

## Methods, Tools, and Strategies

# The Family Caregiver Activation in Transitions (FCAT) Tool: A New Measure of Family Caregiver Self-Efficacy

Eric A. Coleman, MD, MPH; Kelly L. Ground, BS; Andrew Maul, PhD

Family caregivers, when able, willing, and engaged, play an instrumental role in executing the care plan of patients during the vulnerable time of care transitions. This is particularly true when patients' physical or cognitive function is compromised at the time of hospital discharge. Patients may have difficulty following discharge instructions, participating in self-management, and obtaining timely follow-up care.<sup>1</sup> Family caregivers often provide crucial help during this time yet may lack the preparation and confidence to be effective in this role.<sup>2-4</sup>

Family caregivers often feel unprepared to manage the complex care needs of chronically ill older adults.<sup>4-8</sup> Reinhard and colleagues identified the significant contributions made by family caregivers: 46% perform medical/nursing tasks, of whom 78% manage medications, and 53% serve as care coordinators.<sup>9</sup> Adelman et al. conducted a comprehensive review—to conclude that most family caregivers are untrained and often feel unprepared to take on medically skilled tasks.<sup>10</sup> Weinberg et al. reported that better coordination between health professionals and family caregivers resulted in improved pain control, functional status, and mental health among care recipients.<sup>11</sup> National professional organizations' clinical practice guidelines highlight the important contributions made by family caregivers.<sup>12-14</sup>

In spite of the recognition of the importance of family caregivers' contributions to care plan execution, there has been little attempt by health care professionals to identify and strengthen family caregivers' sense of preparation and confidence. To our knowledge, no tools are available that routinely focus on family caregiver self-efficacy during transitions. In response we developed the Family Caregiver Activation in Transitions™ (FCAT™) tool. In a qualitative study of 32 caregivers whose loved ones were recently discharged from an acute care hospital, five themes were identified: (1) family caregivers' contributions to the care of their loved are often dynamic, and family caregivers (2) have unique goals from those of the patient, (3) feel unprepared for postdischarge medication management, (4) need encouragement to assert an identity, and (5) often assume the responsibility for organizing posthospital care plan tasks.<sup>15</sup> The FCAT tool has been employed in the field as part of an enhancement

### Article-at-a-Glance

**Background:** Family caregivers play an instrumental role in executing the care plan of patients during care transitions and yet may lack preparation and confidence to be effective. Yet there has been little attempt by health care professionals to identify and strengthen family caregivers' sense of preparation and confidence. The Family Caregiver Activation in Transitions™ (FCAT™) tool was developed to guide the care team in better understanding patient and family needs and deploying appropriate resources accordingly.

**Methods:** The development and psychometric testing of the FCAT tool was guided by a "partial credit" Rasch model. The validation was completed in three phases. In Phase 1, cognitive testing was conducted in convenience samples of family caregivers ( $N = 54$ ) participating in support groups in two geographic locations. In Phase 2, pilot testing was conducted ( $N = 50$ ) to determine item fit and item difficulty. In Phase 3, the tool's psychometric properties were examined in two waves of recruitment ( $N = 187$ ;  $N = 247$ ) from Web-based national samples.

**Results:** Participants recommended revising the script, reducing redundancy, and simplifying item structure and language. Analysis of item fit and difficulty guided subsequent item reduction. The estimated person-separation reliability was 0.84.

**Conclusions:** The FCAT tool was developed to foster more productive interactions between health care professionals and family caregivers. Because it was developed with direct input from family caregivers, the items are both relevant to actual experience and relatively easy to understand. Psychometric testing supports the hypothesis that the FCAT tool items function as a unidimensional construct with a high level of reliability. The FCAT tool has the potential to guide interventions intended to enhance family caregiver preparation and confidence, and thereby positively influence clinical practice during care transitions.

to the evidence-based Care Transitions Intervention, which was designed to promote greater preparation, confidence, and skills among patients and family caregivers.<sup>16</sup>

The FCAT tool was initially conceived as a mechanism to guide professionals (Transitions Coaches) who interact with patients and family caregivers across care settings in the course of delivering the evidence-based Care Transitions Intervention, which was designed to promote greater preparation, confidence, and skills among patients and family caregivers.<sup>16</sup>

In the 10-item FCAT tool, respondents are asked to indicate the extent of their agreement or disagreement to “statements about challenges commonly faced by those caring for a loved one.”<sup>17\*</sup> It is administered by a health professional or self-administered by the family caregiver at the time of transition or shortly thereafter. At present there are few feedback loops at the point of care that might promote productive interactions between health care professionals, patients, and family caregivers to guide the care team in understanding patient and family needs and deploying appropriate resources accordingly.<sup>18</sup>

The overarching aim of the study reported in this article was to provide evidence for the validity of this new tool. The specific aims were to (1) conduct cognitive testing to determine the FCAT tool’s item relevance and ease of understanding, (2) pilot test the FCAT tool to evaluate item fit and item difficulty to guide subsequent item reduction or modification, and (3) examine the psychometric properties of the FCAT tool in selected populations of family caregivers.

## Methods

Validation of the FCAT tool was conducted in three phases, each addressing a specific study aim:

- Phase 1: Cognitive testing was conducted in convenience samples of family caregivers in two distinct geographic locations.
- Phase 2: Pilot testing was conducted to determine further opportunities for refinement.
- Phase 3: Further psychometric testing was explored in two waves of recruitment from a nationally representative sample.

The Colorado Multiple Institutional Review Board (Protocol 11-0851) approved these phases.

## DATA ANALYSIS

Item response data from the FCAT tool were fit to a “partial credit” Rasch model,<sup>19,20</sup> which was specifically developed for handling polytomous data. (A response is *polytomous* if it is restricted to one of a fixed set of possible values, as in, for exam-

\* The Family Caregiver Activation in Transitions™ (FCAT™) tool is accessible without cost, with written permission required before use.

ple, bloodtype (A, B, AB, O, . . .).<sup>21</sup> The Rasch model represents a stochastic (that is, probabilistic, as opposed to deterministic) formulation of the theory that item-response behavior can be modeled as a function of a single, continuous underlying attribute. This allows for a variety of partial tests of this hypothesis at the item level. Item-fit statistics and investigations of differential item functioning are used to identify potential sources of bias by examining whether the psychometric properties of questionnaire items differ as a function of group membership (for example, gender/sex or race/ethnicity). The primary reason for using the Rasch model rather than classical test theory is that the former is a model of item responses, whereas the latter is a model of total test performance.

## PHASE 1. COGNITIVE TESTING (JULY 2013–AUGUST 2013)

Cognitive testing was conducted to determine family caregivers’ comprehension of each item and the relevance of each item to actual experience. Participants were encouraged to provide candid feedback on how to improve individual items, as well as the overall measure. Telephone one-on-one interviews were conducted by trained research staff with 54 family caregivers, who were asked to self-administer the tool and then respond to a series of open-ended questions designed to elicit their impressions and suggestions. Participants were recruited equally from attendees of family caregiver support groups in two locations—the Northwest Washington Area Agency on Aging (Bellingham, Washington) and the Alzheimer’s Association/Program of All-Inclusive Care for the Elderly (PACE) site, both in Denver. Participants needed to be English speaking and at least 18 years of age, and the patient or loved one must have been hospitalized within the last 90 days. Participants’ responses were aggregated and then used to further refine the wording of the items and in some cases remove nearly duplicate items.

## PHASE 2. PILOT TESTING (SEPTEMBER 2013–OCTOBER 2013)

In pilot testing conducted to further refine the tool, 50 family caregivers recruited from the same organizations as in Phase 1 but who were not previously recruited completed a 17-item version of the FCAT tool.

## PHASE 3. TESTING OF REFINED VERSIONS OF THE FAMILY CAREGIVER ACTIVATION IN TRANSITIONS TOOL (NOVEMBER 2013–MARCH 2014)

Two sequentially refined versions of the FCAT tool were then tested in two larger samples. The project team contracted with GfK (Palo Alto, California) to obtain representative sam-

ples of the entire United States population via online surveys. Participants were randomly recruited, conditional on being at least 18 years of age, English speaking, and providing support (such as taking to the doctor, helping with medical decisions) for a family member 65 years of age or older for four or more hours per week. In addition, the care recipient must have been hospitalized within the previous 12 months for one or more of the following conditions: chronic lung disease (asthma, chronic bronchitis, or chronic obstructive pulmonary disease), atrial fibrillation, cancer (any type except skin cancer), diabetes, heart disease, kidney disease, or stroke.

Two randomly equivalent waves of participants were recruited. The first wave contained 187 participants, with whom we tested a 15-item version of the FCAT tool. We then made a series of refinements and improvements, including reducing the number of items to 10 and simplifying the language and sentence structure of many items. We tested this version in the second wave, which contained 247 participants, who took an average of three minutes to complete it (self-administered).

We hypothesized that family caregiver perceived self-efficacy can be modeled as a quantitative attribute of persons and can be measured via responses to the FCAT tool items. The fit of response data to a partial credit Rasch model<sup>19,20</sup> provides evidence relevant to these hypotheses. These analyses also provide tests of more specific hypotheses concerning the functioning of individual items. Data from each wave were fit to the Rasch model using ConQuest 2.0.<sup>22</sup>

## Results

### PHASE 1. COGNITIVE TESTING

Participants ( $N = 54$ ) made a number of valuable recommendations, which were used to make improvements to the tool before testing in a larger sample. Participants recommended including a more detailed script for self-administration and noted that many of the items were redundant and could be either combined or deleted. Further, some of the items were unnecessarily wordy and had confusing verb tense, and too many items were devoted to medication management. Participants expressed a preference for the term *confidence* over other tested terms such as *understanding* or *certainty*. The project team addressed each of these issues and recommendations.

### PHASE 2. PILOT TESTING

Participants ( $N = 50$ ) indicated a relatively higher level of confidence in items pertaining to ensuring attendance of follow-up physician visits, filling prescriptions, and bringing a list of questions to health care encounters, and a relatively lower

level of confidence in recognizing medication side effects and asserting their identity. Although the fit of data to the Rasch model was acceptable and the item difficulties appeared to be well matched to the respondents, this phase of testing also identified additional opportunities to clarify item wording and to further reduce the total number of items.

### PHASE 3. TESTING OF REFINED VERSIONS OF THE FAMILY CAREGIVER ACTIVATION IN TRANSITIONS TOOL

Table 1 (page 505) provides the demographic characteristics of the two waves of family caregiver participants in Phase 3. The prevalence of chronic health conditions among participants' care recipients in the two sampling waves was chronic lung disease (asthma, chronic bronchitis, or chronic obstructive pulmonary disease) 33.2% and 31.2%, respectively; atrial fibrillation, 28.9% and 19.4%; cancer, 28.3% and 34.4%; diabetes, 40.1% and 37.2%; heart disease, 51.9% and 43.4%; kidney disease, 14.4% and 18.6%; and stroke, 24.6% and 21.5%.

In Wave 1, a 15-item version of the FCAT tool was tested in a sample of 187 participants. The estimated person-separation reliability of the test was 0.90 (like Cronbach's alpha, the person-separation reliability coefficients estimates the "proportion of observed sample variance which is not due to measurement error"<sup>23(p. 106)</sup>).

Item level fit mean-square fit statistics are used to evaluate the hypothesis that each individual item functions as predicted by the Rasch model. Mean-square fit statistics are calculated in two steps. In the first step, deviations between (coded) observed and model-predicted item responses are squared and averaged across all responses. In the second step, for each item, we take the ratio between the observed variance and the model-expected variance in the deviations calculated in the first step; thus, a value of 1.00 would indicate that the item was exactly conforming to model expectations. Items displaying significantly higher or lower average deviations (that is, more or less randomness) than expected may be flagged as "misfits" for further investigation. Given that one of the reasons items may misfit the model is an incorrect specification of dimensionality, evaluation of item-fit statistics also helps evaluate the hypothesis of unidimensionality. Mean-square fit statistics of each item are displayed in Table 2 (page 506), along with the mean person location estimate for respondents who endorsed each response category. Two items significantly misfit the model by displaying more randomness than expected: Item 2 ("I make sure that my loved one or I take a written list of questions to medical appointments") and item 10 ("I have a trusting relationship with a pharmacist or pharmacy in my community that I can contact if I have medication ques-

**Table 1. Phase 3 Family Caregiver Participant Demographics**

Information		Wave 1 Frequency	Wave 1 Percentage	Wave 2 Frequency	Wave 2 Percentage
Age (years)	18–29	7	3.7	4	1.6
	30–44	16	8.6	25	10.1
	45–59	65	34.8	97	39.3
	60+	99	52.9	121	49.0
	Total	187	100.0	247	100.0
Gender/Sex	Men	55	29.4	57	23.1
	Women	132	70.6	190	76.9
	Total	187	100.0	247	100.0
Education	Less than high school	7	3.7	4	1.6
	High school	31	16.6	34	13.8
	Some college	73	39.0	91	36.8
	Bachelor's degree or higher	76	40.6	118	47.8
	Total	187	100.0	247	100.0
Race/ Ethnicity	White, Non-Hispanic	143	76.5	193	78.1
	Black, Non-Hispanic	13	7.0	22	8.9
	Other, Non-Hispanic	3	1.6	2	.8
	Hispanic	22	11.8	22	8.9
	2+ Races	6	3.2	8	3.2
	Total	187	100.0	247	100.0
Metropolitan Service Area	Non-Metro	32	17.1	34	13.8
	Metro	155	82.9	213	86.2
	Total	187	100.0	247	100.0
Region of the United States	Northeast	34	18.2	41	16.6
	Midwest	53	28.3	76	30.8
	South	62	33.2	74	30.0
	West	38	20.3	56	22.7
	Total	187	100.0	247	100.0

tions”). This finding was anticipated because these two items addressed behaviors that are less routine. Three items significantly misfit the model by displaying less randomness than expected. All three of these items concerned understanding a health care professional’s recommendations. After a qualitative review and triangulation with the cognitive testing, it was judged that these items contained some redundancies and could be combined.

In Wave 2, 5 items were removed from the tool, and 2 of the remaining items were reworded, yielding a revised 10-item version of the FCAT tool. This version was administered to 247 participants in Wave 2. Missing data were minimal (< 1%). Response patterns appeared to conform to the expectations of

the Rasch model within generally accepted bounds of tolerance,<sup>19</sup> with the exception of Item 2, (“I make sure a written list of questions is taken to each of my loved one’s medical appointments”), which had also misfit in the first wave. This item was retained because of its perceived central relevance to the actions family caregivers routinely perform. Table 3 (page 506) displays the infit and outfit mean-square statistics of each item in Wave 2.

In these exploratory analyses, overall, women appeared to have slightly higher estimated levels of family caregiver perceived self-efficacy than did men. In terms of individual items, Item 1 (“I am able to make sure my loved one goes to every scheduled medical appointment”) was estimated as being significantly easier for men to endorse (meaning that men more frequently selected options indicating high levels of agreement than did females); whereas Item 9 (“I understand which of the instructions in my loved one’s care plan are most important and need to be completed first and which instructions are less urgent”) was estimated as being significantly easier for women to endorse. The differential functioning of Items 1 and 9 between men and women was judged to not be necessarily problematic for the tool. It is possible that there are actual differences between men and women in their confidence in these issues, or these findings could be due to random chance. In any case, there was no definitive evidence of problematic bias. No

other item-level differences were statistically significant. Similarly, there was no evidence of significant differences in item-response behavior by gender/sex or race/ethnicity.

The estimated person-separation reliability of the test was 0.84. The slightly lower estimate compared to Wave 1 can be explained by the elimination of five items from the tool. Evaluation of an item-person map revealed a slight mismatch between the distribution of participants and the distribution of item categories, suggesting that the standard error of measurement is slightly higher for participants with very high levels of family caregiver perceived self-efficacy. However, this was judged to not be problematic, as the loss of information is minimal, and

Table 2. Item-Fit Statistics for Wave 1

Item	Estimate	Error	Mean-Square	t
1 Q1	-0.438	0.086	1.02	0.2
2 Q2*	0.367	0.075	1.57	4.7
3 Q3	0.262	0.092	1.01	0.1
4 Q4	-0.274	0.089	1.07	0.7
5 Q5	-0.372	0.085	1.01	0.2
6 Q6	-0.267	0.078	0.95	-0.4
7 Q7	-0.266	0.079	0.98	-0.1
8 Q8	-0.256	0.079	1.07	0.7
9 Q9	0.569	0.078	0.94	-0.6
10 Q10*	0.094	0.077	1.21	1.9
11 Q11	0.059	0.076	0.94	-0.6
12 Q12†	0.071	0.085	0.77	-2.4
13 Q13†	0.421	0.093	0.78	-2.2
14 Q14†	0.080	0.082	0.82	-1.9
15 Q15	-0.050		0.99	

Q, quarter.  
 \* Misfit due to more-than-expected randomness.  
 † Misfit due to less-than-expected randomness.

also less critical in the highest ranges of perceived self-efficacy.

**Discussion**

An ideal tool to guide the care team in better understanding patient and family needs during times of transitions and deploying appropriate resources accordingly would apply to a broad-based population of care recipients (that is, not be disease-specific), be actionable at the point of care, and be brief (require no more than three minutes to administer). The FCAT tool, which was designed in accordance with these specifications, is intended to elucidate family caregiver perceived self-efficacy with respect to discharge- or transition-specific tasks. Family caregivers reported that the tool largely captured the challenges they routinely face during transitions and offered valuable recommendations for reducing response burden and improving the clarity and relevance of individual items. The validation testing reported herein indicates that the tool demonstrates desirable measurement properties, including reliability, item fit, and no definitive evidence of problematic bias.

**CLINICAL IMPLICATIONS**

After review by the hospital care team (including some combination of the hospitalist, primary nurse, clinical pharmacist discharge planner, and home health care liaison) of a family caregiver’s FCAT tool responses, the areas identified as ones in which he or she did not feel confident or prepared could then be specif-

Table 3. Item-Fit Statistics for Wave 2

Item	Estimate	Error	Mean-Square	t
1 Q1	-0.332	0.066	0.95	-0.5
2 Q2*	0.804	0.060	1.32	3.2
3 Q3	-0.090	0.072	0.76	-2.9
4 Q4	-0.265	0.070	0.82	-2.1
5 Q5	-0.303	0.066	0.75	-3.0
6 Q6	-0.200	0.064	0.96	-0.5
7 Q7	0.178	0.068	1.01	0.2
8 Q8	0.559	0.065	0.89	-1.2
9 Q9	-0.178	0.073	0.71	-3.5
10 Q10	-0.173		1.10	-0.9

Q, quarter.  
 \* Misfit due to more-than-expected randomness.

ically addressed during discharge preparation instruction. When possible, the hospital care team might incorporate simulation learning during the course of the hospital stay whereby the family caregiver has the opportunity to gain confidence in specific tasks through hands-on learning.<sup>18</sup> However, the responsibility for preparing family caregivers does not rest entirely with the hospital care team. The findings from the FCAT tool and the initial steps taken to address identified challenges should be communicated to the next care team (skilled nursing facility, home health care, primary or specialty care) to continue to offer the needed instruction and reinforcement to build family caregivers’ confidence.

**STUDY LIMITATIONS**

There are a number of potential limitations to the findings included in this report. The FCAT tool is a self-reported rather than a performance-based tool, so that family caregivers who are new to this role and do not have previous experience with the skills and tasks in question may be unsure how to rate the items or may overestimate their ability—that is, they may not know what they do not know. This limitation may be mitigated through discussion of responses with health professionals. The fact that participants in Phases 1 and 2 were recruited from support groups held in an Area Agency on Aging and an Alzheimer’s Association office may raise questions about generalizability. Specifically, those participants were fairly experienced and had purposely sought out additional professional and peer support. Furthermore, the two recruitment waves of nationally representative family caregiver samples reported in Phase 3 was entirely Web-based and as such, less technically proficient individuals are likely underrepresented, and non-English-proficient individuals were not included. Despite our attempts to recruit nonwhite participants, our two waves had lower rates of participation by non-

whites than would be expected, based on their representation in the general population. Also, in our efforts to improve the generalizability of our findings, we were forced to make difficult trade-offs between the optimal timing of administration of the tool. The two waves of samples were not recruited at the point of hospital discharge. Rather they were asked to reflect back on their experiences as much as 12 months later, raising some question about recall bias, although on the basis of our prior work in this area, we have not found that family caregiver insights vary over time in a meaningful way. In a previous study, in which family caregivers self-administered the FCAT tool at the point of transition or within three days following discharge, we observed that the FCAT tool functioned as designed, helping to elucidate the areas in which family caregivers recognized the need to become more confident.<sup>16</sup>

## FUTURE STUDIES

There are numerous opportunities to build on the current study. To further explore the utility of the FCAT tool, greater experience is needed to understand how to approach the question of scalability. Future studies might examine whether elucidating and addressing family caregiver preparation and confidence mitigate preventable hospital readmission or medication errors. Also worth exploring would be the potential of the FCAT tool as an outcome measure rather than as a process of care measure, the consistency of FCAT tool measurement over time without intervention (test-retest) and magnitude of measurable changes in the FCAT tool with intervention, and the FCAT tool's relative usefulness when administered at a different point in time or different location or with parents of children with complex care needs.

## Conclusion

The FCAT tool was developed to foster more productive interactions between health care professionals and family caregivers. Because it was developed with direct input from family caregivers, the items are both relevant to actual experience and relatively easy to understand. Psychometric testing supports the hypothesis that the FCAT tool items function as a unidimensional construct with a high level of reliability. The FCAT tool has the potential to guide interventions intended to enhance family caregiver preparation and confidence and thereby positively influence clinical practice during care transitions. **J**

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**Eric A. Coleman, MD, MPH**, is Professor and Head, Division of Health Care Policy and Research, School of Medicine, and **Kelly L. Ground, BS**, is Fourth-Year Medical Student, School of Medicine, University of Colorado Denver Anschutz Medical Campus. **Andrew Maul, PhD**, is Assistant Professor, Gevirtz School of Education, University of California, Santa Barbara. Please address correspondence to Eric A. Coleman, Eric.Coleman@ucdenver.edu.

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