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## **Patients' and Family Caregivers' Goals for Care During Transitions Out of the Hospital**

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*The aims of this study were to (a) describe the nature of patients' goals upon discharge from hospital, family caregivers' goals for their loved ones, and family caregivers' goals for themselves; (b) determine the degree of concordance with respect to the three elicited goals; (c) ascertain goal attainment across the three elicited goals; and (d) examine factors predictive of goal attainment. Our findings support the position that eliciting patient and family caregiver goals and promoting goal attainment may represent an important step toward promoting greater patient and family caregiver engagement in their care.*

**KEYWORDS** *care coordination, care transitions, family caregiver, goals of care, hospital discharge*

### INTRODUCTION

One promising strategy to achieve greater engagement of patients and their family caregivers in managing their chronic health conditions is to encourage the identification and pursuit of personal goals. Goals provide insight into how these individuals define quality of life as well as a window into what may motivate them to more actively participate in self-care of chronic health conditions.

Despite the potential value of eliciting patient and family goals for promoting greater engagement in self-care of chronic health conditions, this approach is not routinely incorporated into practice. In those instances when goals are discussed, the content is often predefined by health professionals,

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generally to fit the context of mandated quality reporting (such as cholesterol or hemoglobin a1c values) or the needs of a particular care setting (such as an inpatient rehabilitation facility). Presenting predefined goals to the patient or family caregiver to endorse is quite different from encouraging the patient or family caregiver to independently construct his or her own goal. Family caregivers often have goals for their loved ones and also goals for themselves in relation to their caregiving role. We hypothesize that when family caregiver goals are aligned with patient goals, greater mutual support may ensue, thereby enhancing goal attainment.

An examination of the existing literature reveals a number of investigations that have explored the topic of patient goals. Although there remains no gold standard for how to elicit patient goals, published articles have explored various taxonomies for the types of goals elicited (Bogardus et al., 2001, 2004; Bradley et al., 2000; Robben, Perry, Olde Rikkert, Heinen, & Melis, 2011; Yip et al., 1998). Other investigators have examined the process of formulating goals—including exploring the degree of agreement between patients, their family caregivers, and clinicians (Bogardus et al., 2004; Levack, Dean, Sieger, & McPherson, 2011; Robben et al., 2015). A number of authors support the practice of clinician defined goals to promote comparability across practices and reduce the likelihood that patients articulate unrealistic or unattainable goals (Hurn, Kneebone, & Cropley, 2006; Reuben & Tinetti, 2012; Robben et al., 2015). Additional studies have explored psychosocial factors that shape the content of the elicited goals, including degree of risk-taking, perceived self-efficacy, and acceptance of one's disease (Bradley, Bogardus, Tinetti, & Inouye, 1999). In a study of persons living with diabetes, the majority of patients expressed their health care goals in a social and functional language, in contrast to a biomedical language (Huang, Gorawara-Bhat, & Chin, 2005).

A growing number of researchers have advocated for the inclusion of family caregivers and their goals when formulating a plan of care (Aminzadeh et al., 2005; Byrne, Orange, & Ward-Griffin, 2011; Demers, Ska, Desrosiers, Alix, & Wolfson, 2004; Hills, 1998). Rosland and Piette (2010) reviewed programs that aimed to increase effective family caregiver support for chronic illness management. Their findings suggest that programs that guide family caregivers in setting goals for supporting patient self-care behaviors have led to improved implementation of family support roles.

In this exploratory analysis, we set out to build upon this existing literature, adding new contributions to better inform strategies to promote greater engagement of older adults and their family caregivers. To our knowledge, this is first study to elicit patient goals as well as family caregivers' goals for their loved ones and goals for themselves using an open-ended question format. We also believe this is the first study to focus on the vulnerable and dynamic period of care transitions out of the hospital.

Our aims were to (a) describe the nature of the goals elicited from patients, family caregivers' goals for their loved ones, and family caregivers' goals for themselves; (b) determine the degree of concordance with respect to the nature of these three elicited goals; (c) ascertain goal attainment across the three elicited goals; and (d) examine factors predictive of goal attainment.

## METHODS

### Study Setting

The study hospital was a 253 bed nonprofit acute care hospital serving a relatively geographically isolated community of 82,000 people and a surrounding rural population of 120,000 people. Patients and their family caregivers were recruited from the cardiovascular unit, the general medical-surgical unit, and the orthopedics unit.

### Study Population and Eligibility

The project team operationally 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 (Next Step in Care, 2015). The sample included 83 patient-family caregiver partnerships that consented to participate. Patients were Medicare recipients age 65 and older admitted to the study hospital between May 1, 2012 and March 31, 2013. A part-time study nurse identified potential participants admitted to the cardiovascular unit, the general medical-surgical unit, and the orthopedics unit. Permission to approach first the patient and then the family caregiver (identified by the patient) was obtained from the primary nurse. 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 farther than 30 miles from the study hospital. All study activities, 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).

### Study Design

This was a prospective exploratory study of 83 patient-family caregiver partnerships that were recently discharged from hospital. The study reported herein was a preplanned evaluation embedded into a larger trial evaluating a family caregiver enhanced Care Transitions Intervention protocol (Coleman, Roman, Hall, & Min, 2015).

## Study Tools and Measures

There were three points of contact for enrollment or data collection for each patient-family caregiver partnership: (a) enrollment and consent during the initial hospitalization; (b) goal identification during a home visit within the first 2–5 days after hospital discharge; and (c) ascertainment of goal progress during a follow-up telephone interview conducted between 21–31 days posthospitalization.

Patients and family caregivers were asked, “What is one personal goal that is important for you to achieve in the next month?” Each patient-family caregiver partnership provided three responses to the goal question. The patient was asked to respond on behalf of herself or himself. The family caregiver was asked to respond on behalf of herself or himself. The family caregiver was further asked to respond on behalf of her or his loved one (the patient). For the majority of partnerships, the interviewer asked the goal questions in the presence of both the patient and the family caregiver. The interviewer was instructed to ask questions that aimed to further clarify the nature and specifics of the goal. The interviewer was instructed not to suggest possible goals or make any remarks as to the value or appropriateness of the goal.

With respect to goal progress ascertainment, a different interviewer first confirmed the goals as articulated upon enrollment and then asked the patient as well as the family caregiver to characterize progress made toward goal attainment, coded as: (1) I have not worked on it; (2) I have not met the 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. To reduce the potential for self-reporting bias, the interviewer who inquired about goal attainment at the third data collection point had no prior contact or relationship with the patient and family. The source of the goal question and its subsequent goal progress ascertainment is derived from the protocol used in the evidence-based Care Transitions Intervention that has been widely implemented in the United States beginning in 2004 (Coleman, Rosenbek, & Roman, 2013).

In addition to assessing participant demographic characteristics, family caregivers were asked to respond to two brief questions concerning their perception of locus of control (Pearlin & Schooler, 1978): “I have little control over the things that happen to me” (Question 1) and “I often feel helpless in dealing with the problems of life” (Question 2). Response categories ranged from 0 (*strongly disagree*) to 5 (*strongly agree*).

Family caregiver contributions were ascertained using the D.E.C.A.F. 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*) for an overall aggregate score that ranges from 0–15 (Coleman & Williams, 2007).

## Statistical Analysis

Among the 83 patient-family caregiver partnerships that consented to participate, complete data on goals and goal attainment was available for 73 partnerships (due to missing data or a patient or family member declining to respond). As this was an exploratory investigation, the study team did not bring preconceived themes to the analysis. The study team initially reviewed the uncategorized responses to propose possible themes. Next the study team reviewed the published literature to gain insight into how other authors' have approached this challenge and further refinements emerged.

Patient and family caregiver demographic characteristics at the time of enrollment are described using means and standard deviations for continuous variables and frequency counts and percentages for categorical variables. Goal type and goal attainment are described for patient, family caregiver for self, and family caregiver for patient.

We present the results of concordance for (categorical) goal type (as participant characteristics) and correlation for (ordinal) goal attainment (as comparing the three outcome variables), among patient, family caregiver for patient, and family caregiver for self. Correlations among goal attainment of patient, family caregiver for self, and family caregiver for patient were assessed using the Spearman rank correlation coefficient. Linear regression was used to predict each respondent's goal attainment (as a continuous variable) using goal type, concordances, and demographic variables.

## RESULTS

Patient and family caregiver demographic characteristics are provided in [Table 1](#). The typical family caregiver participant in this study was an older female spouse or domestic partner. These family caregivers put forth great effort into this role as measured by time (an average of 113.8 hours per week) and self-report of individual contributions (as measured by an average D.E.C.A.F. cumulative score of 12.7 out of 15).

The categorization and distribution of elicited goals are presented in [Table 2](#). Goals were grouped into four categories: function (activities of daily living/instrumental activities of daily living); employment or volunteer roles (inclusive of educational pursuits); socialization or hobbies; and symptom or health condition management.

Representative examples of each category are provided herein beginning with the patient's goal; followed by the family caregiver's goal for the patient; and finally the family caregiver's goal for herself or himself. Function: "walk the dog outside with minimal assistance"; "walk downstairs to attend congregated meals"; "move back to own home." Employment/volunteer: "return to volunteer work at local food bank"; "return to work at his construction company"; "get school projects done." Socialization or hobbies:

**TABLE 1** Participant Demographics\*

Characteristics	Mean ( <i>SD</i> ) or <i>n</i> (%)
Patient characteristics ( <i>N</i> = 83)	
Age (years), mean ( <i>SD</i> )	75.9 (7.6)
Female, <i>n</i> (%)	27 (33%)
Family caregiver characteristics ( <i>N</i> = 83)	
Age (years), mean ( <i>SD</i> )	65.7 (13.9)
Female, <i>n</i> (%)	64 (77%)
Relationship to patient	
Spouse/domestic partner, <i>n</i> (%)	66 (80%)
Adult child <i>n</i> (%)	14 (17%)
Other <i>n</i> (%)	3 (3%)
Patient resides with spouse/domestic partner, <i>n</i> (%)	64 (77%)
Hours per week spent caregiving, mean ( <i>SD</i> )	113.8 (71.4)
D.E.C.A.F. Family caregiving contributions tool (0–3 scale for each item)	
Direct care, mean ( <i>SD</i> )	2.4 (0.9)
Emotional support, mean ( <i>SD</i> )	2.8 (0.5)
Coordination, mean ( <i>SD</i> )	2.7 (0.5)
Advocacy, mean ( <i>SD</i> )	2.7 (0.5)
Financial support, mean ( <i>SD</i> )	1.9 (1.3)
D.E.C.A.F. total across five items; mean ( <i>SD</i> )	12.7 (2.5)
Locus of control 1 “I have little control over the things that happen to me”	1.0 (1.3)
( <i>Strongly disagree</i> = 0; <i>strongly agree</i> = 5), mean ( <i>SD</i> )	
Locus of control 2 “I often feel helpless in dealing with the problems of life”	0.8 (1.2)
( <i>Strongly disagree</i> = 0; <i>strongly agree</i> = 5), mean ( <i>SD</i> )	

\*Percentages were calculated based on nonmissing cases.

**TABLE 2** Categorization and Distribution of Elicited Goals

Goal type	Patient ( <i>N</i> = 73)	Family caregiver for patient ( <i>N</i> = 73)	Family caregiver for self ( <i>N</i> = 73)
1 = Function (including activities of daily living and instrumental activities of daily living)	20 (27%)	23 (32%)	13 (18%)
2 = Employment or volunteer roles	8 (11%)	4 (5%)	10 (14%)
3 = Socialization or hobbies	23 (32%)	16 (22%)	35 (48%)
4 = Symptom or health condition management	16 (22%)	28 (38%)	9 (12%)
5 = Declined/did not respond	6 (8%)	2 (3%)	6 (8%)

“return to prayer meetings at church”; “celebrate 80th birthday with family at the casino”; “return to quilting.” Symptom or health condition management: “regain energy to attend cardiac rehabilitation”; “reduce pain to minimal or none”; “lose four pounds of weight.”

Concordance between patients’ goal type and family caregivers’ goal type for their loved one was 41%. Patients’ goal type and family caregivers’

**TABLE 3** Goal Progress Ascertainment

Goal attainment	Patient ( <i>N</i> = 74)	Family caregiver for patient ( <i>N</i> = 79)	Family caregiver for self ( <i>N</i> = 75)
1 = Have not worked on	1 (1%)	0 (0%)	1 (1%)
2 = Have not met but working on	35 (47%)	31 (39%)	26 (35%)
3 = Have met as well as expected	19 (26%)	28 (35%)	28 (37%)
4 = Have met better than expected	19 (26%)	20 (25%)	20 (27%)

goal types for herself or himself had a somewhat lower concordance at 32%. Family caregivers' goal types for their loved one and for herself or himself had a substantially lower concordance at 19%.

Goal progress ascertainment is presented in Table 3. Fifty-two percent, 95% CI [40%, 63%], of patients met or exceeded progress toward their goals. The majority of family caregivers attained their goals for their loved ones and for themselves: 60%, 95% CI [49%, 71%], met or exceeded goals for their loved ones; and 64%, 95% CI [52%, 75%], met or exceeded goals for themselves.

Patients' goal attainment was correlated with family caregivers' goal attainment for their loved one (Spearman correlation coefficient .49,  $p < .0001$ ). Family caregivers' own goal attainment was also correlated with patients' goal attainment (Spearman correlation coefficient .34,  $p = .004$ ) and family caregivers' goal attainment for their loved one (Spearman correlation coefficient .38,  $p = .0008$ ).

Linear regression modeling with goal attainment as the dependent variable is provided in detail in Table 4. To summarize, patient goal attainment was predicted by patient's goal type and patient residing with a spouse or domestic partner. Similarly, family caregiver's goal attainment for their loved one was predicted by family caregiver's goal type for her or his loved one and patient residing with a spouse or domestic partner. Family caregiver's goal attainment however, was predicted only by locus of control Question 2: "I often feel helpless in dealing with the problems of life" (ranging from 0 [*strongly disagree*] to 5 [*strongly agree*]).

## DISCUSSION

### Summary and Possible Interpretation of Findings

When given an opportunity to articulate a personal goal using an open-ended question format, patients being discharged from the hospital in this study reported a higher percentage of goals related to functional status or



**TABLE 4** Linear Regression Models for Goal Attainment\*

	Parameter	Estimate	<i>P</i> value
Patient goal for self ( <i>N</i> = 65, <i>R</i> <sup>2</sup> = .22)	Intercept	1.99	<.0001
	Goal type (vs. symptom or health condition management):		
	Function	0.36	.17
	Employment or volunteer roles	0.91	.008
	Socialization or hobbies	0.76	.004
	Patient residing with spouse/domestic partner	0.47	.03
Family caregiver goal for patient ( <i>N</i> = 70, <i>R</i> <sup>2</sup> = .14)	Intercept	2.47	<.0001
	Goal type:		
	Employment or Volunteer Roles (vs. other types)	0.81	.04
	Patient residing with spouse/domestic partner	0.46	.03
Family caregiver goal for self ( <i>N</i> = 75, <i>R</i> <sup>2</sup> = .08)	Intercept	3.05	<.0001
	Locus of control 2	-0.19	.02

\*Each regression model controlled for goal type, concordance, and participant demographics (age and gender for patient; age, gender, whether relationship to patient is spouse/domestic partner, hours per week spent caregiving, D.E.C.A.F. total, locus of control 1 and 2 for family caregiver; and whether patient resides with spouse/domestic partner), where significant variables were selected using a stepwise algorithm.

returning to socialization or hobbies compared with goals related to symptom or health condition management. In contrast, family caregivers reported a higher percentage of goals related to symptom or health condition management for their loved one. When asked to articulate a goal for themselves, family caregivers reported a higher percentage of goals related to returning to socialization or hobbies. We postulate that the types of goals articulated provide valuable insight into how patients and their family caregivers define quality of life. In those instances when the articulated goals did not directly identify symptom or health condition management, one might still envision that improved self-care or self-management of a health condition might be an important step toward eventual goal attainment.

The majority of patients met their goals and the majority of family caregivers met the goals they identified for their loved ones and the goals they identified for themselves. As the research team did not attempt to influence or modify the content of the identified goals, a relatively high level of goal attainment may suggest that participants auto-regulated or “right-sized” goals that were within their reach during a 30-day time period.

As the four categories of goal types reflect different domains and likely required different approaches to pursue, it was not surprising that some types of goal may have been more difficult to attain than others. The finding that those patients whose family caregiver lived with them reported a higher rate of goal attainment may be explained by a greater opportunity

for encouragement and reinforcement. Further, observing that patients' goal attainment was correlated with family caregivers' goal attainment for their loved one may provide some insight into the importance of the strength or cohesion of the patient-family caregiver relationship.

### Implications for Clinical Practice

Although this is an exploratory study, it may inform the efforts of front line clinicians interacting with adults with complex conditions and their family caregivers. By not using an existing taxonomy of predefined goals to select from, the findings may help both researchers and clinicians understand the nature of what may motivate patients to engage in self-care of chronic health care conditions in order to continue to improve following discharge from the hospital. The observation that the goals established by patients and their family caregivers are interrelated may serve to reinforce the value of including family caregivers in formulating the care plan and in other aspects of providing care. Several national professional organizations have developed clinical practice guidelines that call out the need to recognize the important contributions made by family caregivers (Coleman, Boulton, & American Geriatrics Society Health Care Systems Committee, 2003; Miller et al., 2010; Snow et al., 2009)

### Strengths and Limitations

In terms of strengths, this analysis has reported on the types of goals identified and the interrelationships between patient and family caregiver goals. To our knowledge these findings have not been reported previously. We also believe this is the first study to focus on the vulnerable and dynamic period of care transitions out of the hospital.

In terms of limitations, goal attainment was self-reported. We attempted to mitigate some of the potential for bias by having a research assistant with no prior relationship with the patients or family caregivers ascertain progress toward goal attainment. The fact that for the majority of partnerships, the interviewer asked the goal questions in the presence of both the patient and the family caregiver, may have influenced the articulated goals (although goals would eventually be made known to both parties). The 30-day time period to evaluate goal attainment was admittedly arbitrary and may have constrained the types of goals elicited and their potential for attainment. There was a relatively modest selection of demographic variables available to be entered into the regression models and as such, the ability to explore the relationships articulated by the study aims may have been constrained. Further, this is a study conducted in a single community hospital setting and the results may not generalize to the larger U.S. population.

Finally, we did not screen for cognitive impairment in either the patients or the family caregivers who participated in this study. We do recognize the work of Bogardus and colleagues (Bogardus, Bradley, & Tinetti, 1998) who maintain that cognitive impairment should not exclude the opportunity for identification of goals.

### Opportunities for Future Research

Through conducting this project, we did not have the opportunity to address the stability of articulated goals but we do envision that goals likely change over time with respect to type and scope. From a practical perspective, additional relevant questions might begin to address how to incorporate goal setting into clinical practice, including who should elicit the goals, which members of the care team should be informed of the goals, where should goals be recorded, and how often should goals be re-evaluated. This line of investigation would benefit from future investigations that explore the influence of ethnic and racial diversity on goal articulation and ascertainment.

Finally, the authors are particularly interested in how goal elicitation may serve to build awareness among patients and family caregivers for how positive accomplishments and accompanying confidence gained in other areas of their lives (e.g., education, occupation, raising a family, hobbies) may carry over to support efforts to self-manage chronic health conditions.

### CONCLUSIONS

Patients discharged from the hospital reported a higher percentage of goals related to function and returning to socialization or hobbies while family caregivers more often identified goals reported a higher percentage of goals related to symptom or health condition management for their loved one; with an overall concordance of 41%. Family caregivers reported a higher percentage of goals related to socialization or hobbies for themselves. Across all three articulated goals (patient goal for self, family caregiver goal for loved one, family caregiver goal for self), the majority of goals were attained and goal attainment was correlated across the three articulated goals. Patient's goal attainment was predicted by patient's goal type and patient residing with a spouse or domestic partner. Eliciting patient and family caregiver goals and promoting goal attainment may represent an important step toward promoting greater patient and family caregiver engagement in their self-care of chronic health conditions.

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