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RESEARCH BRIEF

Feasibility of Collecting Patient-Reported Outcomes for Inpatient Rehabilitation Quality Reporting

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Objective. To evaluate rehabilitation inpatients' willingness and ability to complete patient-reported outcomes (PROs) and the burden of completion on patients and staff.

Data Sources/Study Setting. Two inpatient rehabilitation facilities.

Study Design. Patients with neurological disorders were assigned randomly to receive a nominal monetary incentive during or 1 month after the stay.

Data Collection. Patients responded using a tablet computer or paper.

Principal Findings. Of the 1,055 admissions, 74 percent were eligible, and 51 percent of eligible patients completed the survey. Most answered without assistance. A majority completed the survey 1 month after discharge; incentive timing was unrelated to post-discharge completion. Half of the 285 follow-up respondents required at least two reminder calls.

Conclusions. Collection of PROs from rehabilitation patients is feasible. Results inform policy makers regarding feasibility of PRO data in evaluating rehabilitation quality.

Key Words. Quality of care/patient safety (measurement), quality improvement/report cards (interventions), rehabilitation services, patient assessment/satisfaction, disability

Health care quality in the United States varies widely (Agency for Healthcare Research and Quality [AHRQ] 2010; Fisher et al. 2003; Institute of Medicine 1999, 2001; McGlynn et al. 2003; The Commonwealth Fund Commission on a High Performance Health System 2011); this variation places increasing focus on performance improvement and provider accountability to improve care quality. Policy makers' concerns resulted in passage of the Patient Protection and Affordable Care Act that seeks to improve quality and decrease costs

(2010). These goals are particularly salient for people with disabilities given their high utilization of health services and the consequences of receiving poor quality services.

The Centers for Medicare and Medicaid Services (CMS) implemented an inpatient rehabilitation facility (IRF) Quality Reporting Program. In 2012, initial quality measures focused on health care–acquired conditions (Centers for Medicare and Medicaid Services 2015), including 13 quality measures, none of which are based on data reported directly by patients. Many IRFs collect patient-reported data to evaluate services and satisfaction, but a standardized survey for IRFs does not exist. Evaluating the feasibility of collecting patient-reported data for use in quality measurement is a necessary first step.

In 2012, the National Quality Forum (NQF) convened an expert panel to identify key features required in patient-reported outcome (PRO) quality measures (2012; Cella et al. 2015b). A PRO is a rating of satisfaction, experience of care, symptom status, functional ability, or perception of health status that comes directly from the patient and may target physical, mental, and social well-being (Cella et al. 2011, 2012, 2015b; Cella 2015a).

Two issues limit adoption of PROs in performance measurement. PROs are not commonly used and are therefore unfamiliar to clinicians and other stakeholders. Second, apart from experience of care measures, PROs are rarely used to measure and evaluate performance at the health care provider or organization level. PROs are a promising complement to current quality measures, demonstrating which patient-reported data are important to stakeholders and the feasibility of data collection is a prerequisite of PRO-based, quality measure development.

In this report, we evaluate IRF patients' willingness and ability to complete patient experience of care and health status questions during and after hospitalization. We describe burden on patients and staff the feasibility of

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collecting PROs at the end of the IRF stay versus 1 month later. The hypotheses were as follows:

1. A majority of rehabilitation inpatients with neurological disorders are willing and able to complete questions describing their experience of care and health status.
2. The time required by patients to complete questions is acceptable to them.
3. Most patients can answer questions independently using a tablet computer or paper form.
4. Without considerable staff support, postdischarge response rate is likely to be below 50 percent.

METHODS

Sample

We recruited patients from two IRFs in metropolitan Chicago, a 182-bed free-standing hospital in downtown Chicago and a 72-bed IRF unit in a suburban community. The IRFs were a sample of convenience, resulting from funding constraints; we did not compare all IRFs in the metropolitan area on key characteristics and then select maximally different facilities. The IRFs serve distinct communities, and each has a large volume of discharges; their patients reflect diverse impairment and demographic characteristics that span the range of patients served by IRFs. We focused on patients with neurological disorders. Nationally, patients with neurological disorders, including stroke, are the largest group admitted to IRFs (Medicare Payment Advisory Commission 2016). These patients experience motor, communicative, and cognitive deficits that limit their ability to participate in a survey. Given the paucity of work in this area, we decided to focus on patients who would likely experience the greatest challenges in completing patient-reported measures. Additional criteria were age 18 years of age and older, ability to speak and comprehend English, and clinician determination that a patient was capable of providing accurate reports.

Instrumentation

We identified quality themes that are important to patients, caregivers, and clinicians using focus groups (Deutsch et al. unpublished data) and a literature review. We identified six broad themes, including interpersonal relationships, patient and family engagement, care planning and delivery, access to support,

and quality of life. We searched for publically available instruments that operationalize these concepts:

- Pain items from the Minimum Data Set (*MDS*) Version 3.0 (Saliba and Buchanan 2012), a dataset used in nursing home care, assessing pain intensity, frequency, and interference with activities of daily living.
- The PROMIS-Pain interference item bank consists of 41 items (Amtmann et al. 2010); we selected five items that reflect pain effects on concentration, memory, activities of daily living, and relationships. We modified the time frame to reference “over the last day” at the end of the IRF stay and “at the end of your stay” for the follow-up assessment.
- The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey has 27 questions, including communication with nurses and doctors, responsiveness of staff, the hospital environment, pain management, communication about medicines, discharge information, overall rating of hospital, and recommendation of the hospital.
- HCAHPS rehabilitation is a modified version of the HCAHPS that adds three questions about therapist communication that parallels the HCAHPS nurse and doctor questions.
- The Care Transition Measure-15 (CTM-15), for which reliability and validity evidence have accumulated, is a 15-item instrument assessing patients’ perspective of how to manage their disease, patient preferences, preparation to manage care, and clear care plan (Coleman, Mahoney, and Parry 2005). We modified the stem to be consistent with our modifications to the PROMIS stem.

Cognitive Assessment

The Cognitive Capacity Screening Examination (CCSE) is a motor-free, 30-item mental status questionnaire designed to detect cognitive limitations in nonpsychiatric patients (Jacobs et al. 1977). A score <20 indicates cognitive impairment. We modified instructions so that persons with aphasia could complete the CCSE.

Functional Status

We extracted from the electronic medical records admission FIM scores (Granger et al. 2007) to compute cognition, self-care, and mobility subscores (Heinemann et al. 1994).

Procedures

An advisory committee of patient, clinician, and advocacy organization's stakeholders helped prioritize quality concepts and provided feedback on candidate items and instruments to measure them. A literature review identified instruments with good psychometric properties that operationalized target quality concepts. Next, we pilot-tested data collection with 21 patients. We collected data using a form-processing application that develops scannable paper forms and a secure, online website that is accessible using a tablet computer.

Research assistants (RAs) monitored admissions at both IRFs, reviewed medical records to assess eligibility, contacted the attending physician or other clinician to verify eligibility, and then approached patients to obtain informed consent. They strove to collect data within two days of discharge. RAs administered the CCSE, completed a debriefing interview, and obtained contact information for patients and a family member or friend. Patients indicated preferences for follow-up contact. Twenty-one days after discharge, RAs emailed a link to a secure website to patients who preferred email communication and sent a reminder email 2 days later. We mailed a paper version 2 days later to nonrespondents. Nineteen days after discharge, RAs mailed the survey to patients who preferred paper forms and mailed a reminder 10 days later to nonrespondents. Thirty-five days after postdischarge, RAs made up to five telephone calls during days, evenings, and weekends to patients who had not responded.

We assigned patients randomly to receive a \$10 cash honorarium immediately following completion of the questions while in the IRF or by checking following discharge.

Statistical Analysis

We used *SPSS* version 23 (IBM Corporation 2014) to compute descriptive and chi-squared statistics.

RESULTS

Patient Accrual and Consent

From March 25, 2015, to October 23, 2015, 1,055 patients were admitted. As Table 1 reports, stroke was the most frequent diagnosis followed by nontraumatic and traumatic brain injury (TBI). Figure 1 shows that about half of those

Table 1: Eligible Patients and Consented Participants Who Completed Surveys by Rehabilitation Condition

<i>Rehabilitation Condition</i>	<i>Total Admissions</i>	<i>Eligible (% of Admissions)</i>	<i>Completed Inpatient Survey (% of Eligible Admissions)</i>	<i>Completed Follow-Up Survey (% of Completed Inpatient Surveys)</i>
Stroke	448	308 (69%)	149 (48%)	101 (68%)
Nontraumatic brain injury	136	95 (70%)	45 (47%)	32 (71%)
Traumatic brain injury	123	110 (89%)	59 (54%)	42 (71%)
Nontraumatic spinal cord injury	120	69 (58%)	32 (46%)	20 (63%)
Traumatic spinal cord injury	85	78 (92%)	41 (53%)	30 (73%)
Parkinson's disease	57	47 (82%)	28 (60%)	18 (64%)
Multiple sclerosis	35	31 (89%)	24 (77%)	23 (96%)
Other neurological disorders*	51	44 (86%)	24 (55%)	19 (79%)
Total	1,055	782 (74%)	402 (50%)	285 (71%)

*Other neurological disorders include unspecified neuromuscular disease (11), Guillain-Barre syndrome (7), cerebral palsy (4), amyotrophic lateral sclerosis (4), neuromyelitis optica (3), stiff person syndrome, cervical radiculopathy; lumbar spinal stenosis, lumbar radiculopathy, chronic inflammatory demyelinating polyneuritis, Huntington's disease, inflammatory amyloid angiopathy of the central nervous system, lumbar plexopathy, other cerebellar ataxia, peripheral neuropathy, postpolio syndrome, spina bifida; tremor, Wilson's disease, Dandy-Walker syndrome, multiple system atrophy-C, myasthenia gravis; neurofibromatosis; posterior reversible ischemic encephalopathic syndrome, Todd's paralysis; seizure disorder and toxic metabolic encephalopathy.

eligible consented and most of those who provided responses while hospitalized returned the survey 1 month after discharge. Survey completion rates ranged from 46 percent for patients with nontraumatic SCI to 77 percent for patients with MS.

Study eligibility did not vary by age or sex, but it did vary by race such that a greater proportion of black (82 percent) and white (75 percent) patients were eligible compared to patients in other race groups (60 percent). Eligibility was also related to diagnosis such that a greater proportion of patients with traumatic and nontraumatic SCI and other neurological disorders were eligible than patients with stroke, TBI, and nontraumatic brain injury. Ineligible

Figure 1: Patient Accrual and Retention for Patient-Reported Outcome (PRO) Collection [Color figure can be viewed at wileyonlinelibrary.com]

patients had a nearly 3-day longer length of stay than eligible patients; they also had lower admission FIM cognition (9.8 points), self-care (4.2), and mobility scores (7.5 points) than eligible patients.

Patients' willingness to consent was unrelated to sex or race. However, consent rates varied by diagnosis such that patients with TBI, nontraumatic brain injury, and stroke were more likely to consent than patients with other conditions. Consenting patients had longer stays (3.7 days), were an average of 4.3 years younger, and had higher mean admission FIM cognition scores (1.7 points) than nonconsenting patients.

Cognitive Status

Cognitive Capacity Screening Examination scores for 14 percent of the sample were below 20, suggesting cognitive impairment. The CCSE and FIM cognition scores were correlated 0.40 ($p < .001$).

Inpatient Survey Data Collection

Research assistants documented the types of assistance provided to participants. As shown in Figure 2, most (73 percent) participants required no assistance. Of those needing assistance, most (17 percent) required reading of items and recording of responses. Level of assistance was related to status based on CCSE cut score: 45 percent of those below the cutoff required assistance

Figure 2: Assistance Required for Patients to Complete Patient-Reported Outcomes during Inpatient Rehabilitation [Color figure can be viewed at wileyonlinelibrary.com]

Note. RA, research assistant.

compared to 23 percent of those above it. Patients receiving assistance had lower self-care (5.8 points) and cognition scores (3.9 points) than those answering independently.

Because discharge dates sometimes changed with little notice, some patients completed the survey in anticipation of discharge but had their stay extended. On other occasions, discharge date were moved up and patients left before we could approach them. We recruited 60 percent of patients within 2 days of discharge; 5 percent were recruited more than 7 days before discharge due to extended stays.

Debriefing Interview

After completing the inpatient survey, we asked participants whether they were willing to complete a survey as part of their routine IRF care. The majority (65 percent, $n = 232$) were “very willing,” 30 percent ($n = 106$) “willing,” 4 percent ($n = 14$) “somewhat willing,” and 1 percent ($n = 3$) “somewhat unwilling.” We asked whether they would be willing to answer the questions without an honorarium; nearly two-thirds (73 percent, $N = 260$) were “very willing;” others were “somewhat willing” (23 percent, $n = 82$), “somewhat unwilling” (3 percent, $n = 10$), or “very unwilling” (1 percent, $n = 3$). The majority, 60 percent, reported preference for answering questions independently ($n = 212$). Others preferred assistance (22 percent, $n = 76$) or had no

preference (18 percent, $n = 63$). We asked participants from whom they preferred assistance if it was offered; 62 percent ($n = 214$) preferred someone outside of their clinical team, 17 percent ($n = 60$) someone involved in their care, and 21 percent ($n = 73$) had no preference. Tablet computer was preferred by 63 percent ($n = 220$), paper was preferred by 15 percent ($n = 55$), and 22 percent ($n = 76$) had no preference.

Patients reported greater likelihood of responding to questions if they “felt treated with respect and courtesy” and if questions were “clear and made sense” and had a multiple-choice format. Patients indicated less likelihood of responding to surveys whose length was excessive or if they had to write answers; they also reported less likelihood of answering if they were close to discharge or had not experienced improvement. Another reason for not responding was “Fear, not wanting to offend anybody.”

Time to Complete the Survey

The median time to complete the survey was 15 minutes (range: 4–73 minutes; $n = 401$). We asked patients how long they would be willing to answer questions that could be used for quality measurement. The mean response was 25 minutes (median = 20 minutes, range: 2–90 minutes). Median time for a research assistant to consent patients and complete all procedures was 46 minutes (range: 16–123 minutes; $n = 401$).

Follow-Up Data Collection

We obtained follow-up responses from 71 percent of those completing the inpatient survey (Figure 1). Patients opted for online or mailed follow-up surveys. A majority (55 percent, $N = 158$) completed the survey by their preferred method, while the rest did so using a different method after reminders. Only 37 percent ($N = 105$) completed the follow-up without reminders. One call was required for 12 percent ($N = 34$) and at least two calls for 51 percent ($n = 146$). The remainder ($n = 111$) did not respond after more than two reminder telephone calls. We made fewer than two phone calls to six individuals because of death, health issues, unavailability via shared contact information, or research protocol error.

There were no differences in patient characteristics between the groups that did and did not need reminders (Table 2), except admission FIM self-care and mobility scores. Patients who received two or more reminder calls had

Table 2: Comparison of Patients by Eligibility, Consent, Completion, and Assistance Need Status

	Eligible		Consented		Postdischarge Survey		Needed Assistance ^d	
	Yes (n = 782)	No (n = 273)	Yes (n = 413)	No (n = 369)	Yes (n = 285)	No (n = 117)	Yes (n = 110)	No (n = 292)
<i>Age Mean (SD)</i>	61 (18.7)	65 (19.1) **	58 (18.1)	64 (18.9) ***	58 (18.2)	59 (18.1)	63 (16.5)	56 (18.4) ***
Min-max	18-98	18-96	18-91	18-98	18-91	19-90	23-91	18-89
Interquartile range	26	24	73	25	28	25	23	29
Percentiles 25, 50	50, 64	55, 67	45, 61	54, 67	44, 61	49, 62	54, 67	42, 60
<i>Length of Stay Mean (SD)</i>	21 (15.7)	23 (17.6) *	22 (16.9)	19 (14.1) **	24 (17.8)	23 (17.6)	29 (23.7)	20 (12.9) ***
Min-max	1-148	1-171	1-148	1-110	3-148	1-118	4-148	1-90
Interquartile range	13	13	14	12	14		14	12
Percentiles 25, 50	12, 17	14, 19	13, 18	10, 15	14, 20	14, 19	17, 22	13, 17
<i>CCSE Mean (SD)</i>					25.4 (4.3)	24.8 (4.1)	24 (5.0)	26 (3.8)
Min-max				Data not available	8-30	13-30	23-91	8-30
Interquartile range					5		7	5
Percentiles 25, 50					24, 27	23, 26	21, 25	24, 27
					n = 264	n = 87	n = 89	n = 264
<i>FIM Cognition Mean (SD)</i>	23 (7.5)	13 (6.9) ***	24 (7.2)	22 (7.8) **	24 (7.1)	22 (7.0) ***	21 (7.9)	25 (6.6) ***
Min-max	5-35	5-35	5-35	5-35	5-35	5-35	5-35	5-35
Interquartile range	10	12	10	11	9	9	11	9
Percentiles 25, 50	18, 23	6, 12	19, 24	17, 23	20, 25	18, 21	16, 20	20, 25
<i>FIM Mobility Mean (SD)</i>	10 (5.6)	7 (5.1) ***	10 (5.4)	9 (5.7)	9.9 (5.6)	9.4 (5.1)	8 (4.9)	11 (5.5) ***
Min-max	0-30	1-25	1-30	0-26	1-30	1-27	23-Jan	1-30
Interquartile range	8	8	9	8	9	8	8	7
Percentiles 25, 50	5, 9	3, 5	5, 9	5, 8	5, 9	5.5, 9	4, 7	7, 10
<i>FIM Total Self-Care Mean (SD)</i>	18 (7.1)	13 (7.0) ***	18 (7.0)	17 (7.3)	18 (7.0)	18 (7.0)	14 (6.7)	20 (6.4) ***
Min-Max	5-35	5-30	5-35	5-32	5-35	5-30	29-May	6-35
Interquartile range	12	13	11	12	11	11	12	10
Percentiles 25, 50	12, 18	6, 12	12, 18	12, 17	13, 18	12, 18	7, 13	15, 21
Sex								
Male	450 (58%)	145 (53%)	229 (55%)	221 (60%)	154 (54%)	68 (58%)	69 (63%)	153 (52%)
Female	332 (42%)	128 (47%)	184 (45%)	148 (40%)	131 (46%)	49 (42%)	41 (37%)	139 (48%)

Continued

Table 2: Continued

	Eligible		Consented		Postdischarge Survey		Needed Assistance ^a	
	Yes (n = 782)	No (n = 273)	Yes (n = 413)	No (n = 369)	Yes (n = 285)	No (n = 177)	Yes (n = 110)	No (n = 292)
<i>Race</i>	n = 765	n = 266***			n = 283	n = 116	n = 108	n = 291
White	555 (73%)	184 (69%)	303 (74%)	252 (71%)	212 (75%)	84 (73%)	75 (70%)	221 (76%)
Black/African American	132 (17%)	30 (11%)	74 (18%)	58 (16%)	50 (18%)	22 (19%)	25 (23%)	47 (16%)
Asian	22 (3%)	15 (6%)	9 (2%)	13 (4%)	4 (1%)	5 (4%)	1 (1%)	8 (3%)
More than once race	6 (1%)	—	6 (2%)	—	5 (2%)	1 (1%)	3 (2%)	3 (1%)
Other	50 (6%)	37 (14%)	17 (4%)	33 (9%)	12 (4%)	4 (3%)	4 (4%)	12 (4%)
<i>Ethnicity</i>								
Hispanic		Data not available	Data not available		12 (4%)	6 (5%)	2 (2%)	16 (6%)
Not Hispanic or Latino					268 (96%)	109 (95%)	106 (98%)	271 (94%)
<i>Education</i>								
<HS		Data not available	Data not available		11 (4%)	5 (4%)	6 (6%)	10 (3%)
HS/GED					63 (22%)	27 (25%)	26 (25%)	64 (22%)
Some college					80 (29%)	30 (28%)	28 (27%)	82 (29%)
College degree					127 (45%)	47 (43%)	43 (42%)	131 (46%)
<i>Marital Status</i>	n = 774	n = 271	n = 406	n = 368				
Single (never married)	194 (25%)	62 (23%)	109 (27%)	85 (23%)	75 (26%)	32 (28%)	23 (21%)	84 (29%)
Married	380 (49%)	130 (48%)	185 (45%)	195 (53%)	138 (49%)	46 (40%)	55 (50%)	129 (44%)
Divorced	83 (11%)	15 (5%)	52 (13%)	31 (8%)	33 (12%)	18 (15%)	18 (17%)	33 (11%)
Widowed	106 (14%)	57 (21%)	54 (13%)	52 (14%)	34 (12%)	18 (15%)	12 (11%)	40 (14%)
Separated	11 (1%)	7 (3%)	6 (2%)	5 (2%)	4 (1%)	2 (2%)	1 (1%)	5 (2%)
<i>Occupational Status</i>					n = 283	n = 117	n = 109	n = 291*
Working, full time		Data not available	Data not available		79 (28%)	32 (27%)	24 (22%)	87 (30%)
Working, part time					16 (5%)	9 (8%)	5 (5%)	21 (7%)
Retired, due to age					77 (27%)	33 (28%)	37 (34%)	73 (25%)
Retired, due to disability					33 (12%)	17 (15%)	18 (16%)	32 (11%)
Volunteer					1 (1%)	1 (1%)	—	2 (1%)
Not working					31 (11%)	13 (11%)	11 (10%)	33 (11%)
Not working, due to disability					27 (9%)	6 (5%)	9 (8%)	24 (8%)
Other					19 (7%)	6 (5%)	5 (5%)	19 (7%)

Continued

Table 2: Continued

	Eligible		Consented		Postdischarge Survey		Needed Assistance ^a	
	Yes (n = 782)	No (n = 273)	Yes (n = 413)	No (n = 369)	Yes (n = 285)	No (n = 117)	Yes (n = 110)	No (n = 292)
<i>Interrupted Stay</i>								
Yes	32 (4%)	8 (3%)	n = 413 14 (3%)	n = 369 18 (5%)	12 (4%)	2 (2%)	7 (6%)	7 (2%)
No	750 (96%)	265 (97%)	399 (97%)	351 (95%)	273 (96%)	115 (98%)	103 (94%)	285 (98%)
<i>Discharge Location</i>								
Home	n = 781 374 (48%)	n = 273*** 77 (28%)	n = 413 218 (53%)	n = 368** 156 (42%)	162 (57%)	51 (44%)	42 (38%)	171 (58%)
Short-term general hospital	90 (11%)	38 (14%)	22 (5%)	68 (19%)	15 (5%)	5 (4%)	6 (5%)	14 (5%)
Skilled nursing facility	133 (17%)	87 (32%)	78 (19%)	55 (15%)	45 (16%)	32 (27%)	21 (31%)	43 (15%)
Home health organization	180 (23%)	65 (24%)	94 (23%)	86 (23%)	63 (22%)	28 (24%)	27 (25%)	64 (22%)
Hospice (home)	1 (<1%)	—	1 (<1%)	—	—	1 (1%)	1 (1%)	—
Another rehabilitation facility	2 (1%)	—	—	2 (1%)	—	—	—	—
Other	1 (<1%)	6 (2%)	—	1 (<1%)	—	—	—	—
<i>Discharge Living Arrangement</i>								
Alone	n = 374 24 (6%)	n = 77 1 (1%)	n = 218 19 (9%)	n = 156* 5 (3%)	12 (7%)	7 (14%)	n = 42 4 (10%)	n = 171 15 (9%)
Family/relatives	333 (89%)	74 (97%)	191 (87%)	142 (91%)	143 (88%)	43 (84%)	37 (88%)	149 (87%)
Friends	8 (2%)	—	4 (2%)	4 (3%)	3 (2%)	1 (2%)	—	4 (2%)
Attendant	2 (1%)	1 (1%)	1 (<1%)	1 (1%)	1 (1%)	—	—	1 (1%)
Other	7 (2%)	1 (1%)	3 (1%)	4 (3%)	3 (2%)	—	1 (2%)	2 (1%)

Notes: Bolded values are significant at *** $p > .001$ | ** $p > .01$ | * $p > .05$.

^aYes—patients required reading of items and recording of responses, required response recording only, and required assistance with turning pages during inpatient survey completion; No—patients did not require assistance during inpatient survey completion.

Analysis: We combined the response categories for the following variables: race (white vs. black vs. all other), marital status (married. vs. all other), occupational status (working vs. all other), discharge location (home, home under care of home health, home hospice vs. all other), discharge living arrangement (alone vs. all other).

CCSE, Cognitive Capacity Screening Examination; FIM, Functional Independence Measure.

lower self-care (3.2 points) and mobility scores (1.9 points) than patients who received no calls.

Follow-Up Bias

Patients who did and did not complete the follow-up were similar with respect to the characteristics reported in Table 2, except admission FIM cognition score and discharge destination. Follow-up completers had FIM cognition scores that were 2.7 points higher, on average, than noncompleters. Patients discharged home were more likely to complete the survey (76 percent) than patients discharged to institutional settings (65 percent). Follow-up response rate was unrelated to timing of the incentive.

DISCUSSION

Summary of Findings

Of the 1,055 consecutive admissions during the 7-month recruitment period, 74 percent met the inclusion criteria, and 50 percent of eligible patients completed the questions a few days before IRF discharge. A majority of patients (74 percent) were able to answer the survey using a tablet computer (84 percent) or paper document (16 percent) without assistance in reading questions or recording responses. Patients with cognitive limitations were more likely to require assistance (45 percent) than were patients scoring in the normal range (23 percent). Median time to complete the 55 items was 15 minutes. The majority of patients who completed the survey during their IRF stay (71 percent) did so again about 1 month after discharge; postdischarge survey completion was unrelated to timing of the incentive. Most participants required none (42 percent) or 1–2 telephone reminder calls (23 percent) to complete the surveys, although 35 percent required 3–5 calls.

Tests of Hypotheses

Results support the hypotheses guiding the study. A majority of rehabilitation inpatients with neurological disorders were willing and able to complete the survey using a tablet computer or paper. However, eligibility and willingness varied by diagnosis, race, functional status, and length of stay. Older patients and those with lower cognition scores, longer stays, and primary diagnoses of SCI, MS, PD, and other neurological disorders were less likely to be

consented and thus are under-represented. As length of stay varies by diagnosis, and patients with lower functional status tend to have longer stays, care quality measures may need to consider differences in participation by patient characteristics to make fair comparisons among IRFs.

Although the 55-item survey is longer than what hospitals are likely to administer, the mean completion time was well below the time patients reported being willing to spend. A majority of patients completed the survey independently using a tablet computer or paper form; it was important to provide electronic and paper options given patients' functional abilities and preferences. A sizeable proportion of patients required assistance with both modes of administration. Staff provided assistance more often to patients with below normal mental status and lower cognition and self-care skills.

The follow-up response rate would have been much lower without considerable staff effort. We obtained half of the follow-up respondents only after making two or more phone calls after initial reminders to noncompleters. We made multiple telephone calls to patients who did not log-on to a website or return a paper document; this level of resource commitment would be required to minimize response bias by IRFs adopting PROs routinely. Patients with lower levels of cognition and those discharged to institutional settings were less likely to complete the follow-up.

These results support preliminary evidence regarding what PRO information could be collected and when it should be collected. Patients' experience of care and pain management can be assessed shortly before discharge when perceptions of care are fresh. Perceptions of discharge preparation and readiness to return to the community may be best assessed one month after discharge when patients have had an opportunity to assess how well prepared they actually were. Policy decisions regarding what aspects of care to assess and timing should consider the reduced response rate.

Limitations

We recruited patients from only two facilities in the Midwest, limiting generalizability to IRFs in other regions. We also encountered technical problems with the web-based data collection platform. Default storage limitations on a secure, local server network resulted in the loss of 11 inpatient surveys. Seven participants had difficulty using the touch screen, and data collectors provided assistance to enter responses. Discharge dates changed frequently, often with little notice, creating challenges for research assistants to complete interviews.

Considerable effort was required to locate patients who were off their nursing unit because of therapy, tests, and other procedures. Therapy schedules changed frequently, creating challenges in scheduling. Patients often napped or had visitors during nontherapy hours, further limiting their availability.

It is possible that the \$10 compensation affected the participation rate. We evaluated this possibility by examining the response rate to a satisfaction survey conducted 1 month postdischarge by the two IRFs. The satisfaction survey response rate of 31 percent without an incentive is similar to the 27 percent we observed in this study. During study debriefing, we asked whether payment would affect the likelihood of responding to a patient experience of care survey; 96 percent stated it would not. While we cannot rule out response bias due to consenting and payment, the token amount seems unlikely to have created a large bias.

Implications

Findings inform CMS's work to develop IRF PRO quality measures. Patients' perspectives on IRF services can provide valuable feedback to hospitals and payers regarding opportunities for service improvement.

Future Research Directions

Future studies should evaluate strategies to integrate PRO collection into routine care, maximize response rates during and following IRF hospitalization, assess the use of proxy respondents in cases when patients are unable to report their experience of care, and consider risk adjustment methods. Including CMS and NQF as stakeholders is critical to harmonize instrumentation and quality measure development across care settings.

CONCLUSIONS

Collection of experience of care and health status data during and after an IRF stay from persons with neurological disorders is feasible, although a substantial proportion are likely to require assistance. The majority of patients used a tablet computer and were willing to complete the survey 1 month after discharge, although multiple reminders and telephone interviews were required.

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REFERENCES

2010. "Patient Protection and Affordable Care Act." *Public Law No. 111-148, Sec. 3011*.
2012. "Review of Patient Reported Outcomes in Performance Measurement." N. M. A. Public, p. 36. Washington, DC: National Quality Forum.
- Agency for Healthcare Research and Quality (AHRQ). 2010. "National Healthcare Disparities and Quality Reports" [accessed on October 1, 2010]. Available at <https://archive.ahrq.gov/research/findings/nhqrdr/nhqrdr10/qdr10.html>
- Amtmann, D., K. F. Cook, M. P. Jensen, W.-H. Chen, S. Choi, D. Revicki, D. Cella, N. Rothrock, F. Keefe, and L. Callahan. 2010. "Development of a PROMIS Item Bank to Measure Pain Interference." *Pain* 150 (1): 173–82.
- Cella, D. 2015a. "Development and Initial Validation of Patient-Reported Item Banks for Use in Neurological Research and Practice" [accessed on July 11, 2016]. Available at http://www.healthmeasures.net/images/neuro_qol/Neuro-QoL_Manual_Technical_Report_v2_24Mar2015.pdf
- Cella, D., C. Nowinski, A. Peterman, D. Victorson, D. Miller, J. S. Lai, and C. Moy. 2011. "The Neurology Quality-of-Life Measurement Initiative." *Archives of Physical Medicine and Rehabilitation* 92 (10 suppl): S28–36.
- Cella, D., C. J. Nowinski, A. Peterman, D. Victorson, D. Miller, F. Bethoux, A. W. Heinemann, S. Rubin, J. Cavazos, A. Reder, R. Sufit, T. Simuni, G. Holmes, A. Siderowf, V. Wojna, R. Bode, N. Rohtrock, and C. S. Moy. 2012. "Neuro-QOL: Brief Measures of Health-Related Quality of Life for Clinical Research Neurology." *Neurology* 78: 1860–7.
- Cella, D., E. A. Hahn, S. E. Jensen, Z. Butt, C. J. Nowinski, N. Rothrock, and K. N. Lohr. 2015b. *Patient-Reported Outcomes in Performance Measurement*. Research Triangle Park, NC: RTI Press Publication.
- Centers for Medicare and Medicaid Services. 2015. "Inpatient Rehabilitation Facilities (IRF) Quality Reporting Program (QRP)" [accessed on May 8, 2017]. Available at <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/IRF-Quality-Reporting/>
- Coleman, E. A., E. Mahoney, and C. Parry. 2005. "Assessing the Quality of Preparation for Posthospital Care from the Patient's Perspective: The Care Transitions Measure." *Medical Care* 43 (3): 246–55.
- The Commonwealth Fund Commission on a High Performance Health System. 2011. *Why Not the Best? Results from the National Scorecard on US Health System Performance*. New York: The Commonwealth Fund.

- Fisher, E. S., D. E. Wennberg, T. A. Stukel, D. J. Gottlieb, F. L. Lucas, and E. L. Pinder. 2003. "The Implications of Regional Variations in Medicare Spending. Part 1: The Content, Quality, and Accessibility of Care." *Annals of Internal Medicine* 138 (4): 273–87.
- Granger, C. V., A. Deutsch, C. Russel, T. Black, and K. J. Ottenbacher. 2007. "Modifications of the FIM Instrument Under the Inpatient Rehabilitation Facility Prospective Payment System." *American Journal of Physical Medicine and Rehabilitation* 86 (1): 883–92.
- Heinemann, A. W., J. M. Linacre, B. D. Wright, B. B. Hamilton, and C. Granger. 1994. "Prediction of Rehabilitation Outcomes with Disability Measures." *Archives of Physical Medicine and Rehabilitation* 75 (2): 133–43.
- IBM Corporation. 2014. *SPSS Statistics for Windows, Version 23. (Release)*. Armonk, NY: IBM Corporation.
- Institute of Medicine. 1999. *To Err Is Human: Building a Safer Health System*. Washington, DC: National Academy Press.
- Institute of Medicine. 2001. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press.
- Jacobs, J. W., M. R. Bernhard, A. Delgado, and J. J. Strain. 1977. "Screening for Organic Mental Syndromes in the Medically Ill." *Annals of Internal Medicine* 86 (1): 40–6.
- McGlynn, E. A., S. M. Asch, J. Adams, J. Keesey, J. Hicks, A. DeCristofaro, and E. A. Kerr. 2003. "The Quality of Health Care Delivered to Adults in the United States." *New England Journal of Medicine* 348 (26): 2635–45.
- Medicare Payment Advisory Commission. 2016. *Report to the Congress: Medicare Payment Policy*. Washington, DC: Author.
- Saliba, D., and J. Buchanan. 2012. "Making the Investment Count: Revision of the Minimum Data Set for Nursing Homes, MDS 3.0." *Journal of the American Medical Directors Association* 13 (7): 602–10.

SUPPORTING INFORMATION

Additional supporting information may be found online in the supporting information tab for this article:

Appendix SA1: Author Matrix.