caregiver CTI (Coleman and Roman, 2014). These qualitative findings, combined with subsequent iterative testing, led to a number of key adaptations to the CTI protocol that are summarized in Table 1.

### ***Study Design***

This was a prospective study of 83 patient–family caregiver partnerships that were recently discharged from hospital and completed the enhanced family caregiver (CTI) protocol.

The enhanced family caregiver CTI is a 4-week intervention composed of a hospital visit, a home visit, and at least three follow-up telephone calls. Transitions Coaches encourage patients and family caregivers to take a more active role in their care, better articulate their needs, and improve their ability to meet these needs. Transitions Coaches initially determine whether they will direct the model to the patient, the family caregiver, or both.

The enhanced CTI begins with a brief hospital visit that emphasizes explaining how the model may feel different from case management services or skilled home health care services, building rapport, and scheduling a home visit at a mutual time.

The agenda for the home visit is largely determined by the patient and family caregiver’s self-identified goals. In addition, Transitions Coaches model behavior related to “Four Pillars” of self-management that will help them to effectively negotiate the most common transition-related challenges: medication self-management, use of a patient-centered Personal Health Record, timely primary care follow-up, and identification and response to “red flags” that indicate a worsening in condition.

In accordance with established principles of adult learning, the Transitions Coach engages the family caregiver in practice, simulation, and role-playing upcoming encounters. The Transitions Coach encourages the family caregiver to

**Table 1. Data Elements and Timing of Data Collection**

Domain	Measure (tool/data source)	Data collection period		
		Enrollment in hospital	Home visit and phone calls	Post-CTI follow-up phone call
Family caregiver characteristics				
Family caregiver demographics, contributions	Age, gender, race/ethnicity, relationship to the patient, roles as measured by DECAF, hours per week spent in a family caregiver role	X		
Locus of control of family caregiver	Question 1 “I have little control over the things that happen to me” Question 2 “I often feel helpless in dealing with the problems of life.” (Pearlin and Schooler, 1978)	X		
Process measures				
Program recruitment	Numerator = number of subjects enrolled Denominator = number of subjects approached	X		
Protocol completion	Numerator = number subjects that completed study protocol Denominator = number of subjects enrolled			X
Outcome measure				
Medication safety	Number of medication discrepancies identified using Medication Discrepancy Tool (Coleman et al., 2005)		X	
Quality of care	3-item Care Transitions Measure (Care Transitions Program, 2014)			X
Family caregiver activation	FCAA		X*	
Goal achievement	Family caregiver’s 30-day goal for her/himself		X	X
Satisfaction	Percent of family caregivers that would recommend the enhanced CTI to relative, friend, or neighbor			X

\*FCAA was initially ascertained at the beginning of the home visit. The final determination was made at the end of the third follow-up phone call.  
CTI, Care Transitions Intervention; FCAA, Family Caregiver Activation Assessment.

rehearse effective communication strategies to be better prepared to clearly articulate his or her needs.

A primary focus of the home visit is on medication management. The Transitions Coach helps the family caregiver develop a reliable system for medication administration. Together, they determine what medications the patient is taking and enter this information into the Personal Health Record.

The Transitions Coach uses the Family Caregiver Activation Assessment (FCAA) tool to track progress in activation across the Pillars and a Medication Discrepancy Tool to identify medication problems and errors and facilitate appropriate action. The visit concludes with a summary of what has been discussed and an articulation of what will happen next and what role each participant will play.

After the home visit, the Transitions Coach maintains continuity with the patient and caregiver by phoning three times over a 30-day posthospital discharge time period. These calls begin by evaluating patient and family caregiver progress considering their identified goals. As these calls are generally scheduled to correspond with encounters with a primary care physician, specialist, or home care nurse, the Transitions Coach and family caregiver debrief and identify aspects that went well and those that could have gone better. On completion of each call, the Coach rescores the FCAA.

### ***Study Tools and Measures***

The impact of the enhanced family caregiver CTI protocol was evaluated for a range of process and outcome measures (Table 2). There were three data collection opportunities for each patient–family caregiver partnership: (1) at the time of enrollment in the hospital by the study nurse recruiter, (2) during the home visit and phone calls by the Transitions Coach, and (3) during a follow-up telephone interview conducted by a member of the project team between 21 and 31 days after hospitalization (based on family caregiver availability).

With respect to goal ascertainment, the interviewer first confirmed the goal(s) and then asked the patient and family to characterize progress considering goal achievement, coded as (1) I have not worked on it, (2) I have not met that goal, but am working on it, (3) I have met the goal as well as I expected, or (4) I have met the goal better than I expected.

The FCAA provides the Transitions Coach with feedback on the family caregiver's gain in activation in relation to the Pillars over the course of the intervention. Each Pillar is initially scored and then rescored with a 0 (does not demonstrate skill), 1 (demonstrates skill), and the values are summed over 10 items measuring skills in the domains of the Pillars.

Family caregiver contributions were ascertained using the DECAF tool where D = Direct care, E = Emotional support, C = Coordination, A = Advocacy, and F = Financial support. Each category is scored from 0 (no contribution) to 3 (significant contribution) (Coleman and Williams, 2007).

The three-item Care Transitions Measure (CTM) is National Quality Forum endorsed for national use in capturing the patient's experience in preparation for self-care on discharge from hospital or skilled nursing facility to home (Care Transitions Program, 2014). The scores are transformed to a scale of 0–100 to facilitate comparison.

### ***Statistical Analysis***

Program recruitment and protocol completion rates were calculated. Family caregiver characteristics at the time of enrollment are described using means and standard deviations for continuous variables and frequency counts and percentages for categorical variables. Those who completed protocol and those who did not were compared using *t*-tests (or Wilcoxon tests if skewed) for continuous variables and chi-square tests (or Fisher's exact tests when cell counts were small) for categorical variables. Improvement measures were estimated with corresponding 95% confidence intervals, or improvements were tested using paired tests. Seventy-five completed patient–family

**Table 2. Family Caregiver Characteristics**

Characteristic	Completers (N = 83)	Noncompleters (N = 37)	P
Age (years), mean (SD)	65.7 (13.9)	61.3 (13.2)	.11
Hours per week spent caregiving, mean (SD)	113.8 (71.4)	105.3 (72.2)	.76*
Female, n (%)	64 (77)	28 (76)	.86
Non-White, n (%)	3 (4)	3 (9)	.35 <sup>†</sup>
Spouse/domestic partner, n (%)	66 (80)	20 (56)	.007
DECAF (0–3)			
Direct care, mean (SD)	2.4 (0.9)	2.5 (0.7)	.75
Emotional support, mean (SD)	2.8 (0.5)	2.9 (0.4)	.82
Coordination, mean (SD)	2.7 (0.5)	2.6 (0.6)	.41
Advocacy, mean (SD)	2.7 (0.5)	2.8 (0.4)	.32
Financial support, mean (SD)	1.9 (1.3)	1.5 (1.4)	.16
DECAF total, mean (SD)	12.7 (2.5)	11.3 (4.1)	.06 <sup>‡</sup>
Locus of control 1 (0–5), <sup>§</sup> mean (SD)	1.0 (1.3)	1.3 (1.5)	.37
Locus of control 2 (0–5), <sup>§</sup> mean (SD)	0.8 (1.2)	1.1 (1.3)	.049*
Patient resides with spouse/ domestic partner, n (%)	64 (77)	18 (51)	.006

Percentages were calculated based on nonmissing cases. For continuous variables and categorical variables, *t*-tests and chi-square tests were used, respectively, except.

\*Wilcoxon test.  
<sup>†</sup>Fisher's exact test.  
<sup>‡</sup>Behrens–Fisher test.  
<sup>§</sup>0 = *strongly disagree*, 5 = *strongly agree*.

caregiver partnerships were targeted to provide more than 90% power to detect a mean FCAA score increase of 0.5 in standard deviation unit for a two-sided paired test at Type I error rate = 0.05.

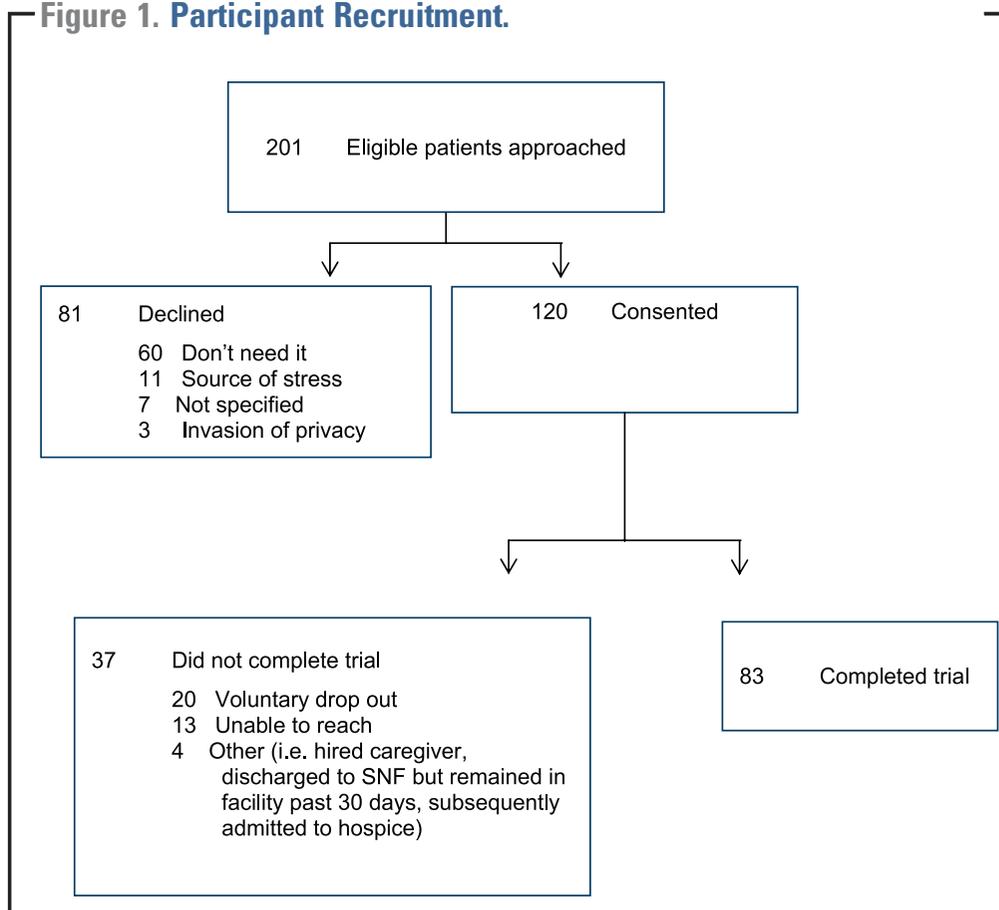
### **Institutional Board Approval**

After completion of an approved consent form and Health Insurance Portability and Accountability Act waiver, family caregiver partnerships were enrolled. All study activities and materials, including the consent process, were approved by the Colorado Multiple Institutional Review Board (protocol number 11-0851) and the PeaceHealth Institutional Review Board (protocol number 11-034).

### **Results**

As illustrated in Figure 1, 60% of family caregivers approached consented to participate. Of the 120 consented participants, 69% completed the protocol. Ninety-nine percent (95% confidence interval [CI], 92–100%) of family caregivers agree or strongly agreed to recommend the program to a relative, friend, or neighbor.

Family caregiver characteristics are provided in Table 2. Family caregivers for the 83 patients who completed the protocol were on average 66 years old and spent 114 hr per week on family caregiving. They were predominantly female (83%), white non-Hispanic (96%), and a spouse or domestic partner (80%). Most patients (77%) resided in a private residence with

**Figure 1. Participant Recruitment.**

a spouse or domestic partner. Among the participants who did not complete protocol, patients were less likely to reside with a spouse or domestic partner (51% vs. 77%,  $P = .006$ ) and the family caregivers were less likely to be spouses or domestic partners (56% vs. 80%,  $P = .007$ ).

The mean gain in FCAA during the 30 days between the initial home visit and the end of the 30-day intervention period was 6.0 ( $P < .0001$ , paired  $t$ -test) where FCAA is measured on a scale of 0–10. Most family caregivers met or exceeded their self-identified goals for themselves: 64% (95% CI, 52–75%). Mean transformed CTM-3 score was 80.89 (95% CI, 76.62–85.16). Finally, Transitions Coaches identified 71% (95% CI, 60–80%) of patients as having one or more medication discrepancies or errors after hospital discharge and coached the patients and family caregivers on how to respond.

### Limitations

The project was conducted at a high performing hospital in a relatively modest-sized community and as such the study generalizability is not known. Furthermore, the project findings may have been influenced by the possibility that those who consented to participate had higher clinical risk or higher perceived risk for adverse posthospital discharge experiences. As discussed above, residing with a spouse or domestic partner made participants more likely to complete the intervention. Finally, as the study of family caregivers' needs during transitions is underexplored, it is possible that important and unidentified variables were not evaluated that may have provided greater insight into the interpretation of these findings.

### Directions for Future Research

Due to the absence of a suitable control group, the impact of the intervention on

subsequent hospital readmission was not examined. In particular, it is currently not possible to determine the suitability of family caregiver controls as their status, roles, and degree of participation is not routinely collected by healthcare providers. Future research may focus on a rigorous strategy for addressing this gap.

## Discussion

The enhanced family caregiver CTI significantly improved quality (as measured by the CTM), medication safety (as measured by the Medication Discrepancy Tool and the subsequent collaboration with Transitions Coaches to facilitate resolution of discrepancies and errors), and family caregivers' activation for their role in implementing the discharge care plan (as measured by the FCAA). Most family caregivers achieve their self-identified goals for themselves. With relatively high levels of acceptance (as measured by the rate of consent to participate) and satisfaction (as measured by the willingness to recommend the enhanced family caregiver CTI to a friend or relative), the enhanced model seems to have application in local and national efforts aimed at improving the transition experience out of the hospital.

## Implications for Practice

Because family caregivers' contributions often go unrecognized, there is relatively little attention to their needs and consequently even less guidance for how to best to incorporate their voice and preferences to more formally engage them at times of care transitions. The project team therefore relied on a previous qualitative study (Coleman and Roman, 2014) to gain insight into how to enhance the evidence-based CTI to better support family caregivers at times of transitions. The major lessons from these discussions resulted in three major types of model enhancements categorized as delivery, content, and logistics.

Regarding delivery, these lessons suggested that a new or enhanced intervention would benefit from a mechanism by

which the readiness of family caregivers and their loved ones might be ascertained along a spectrum with one end being the family caregiver plays a primary role, fully engaged in each aspect of care, to the other end where the patient is rapidly regaining self-care abilities and the family caregiver plays a more modest secondary role. This ability to recognize that the readiness, willingness, and ability of both parties may be in flux throughout the intervention would ensure that the delivery of the intervention is tailored accordingly.

Next, the project team recognized that the content of an enhanced CTI should build on the observation that family caregivers who established a trusting relationship with a pharmacy or pharmacist experienced better care transitions. Additional content modifications included a focus on facilitating family caregivers' ability to anticipate next steps and translate the care plan into an ideal sequence for the events that follow.

Finally, regarding logistics, our findings suggested that an intervention that includes face-to-face or telephonic encounters should be flexible and accommodating of family caregivers' schedules and competing demands. We modified the CTI to accommodate family caregivers need to schedule encounters outside of typical hours.

The enhanced family caregiver CTI significantly improved quality, goal achievement, medication safety, and activation. With high levels of satisfaction, the enhanced model appears to have application to local and national efforts aimed at improving the hospital transition experience.

## Acknowledgments

The project team recognizes the valuable contributions of Shannon Starr, RN, BSN, PCCN, for her exceptional role in recruiting study participants (*permission obtained via e-mail, February 7, 2014*).

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*Supported by the Gordon and Betty Moore Foundation. The sponsor had no role in the preparation, review or approval of this manuscript.*

*The authors declare no conflicts of interest.*