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Designing and Implementing a System for Tracking Functional Status after Stroke: a Feasibility Study

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Abstract

Objective—To determine the feasibility of tracking stroke patients' functional outcomes in an integrated health system across a care continuum using the computer version of the Activity Measure of Post-Acute Care (AM-PAC).

Setting—A large integrated healthcare system in northern California.

Participants—222 stroke patients (aged 18 or older) hospitalized after an acute cerebrovascular accident.

Methods—An AM-PAC assessment was made at discharge from sites of care, including acute hospital, inpatient rehabilitation hospital, skilled nursing facility, home during home care, and in outpatient settings. Assessments were also completed in the patient's home at six months. Data from the AM-PAC program was integrated with the health care system's databases.

Main Outcome Measurements—1) AM-PAC administration time at the various sites of care; 2) assessment of a floor or a ceiling effect, 3) administrative burden of tracking participants

Results—AM-PAC assessment sessions averaged 7.9 minutes for data acquisition in 3 domains: Basic Mobility, Activities of Daily Living, and Applied Cognition. Participants answered, on average, 27 AM-PAC questions per session. A small ceiling effect was observed at 6 months and there was a larger ceiling effect when the instrument was administered in an institution, i.e., using the AM-PAC institutional item bank, rather than the community item bank. It was feasible to track patients and assess their function using the AM-PAC instrument from institutional to community settings. Implementation of the AM-PAC in clinical environments, and success of the project was influenced by instrumental, technological, operational, resource, and cultural factors.

Conclusions—This study demonstrates the feasibility of implementing a single functional outcome instrument in clinical and community settings to measure rehabilitation functional outcomes of stroke patients. Integrating the AM-PAC measurement system into clinical workflows and the electronic medical record could provide assistance to clinicians for medical decisions, functional prognostication, and discharge planning.

Keywords

rehabilitation; post-acute care; care continuum; stroke; cerebrovascular accident; functional outcomes measurement; AM-PAC; computer adaptive testing; electronic medical record; International Classification of Function; ICF

INTRODUCTION

Stroke continues to represent a leading cause of long-term disability in the US. Two-thirds of the 4.8 million stroke survivors in the United States require post-acute care services, including rehabilitation [1]. About a third of this group has severe disabilities and 40% have

moderate disabilities [2, 3]. Stroke survivors currently cope with significant physical, cognitive, and mental impairments, and 25% to 74% of these survivors require some assistance or are fully dependent on caregivers for activities of daily living (ADLs) [4–6].

Post-acute care (PAC) is treatment provided to patients to improve their function after they leave an acute care hospital. Compared with practice patterns in past decades, stroke patients are moved through inpatient settings within days. During the last several decades in the United States, the average acute length of stay for patients with stroke has decreased to approximately 5.3 days [7]. Longitudinal studies indicate that stroke recovery typically continues months after the acute event, long after the majority of patients are discharged from inpatient settings [7–9]. Functional recovery or restoration of some functional abilities may continue for months or even years after the acute event.

Currently, most PAC is fragmented into “silos” based on licensure or payment systems. Rehabilitation after acute inpatient medical and, in some cases, surgical care may be provided at an inpatient rehabilitation facility or hospital (IRH), a long-term acute care facility (LTAC), a skilled nursing facility (SNF), an outpatient clinic (OP), or by home health care (HH). Most rehabilitation health services research has focused on recovery in specific rehabilitation settings. It is often not feasible to evaluate costs and benefits of rehabilitation across sites of care, or even specific care pathways. The general lack of integration in most healthcare delivery systems prevents the most efficient and cost-effective planning for PAC. PAC comparisons across settings have been hindered by the absence of a common metric. Each type of care has adopted (or has been assigned) its own approach to measurement of function or other outcomes [10].

The Centers for Medicare and Medicaid Services (CMS) developed data collection instruments for each type of setting. IRH uses the Inpatient Rehabilitation Facility-Patient Assessment Instrument (IRF-PAI). SNF uses the Minimum Data Set (MDS). HH uses the Outcome Assessment Information Set (OASIS). This fragmentation makes it difficult to measure a patient’s functional improvement across the PAC continuum. In the past decade, the payment methods for PAC facilities have undergone a major transformation. All four provider types are now paid prospectively, as mandated by the U.S. Congress [11].

Health care funding agencies at all levels seek a single assessment system to monitor the quality of care and outcomes. We had an opportunity to address the issue of functional outcomes measurement in an integrated healthcare system in Northern California. The system, Kaiser Foundation Health Plan and Hospitals of Northern California (KPNC), currently with twenty hospitals serving 3.3 million members, provides the entire range of healthcare services from primary care, through acute hospital, and with a PAC continuum. (Although the health system has contracts with LTACs, none of the patients in this study received care in an LTAC.) KPNC is organized into twelve service areas. Members typically receive healthcare services from facilities in the service area where they live. There are currently two neurosurgical hospitals and one regional IRH. SNF facilities and HH care are staffed by KPNC coordinators and physicians. In KPNC the annual stroke incidence is approximately 4,200 cases. This integrated health care organization offered an opportunity to examine the feasibility of developing a system for following stroke patients for six

months after initial stroke, across the continuum of care, using a single measurement instrument, the Activity Measure for Post-Acute Care (AM-PAC).

We had four aims in mind. First, we wanted to determine the AM-PAC burden of measurement on clinical staff. We measured this with administration time for AM-PAC sessions. Second, we wanted to determine if the AM-PAC was a sensitive measure to assess patient function across each site of PAC in the continuum. We measured this with evaluation of the ceiling and floor effect. Third, we wanted to determine if our integrated healthcare system's electronic medical record (EMR) would reduce the administrative burden on study staff to locate and track stroke patients for six months after a stroke, with assistance from care providers who were identified through the EMR and contacted to assist with data acquisition. We measured this by determining the tracking and AM-PAC assessment time for each of the various PAC trajectories. Fourth, we wanted to integrate the AM-PAC program into the KPNC IT network in order to integrate AM-PAC functional data with KPNC administrative and clinical data. We combined AM-PAC scores by treatment group and associated them with demographic and health characteristics. In assessing feasibility, we address instrumental, technological, operational, resource, and cultural factors.

METHODS

This study was conducted as approved by the Kaiser Permanente Northern California Institutional Review Board. We used a prospective cohort design. We recruited a convenience sample of Kaiser Foundation Health Plan (KFHP) members over a rolling enrollment period of twenty-nine months, beginning recruitment in February 2008 and concluding recruitment in July, 2010.

The AM-PAC Instrument

The AM-PAC is an activity limitations instrument developed using the World Health Organization's International Classification of Functioning, Disability and Health (ICF). The AM-PAC instrument was designed to measure functional status in adults with many diagnoses across all post acute care settings. In this study we limited its use to stroke populations. The AM-PAC instrument examines a set of functional activities that are likely to be encountered by most adults during daily routines within the context of either an inpatient episode of care or outpatient PAC services. Because functional activity is multidimensional, AM-PAC item banks are organized into three functional domains: Basic Mobility (101 items), Daily Activity (70 items), and Applied Cognition (69 items) [12]. The AM-PAC instrument uses a 4-point difficulty rating scale (no difficulty, a little difficulty, a lot of difficulty, cannot or unable to do) across 259 functional tasks and activities. Items for the AM-PAC were drawn from two sources: 1) a set of new items that examine the functional content domains listed above; and 2) items from existing outcome instruments used in rehabilitation and PAC programs. The items in the AM-PAC assess multiple aspects (i.e., difficulty, need for assistance, and limitations) of an individual's ability to perform specific daily activities. Early trials of the AM-PAC instrument recruited a sample of 1041 post acute care patients to establish the validity and reliability of the scales and scoring. The developers of the AM-PAC conducted a series of simulated validation tests of the AM-PAC

CAT software on numerous samples, including patients with stroke [13–15], complex medical conditions,[16] and prospective work on patients with orthopedic conditions.[13, 14]

This study used the computer-adaptive test (CAT) version of the AM-PAC. In CAT administration of the AM-PAC, a computer program uses information from a subject's previous responses to tailor item selection. This iterative selection of items eliminates questions that are too difficult or too easy for a particular patient. Item Response Theory (IRT) methods are used to create hierarchically-ordered item banks, graded from activities that are easy to activities that are difficult for patients to accomplish. In the AM-PAC CAT, a small sample of the items in an item bank are administered. All scores are generated on the same metric, regardless of the number of items administered. This facilitates comparisons across time or across groups with different functional levels while reducing respondent burden.[14] CAT can shorten or lengthen the test to achieve the desired precision or it can be governed by a pre-assigned item-stopping rule [17]. In a CAT design, the estimates of a patient's function derive from an optimal choice of test items that are selected based on the person's response to each previous item.

The basic notion of an adaptive test is to mimic what an experienced clinician does. The AM-PAC is designed to perform similarly to a clinician-patient interview. A clinician learns most when directing questions aimed at the patient's approximate level of proficiency. Administering items that represent tasks that are either too easy or too hard for the patient provide little information. Item pools used in IRT implementation are developed by equating outcome items from different sources so that they can be meaningfully compared on a common underlying scale. This allows for fewer items to be administered while gaining precise information regarding an individual's placement along an outcome continuum. Using this methodology offers a resolution to the classic trade-off between feasibility of existing outcome measures and their limitations in detecting clinically relevant functional outcome changes over time.

Within a short period of time, with a few narrowly focused questions, AM-PAC can, with precision, determine a patient's functional level. Because of the CAT implementation, patients seldom receive the same series of questions at subsequent functional measurement sessions. This results in little or no practice effects when measures are repeated over time.^{17, 18} In addition, because of the large item pool that is specific for institutional or community settings, the instrument scoring process results in few ceiling or floor effects.

We wanted to determine if the AM-PAC could be successfully used for a longitudinal study where baseline is in an acute hospital setting and the endpoint is in a community setting. One part of that problem is to determine if the AM-PAC is not only sufficiently sensitive to functions that are restricted in an institutional setting, but also able to capture the broad range of function in a community setting.

Each AM-PAC domain contains two item banks, institutional and community. The institutional scale is most appropriate for individuals in a restricted environment, i.e., an environment that may limit the range of activities, such as a hospital. The community scale

includes activities that cover a wide spectrum of activity. Analyzing the ceiling and floor effect on patient answers is a standard way to demonstrate the sensitivity of an instrument. The term “ceiling effect” is used when a large portion of the sample endorses functions that are difficult for them and the term “floor effect” is used when a large portion of the sample endorses functions that are easy for them.

We trained the research coordinators in use of the instrument prior to initiation of the study. A clinical trainer from the AM-PAC development team spent 8 hours with the research coordinators. Use of the application on a computer was covered to assure that the research coordinators could recognize and recover from common application and network errors. Existing cases in the AM-PAC database were examined to acquaint the research coordinators with common use patterns and data distribution. The research coordinators conducted practice sessions in a development environment using common clinical cases in order to learn to recognize responses that would be expected, given the clinical presentation. The AM-PAC trainer conducted a test of each research coordinator’s skills in order to certify that they were prepared to administer the AM-PAC in a standardized way.

Participant Recruitment

One objective of this study was to test whether the AM-PAC could detect a difference between major treatment settings for post stroke patients. Results of those analyses are reported elsewhere. [19].

Even after careful screening, we found that some enrolled participants could not be included in the analytic cohort. After the final study participant completed the protocol we monitored the AM-PAC tables to identify those records we would be able to analyze. Of the 287 enrolled participants, 55 could not be included in the analysis: 15 withdrew consent during the 6 month study period, 19 were ultimately diagnosed with a condition other than stroke, and 21 expired during their 6-month study period. In rare cases the AM-PAC tables had incomplete data due to an interruption during a session. This was the result of network instability and could be detected by the research coordinator when the application froze. This occurred in 10 cases. Of these 10 cases 4 participants withdrew consent and declined to continue the session when the application was restored. The study records of the analyzed 222 participants were monitored for completeness using our hardcopy forms and the AM-PAC session listings.

Each study participant was enrolled while an inpatient in one of four KPNC acute hospitals and followed for six months after discharge to PAC or to home with no PAC treatments. We used two sources to identify study candidates from the EMR: hospital census and stroke rounds lists for the four medical centers. Our research coordinators attended formal bedside interdisciplinary rounds and reviewed the cases with a neurologist or a physiatrist. Research coordinators completed a screening document to prepare for review with members of the stroke team. The screening documents contained information that would provide support for our recruiting activities such as physician name, nursing contact, admission diagnosis, NIH Stroke Scale score, and treatment plan. We arrived at a convenience sample of patients using these approaches to participant recruitment. Whereas all patients presented at stroke rounds

were considered for recruitment, many of them did not meet our enrollment criteria. Patients with rapidly resolving symptoms and signs, for example, were not recruited.

We reviewed the history and physical examinations, focusing on neurology and psychiatry consultations that were available in the EMR. The notes included clinical impressions, orders for tests, lab results, and treatment plans that determined our recruitment decisions. Providers used a number of labels for patient status when hospice care was under consideration, for example, “comfort care”, “hospice”, and “poor prognosis”. These terms were used to characterize patients who were not likely to survive for six months. These patients were not candidates for this study, since the protocol was designed to follow patients for six months after stroke.

Prior to the enrollment meeting, we determined if we would need a surrogate to obtain informed consent. A surrogate was used if the patient was diagnosed with aphasia, severe dysarthria, dementia, or was unable to ask questions and understand answers about their participation in the study. A formalized decision process was used to determine if the patient was able to provide informed consent and answer the study questions. The following definitions were used: 1) surrogate: the person who gives consent if the patient is unable; in all cases this was a family member or a close friend; and 2) proxy: the person who answers study questions on behalf of the patient. The following 3 criteria had to be met for the patient to provide information; otherwise, a surrogate or proxy was recruited: 1) The patient could understand the informed consent document and the AM-PAC interview questions; 2) the patient could sustain attention for 15 minutes; and 3) the patient could give accurate and consistent responses to questions. Details on proxy versus patient reported data are available in another publication by our research group [18]. We found that in the acute hospital 77 (35%) participants required a proxy and at 6 months 57 (26%) participants required a proxy.

After we identified a study candidate, a research coordinator presented the study to the patient and available family members and secured informed consent. At baseline, the screener was a clinician familiar with the patient. The clinician was a physician, nurse or a therapist (physical, occupational or speech therapist). For follow up visits, the screener was a clinician in IRH or SNF, or a family member in the home setting. The first choice of proxy for patients in an inpatient facility was a clinician. The first choice of proxy for participants at home was a family member. If the patient was capable, we obtained consent from the patient and asked the study questions to the patient directly. In some cases, the patient needed a surrogate or proxy at baseline, but later in the study was able to answer the study questions.

In some cases, we had to withdraw a participant because the final discharge diagnosis was not a stroke. Most often, this was a transient ischemic attack or a tumor that had not been diagnosed at the time of enrollment.

IT Implementation of the AM-PAC

We installed the AM-PAC server program and its data tables in a research test environment within the health system network. A sequence of upgrades and the association of the AM-PAC data tables with other administrative and clinical tables in a virtual data warehouse

(VDW) represent the first phase of adoption into the healthcare system computer and network environment.

The AM-PAC application could be accessed using a browser on any computer in the KPNC network. We used AM-PAC in two access scenarios. First, we introduced it on fixed desktop computers. The desktop computer required no additional configuration because the AM-PAC application runs on a remote server accessed from a local browser across the enterprise network. Traffic between the AM-PAC server and the browser traveled on the same secure enterprise network as all other encrypted patient data. However, bringing the AM-PAC into the patient room in the acute hospital presented some challenges. We decided to use a broadband connectivity device using the enterprise virtual private network (VPN). While this system is commonly in use in many businesses, the need for rigid control of protected health information (PHI) on a healthcare network demands that the AM-PAC is accessed using the same methods as the EMR. Future trials with the AM-PAC will require integration onto the EMR platform, whether by using WiFi portable desktop systems or by continued use of study laptops, but integrated into the production EMR network. We were able to import the native AM-PAC data into the research test environment, setting up tables that were periodically refreshed from the AM-PAC application. We experienced no technical barriers to this migration scheme.

By the end of four years of use in both inpatient and outpatient environments, and over the phone to external facilities and patient residences, we were able to administer the AM-PAC in several use patterns: in patient rooms with patients and family members, at nursing stations with clinical staff, and over the phone from our study offices. This flexibility adds to the potential for AM-PAC to be used in a variety of healthcare settings.

Administration of the AM-PAC Questions

One problem with new measurement tools, whether paper-and-pencil or computerized, is that the administering person must be trained in a standard administration method. While this is the general rule for psychometric tests, it presents a barrier to wide adoption by providers in a healthcare system. The AM-PAC can be administered by a research coordinator without clinical training. It requires a standard administration method of training, but not the extensive clinical training required to competently administer the NIH Stroke Scale (NIHSS), for example. Time to train each research coordinator was approximately 8–16 hours of supervision and modeling.

Clinical staff members are constantly on the move in the inpatient setting, with numerous care protocols, emerging issues, and events requiring immediate attention. The AM-PAC is designed to be administered in a controlled environment. The application can tolerate an extended interruption, even to the extent that it can be closed during administration, and then resumed when the clinician is able to return to finish the assessment. In this situation, the clinician would not be required to remember the specific stopping place or even what domain or question was interrupted because the application controls the presentation of the stimulus questions.

As an assessment instrument that could be used in many environments, the AM-PAC provides both ease of use, low assessment burden on the respondent, but with standardization requirements that extend beyond the routine inpatient setting. We were able to conduct sessions by telephone when participants were in facilities outside the hospital or at home.

Additional Data Collection

We selected two standardized measures, a modified Rankin (mRankin) to characterize the patient's pre-morbid functioning, and a modified NIH Stroke Scale (mNIHSS) as a measure of stroke severity [20, 21]. The mRankin uses a series of six statements to describe the level of autonomy the patient had before the stroke. This instrument uses a 0–5 scale where 0 stands for complete functional independence, and 5 designates a patient who is completely dependent on a caregiver for all functions. The mNIHSS rates the patient on eleven stroke impairments, with a range of 0 to 22, and has been shown to have high reliability and validity. Four questions were removed from the NIHSS to create the mNIHSS, as these items were found to be either redundant (level of consciousness) or to lack reliability (ataxia, facial weakness, and dysarthria). [20]

At each study visit, we collected data on hardcopy forms, including participant identifiers, location of the study visit, respondent identifiers, and contact information for the next level of care. During the enrollment visit we collected descriptive information such stroke type, height and weight (to calculate Body Mass Index) stroke and smoking history, marital status, mRankin score for premorbid function, and mNIHSS score of stroke severity.

The AM-PAC data was stored in a database on the health system network, and data was transferred into tables in the VDW. The hand-collected descriptive data and the AM-PAC functional data were combined in tables with administrative and clinical data in the VDW. These data included utilization, comorbidities, and medications that might affect a patient's capacity to answer study questions. In order to integrate AM-PAC with EMR data the raw data and the functional scores needed to be stored in a searchable condition.

Study staff sent a reminder letter to each participant at 3 months following enrollment, and again at about 2 weeks prior to the 6-month study conclusion visit. Following the study completion visit, study staff used the AM-PAC application to generate a list of all of the participant's AM-PAC sessions. We used this list to determine which sessions had complete data and which sessions needed to be excluded for administrative reasons, such as incomplete or corrupted data.

We analyzed administrative burden (tracking and administering the AM-PAC) by the specific PAC trajectories. These data are shown in Figure 1.

Data Management and Analysis

We maintained a spreadsheet that contained relevant data fields from the EMR hospital census. Data included the date our coordinators reviewed the inpatient chart, patient name, medical record number, hospital unit, patient room number, attending physician, admission date, health plan membership status, study enrollment date, and comments documenting

reasons for non-enrollment. We used this file to track each patient we screened for the study. This chart review file contained enrollment dates for study participants and comments about each patient who was screened for possible inclusion but not enrolled, most commonly because the final diagnosis was not a stroke, the patient had lost their health plan membership, or the prognosis was considered poor.

After a patient was enrolled, we transferred information about the patient from the chart review document to a separate spreadsheet for study-visit tracking. This file contained the name, medical record number, date we reviewed the chart, the name of the acute hospital, date of admission, and the first study visit assessment. We also documented the site of care and assessment date for each succeeding visit. We developed a tracking document for status of each site of care, contact person for each site, and anticipated discharge date. We used this file to maintain our visibility to each participant as they moved through the care continuum.

We wanted to be able to analyze the AM-PAC data within each PAC setting. However, patients followed many different trajectories. We decided to assign participants to four groups based on the intensity of PAC. We considered PAC for these participants who received any of the following rehabilitation services: physical therapy (PT), occupational therapy (OT), and speech therapy (ST). Participants in the IRH received at least 3 hours of PAC 6 days per week. Participants in SNF received on average 1.3 hours of PAC 5 days per week. Both home health and outpatient PAC were provided at a rate of an hour per encounter. Therefore, we had a gradient of PAC treatment intensity from 0 (home with no services) to 3 hours per day, 6 days per week (IRH).

RESULTS

For this study, we focused our analysis on certain aspects related to feasibility: 1) ceiling and floor measurement effects, 2) number of questions and administration time by treatment group, and 3) amount of tracking and assessment time on the part of our research coordinators as they followed these patients through the care continuum, which we refer to as ‘administrative burden’.

Patient characteristics are summarized in Tables 1 and 2. These tables summarize the demographics and health characteristics of the cohort.

AM-PAC uses an institutional item pool in an acute hospital, an IRH or a SNF. The institutional scale was administered to all participants at baseline in the acute hospital. In addition, 2 participants were in SNF at 6 months so they received the institutional scale at that time point. The community item pool was used when the care setting was HH, OP, or home with no PAC treatment. All of the 222 participants received questions from the institutional item bank at the baseline session. Of the 222 participants, 220 received the community scale at 6 months. Table 3 presents the distribution of scores, by domain, that were at floor and ceiling. The results varied by domain. We found a small floor effect on the institutional items as follows: Basic Mobility—3.60%, ADL—2.70%, and none for Applied Cognition. A larger portion of the participants scored at the top of the community scale. We

found a modest ceiling effect as follows: Basic Mobility—2.70%, ADL—3.60%, and Applied Cognition—10.10%.

We looked at the assessment burden of using the AM-PAC by examining the assessment time and the number of AM-PAC items administered by treatment group. Table 4 shows how participants responded to the AM-PAC questions by treatment group. We found that AM-PAC assessment sessions averaged 7.9 minutes for data acquisition in 3 domains. A research coordinator administered, on average, 27 AM-PAC questions per session. The number of items was, on average, 9 in each of the three functional domains. On average, the IRH group spent 7.1 minutes answering the questions at six months while the SNF group spent 7.7 minutes, on average, answering the questions.

We wanted to determine the administrative burden driven by the tracking activities used to follow patients for six months. Tracking varied within treatment groups depending on the sequence and site of PAC. We found that disaggregating the PAC trajectories from the treatment groups helped us to determine the administrative effort. Tracking and contact time varied according to the number of PAC treatment sites and types of site. Figure 1 shows the PAC trajectories, the number of participants in each trajectory, and the mean time in minutes spent tracking and assessing participants in each of these trajectories. Figure 1 shows the mean tracking and assessment time per participant by PAC treatment trajectory. Tracking and assessing participants with one PAC treatment site took less than an hour per participant over the 6 month period. An exception was HH, which in the 27 cases where it was the only PAC, required, on average, 80 minutes per participant. As predicted, treatment trajectories with multiple PAC treatment sites took longer periods of time for administration.

In assessing feasibility of the AM-PAC functional measurement system, we focused on 5 factors of importance: 1) AM-PAC instrument factors, 2) technological factors, 3) operational factors, 4) resource factors, and 5) cultural factors. Each area of focus is summarized below.

Instrument Factors: AM-PAC Ceiling and Floor Effects

We detected a larger ceiling effect in the institutional version and a smaller ceiling effect in the community version. The main reason for this finding is that the full AM-PAC item pool was used for community assessment. It included a large number of items calibrated to cover a broad range of function in this sample. In contrast, the institutional version of the AM-PAC was restricted to a smaller subset of functional items that were relevant to persons within an institution. It should be noted that standard questionnaires, which ask all respondents the same questions, either carry a large assessment burden in order to be inclusive, or are limited in scope and precision in order to reduce the assessment burden. Using CAT technology, AM-PAC reduces the number of questions and restricts the questions to that part of the functional range that best fits the respondent. The institutional scale was administered to all study participants at the baseline, acute care visit; and to 2 participants living in an institutional setting at the 6-month visit. The floor effect would be seen in the institutional scores and the ceiling effect in the community scores. Very few participants were found at the bottom (most impaired) end of the institutional scale. A larger portion of the participants scored at the top of the community scale. These results indicate

that the AM-PAC is sensitive to a broad range of function and can be used to assess function across the care continuum.

Instrument Factors: AM-PAC Measurement Burden

We also looked at the feasibility of using the AM-PAC by examining the assessment time and the number of AM-PAC items administered by PAC treatment setting. We found that AM-PAC administration sessions averaged 7.9 minutes for data acquisition in 3 domains. A research coordinator administered, on average, 27 AM-PAC questions per session. The number of items was, on average, 9 in each of the three functional domains. On average, the IRH group spent 7.1 minutes answering the questions at six months after the stroke while the SNF group spent 7.7 minutes, on average, answering the questions. These results suggest that participant measurement time was similar for each of the groups and that the type of setting did not influence participant use of the instrument. The amount of time to administer the assessment was on average 1.5 minutes longer in the acute hospital setting than at 6 months for all treatment groups. These results also show the influence of the CAT and IRT features of AM-PAC. These capabilities narrowed the range and number of questions uniformly across all treatment groups. All participants responded to AM-PAC with similar assessment times and numbers of questions.

Technological Factors

Our health system was migrating from a mixed paper-electronic system to a system-wide EMR during the study period. Because of a gradual roll-out of the EMR system across the facilities where the study took place, there were varying degrees of familiarity and expertise with the EMR system, and a need for both clinicians and research coordinators to become competent to use it. In addition, we had to develop connectivity solutions for the use of laptops at the beginning of the study in order to collect AM-PAC data in patient hospital rooms. Data encryption software was required on the network. Implementation of the AM-PAC application took time before we began enrollment. Once the AM-PAC application and network connectivity were stable, enrollment began and assessment sessions took place seamlessly.

Operational Factors

In order to engage providers and clinical teams in the process of enrollment and tracking, we held educational sessions at each of the study sites. This helped with buy-in to assist the research team and led to collaborations that helped us meet our enrollment targets. Presentations to hospital stroke teams, nursing staff, and administrative leadership were conducted in the early phases of the study. As the health system was committed to Joint Commission Stroke Certification of its hospitals, stroke team approaches were already in place to allow for identification of the staff most likely to collaborate in enrollment and tracking. The SNF and HH providers also received information about the research project during the early phases. Some of this variation was due to difficulty reaching busy SNF and HH coordinators and therapists. Barriers to integration of the AM-PAC interviews into clinical workflows were expected, namely those that result from responsibilities of clinical staff to provide minute-to-minute care to patients, to document clinical activities in a

relatively new EMR system, and also to respond to urgent and emergent issues and events that were not predictable in most cases.

Resource Factors

In order for implementation of a system of tracking functional outcomes using CAT technology, human and technological resources need to be allocated. We learned that although the administration time of the AM-PAC was less than 8 minutes, unless the work is integrated into existing workflows with EMR decision-support, the resource requirements will be unacceptably high, as telephoning to track down providers was labor-intensive. However, if a health system EMR builds supports for a monitoring and tracking system using an application such as the AM-PAC, functional outcomes could be tracked across the care continuum with many fewer resource requirements.

Cultural Factors

As health care systems transition to EMRs, many cultural changes are taking place. Our research team was enrolling and tracking during a period of EMR adoption in which these cultural changes were occurring. In addition, acute care nurses and physicians value acute medical and surgical assessment and interventions, while functional assessment and interventions are the focus of therapists and physical medicine and rehabilitation physicians. Therefore, some acute care clinicians were unable to answer questions as proxy respondents in certain domains, if they had no direct experience with the functional status of the patient within that domain. This required work on the part of the research assistants to find a therapist or other clinician with the ability to answer the questions.

Additional cultural changes will occur as “value-based” health care delivery models replace existing models, and as the new models require tracking of functional and other outcomes across settings of care. This value-based approach is centered on an assumption that treatment outcomes, tracked and used for comparison using standardized and transparent methods, will improve both the efficiency and the quality of care and provide a more patient-centered approach to care delivery ²².

CONCLUSION

In the integrated healthcare system in which this study was conducted, it is possible to identify and track stroke patients in the acute hospital and follow them across various care trajectories, evaluating functional status using the computerized AM-PAC instrument. This can be accomplished by in-person and telephone contacts with clinicians, patients, or family members. Identifying patients, enrolling, and tracking them was facilitated by a sophisticated EMR and by portable computers that could be operational in clinical settings or at a telephone. Some crucial variables, such as the mNIHSS had to be extracted from physician notes in the EMR. Important variables such as the mRankin had to be added to data collection during the AM-PAC acute session. Coding of these variables within the EMR could assist researchers and quality analysts in the future to track, measure, and predict functional outcomes, and to assist physicians and discharge planners to identify the best PAC settings for patients with stroke as well as other patient populations. We identified

a variety of feasibility factors that must be considered in design and implementation of a functional outcome system, namely instrumental, technological, operational, resource, and cultural factors. In the future, establishment of a system for tracking functional outcomes for stroke patients, and other populations who receive post-acute rehabilitation care in multiple settings, can position health systems to improve both the quality and efficiency of care and potentially improve patient outcomes, outcomes that are meaningful to patients and their families.

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References

1. Lloyd-Jones D, Adams R, Carnethon M, et al. Heart disease and stroke statistics--2009 update: a report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation*. Jan 27; 2009 119(3):e21–181. [PubMed: 19075105]
2. Ferrucci L, Bandinelli S, Guralnik JM, et al. Recovery of functional status after stroke. A postrehabilitation follow-up study. *Stroke*. Feb; 1993 24(2):200–205. [PubMed: 8421819]
3. Kelly-Hayes M, Beiser A, Kase CS, Scaramucci A, D'Agostino RB, Wolf PA. The influence of gender and age on disability following ischemic stroke: the Framingham study. *J Stroke Cerebrovasc Dis*. May-Jun;2003 12(3):119–126. [PubMed: 17903915]
4. Anderson CS, Linto J, Stewart-Wynne EG. A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke*. May; 1995 26(5):843–849. [PubMed: 7740578]
5. Briggs DE, Felberg RA, Malkoff MD, Bratina P, Grotta JC. Should mild or moderate stroke patients be admitted to an intensive care unit? *Stroke*. 2001; 32(4):871–876. [PubMed: 11283385]
6. Kalra L, Langhorne P. Facilitating recovery: evidence for organized stroke care. *J Rehabil Med*. Mar; 2007 39(2):97–102. [PubMed: 17351689]
7. Chan L, Wang H, Terdiman J, et al. Disparities in outpatient and home health service utilization following stroke: results of a 9-year cohort study in Northern California. *PMR*. Nov; 2009 1(11):997–1003.
8. Jorgensen HS, Nakayama H, Raaschou HO, Vive-Larsen J, Stoier M, Olsen TS. Outcome and time course of recovery in stroke. Part I: Outcome. The Copenhagen Stroke Study. *Arch Phys Med Rehabil*. May; 1995 76(5):399–405. [PubMed: 7741608]
9. Jorgensen HS, Nakayama H, Raaschou HO, Vive-Larsen J, Stoier M, Olsen TS. Outcome and time course of recovery in stroke. Part II: Time course of recovery. The Copenhagen Stroke Study. *Arch Phys Med Rehabil*. May; 1995 76(5):406–412. [PubMed: 7741609]
10. Kane RL. Assessing the effectiveness of postacute care rehabilitation. *Arch Phys Med Rehabil*. Nov; 2007 88(11):1500–1504. [PubMed: 17964896]
11. Chan L. The state-of-the-science: challenges in designing postacute care payment policy. *Arch Phys Med Rehabil*. Nov; 2007 88(11):1522–1525. [PubMed: 17964899]
12. Haley SM, Coster WJ, Andres PL, et al. Activity outcome measurement for postacute care. *Med Care*. Jan; 2004 42(1 Suppl):149–61. [PubMed: 14707755]
13. Haley SM, Ni P, Jette AM, et al. Replenishing a computerized adaptive test of patient-reported daily activity functioning. *Qual Life Res*. May; 2009 18(4):461–471. [PubMed: 19288222]
14. Jette AM, Haley SM, Tao W, et al. Prospective evaluation of the AM-PAC-CAT in outpatient rehabilitation settings. *Phys Ther*. Apr; 2007 87(4):385–398. [PubMed: 17311888]

15. Andres PL, Black-Schaffer RM, Ni P, Haley SM. Computer adaptive testing: a strategy for monitoring stroke rehabilitation across settings. *Top Stroke Rehabil.* Spring;2004 11(2):33–39. [PubMed: 15118965]
16. Siebens H, Andres PL, Pengsheng N, Coster WJ, Haley SM. Measuring physical function in patients with complex medical and postsurgical conditions: a computer adaptive approach. *Am J Phys Med Rehabil.* Oct; 2005 84(10):741–748. [PubMed: 16205429]
17. Cella DCC-H. Response to Hays et al and McHorney and Cohen: A Discussion of Item Response Theory and Its Applications in Health Status Assessment. *Medical Care.* 2000; 38:66–72.
18. Jette AM, Ni P, Rasch EK, et al. Evaluation of patient and proxy responses on the activity measure for postacute care. *Stroke.* Mar; 2012 43(3):824–829. [PubMed: 22343646]
19. Chan L, Sandel ME, Jette AM, et al. Does Post-Acute Care Site Matter? A population based, longitudinal cohort study assessing functional outcomes at 6 months in patients with stroke. 2012 In press.
20. Meyer BC, Hemmen TM, Jackson CM, Lyden PD. Modified National Institutes of Health Stroke Scale for use in stroke clinical trials: prospective reliability and validity. *Stroke.* 2002; 33(5): 1261–1266. [PubMed: 11988601]
21. Schlegel D, Kolb SJ, Luciano JM, et al. Utility of the NIH Stroke Scale as a Predictor of Hospital Disposition. *Stroke: Journal of the American Heart Associan.* Jan; 2003 34(1):134–137.
22. Porter DL. What is value in healthcare? *New England Journal of Medicine.* 2010; 363(26):2477–2481. [PubMed: 21142528]

Table 1

Demographic Data

Age	Mean (SD)
Years	70.5 (11.9)
Gender	%
Male	52.5
Female	47.5
Race-ethnicity	%
White	69.35
Black	9.45
Asian	5.975
Hispanic	10.625
Other	4.6
Marital Status	%
Single	7.975
Married	58.175
Divorced	9.4
Widowed	24.475
Living Situation	%
Living alone	22.475
Living with others	77.525
Education	%
High school	34.075
Some college	45.825
Professional/graduate school	20.1

Table 2

Health characteristics

Smoking History	%
No	40.5
Yes	59.5
Stroke Type	%
Ischemic	91.0
Hemorrhagic	9.0
History Prior Stroke	%
No	71.2
Yes	28.8
Health Metrics	
BMI	28.9 (7.1)
Modified NIH Stroke Scale	3.5 (3.1)
Modified Rankin Scale	0.5 (0.9)
Charlson Index ³	1.7 (1.5)

Table 3

Ceiling and floor effect at baseline and 6 months

At Baseline	Floor Effect n (%)		Ceiling Effect n (%)	
Domain	No	Yes	No	Yes
Basic Mobility (n=222)	214(96.40%)	8(3.60%)	211(95.05%)	11(4.95%)
Daily Activity (n=222)	216(97.30%)	6(2.70%)	196(88.29%)	26(11.71%)
Applied Cognitive (n=222)	222 (100.0)	0(0.00%)	198(89.19%)	24(10.81%)

At Six Months	Floor Effect n (%)		Ceiling Effect n (%)	
Domain	No	Yes	No	Yes
Basic Mobility (n=220)	217(98.64%)	3(1.36%)	214(97.27%)	6(2.73%)
Daily Activity (n=220)	219(99.55%)	1(0.45%)	212(96.34%)	8(3.64%)
Applied Cognitive (n=220)	219(99.55%)	1(0.45%)	196(89.09%)	24(10.91%)

Note: 2 participants were in an institution at the 6-month session; the remaining participants were in the community at the 6-month session.

Table 4

Administration time of AM-PAC by treatment group

Mean (SD)	Total (n=222)	IRH (n=66)	SNF(n=29)	HH/OP (n=48)	Home, no PAC Treatment (n=79)
Administration Time (minutes)					
Acute Care Session	8.9 (4.36)	8.7 (5.34)	9.4 (4.97)	9.6 (3.74)	8.6 (3.51)
6 Months Session	7.4 (3.11)	7.1 (3.26)	7.7 (2.34)	7.7 (4.00)	7.2 (2.59)
Items Administered Per Session					
Acute Care Session	27.8 (1.97)	27.4 (1.80)	27.5 (1.79)	27.4 (2.12)	28.3 (1.97)
6 Months Session	26.8 (3.18)	25.2 (3.12)	26.5 (2.91)	26.8 (3.51)	28.3 (2.36)

¹ HH=Home health
² OP=Out patient
³ IRH=Inpatient rehabilitation facility
⁴ SNF=Skilled nursing facility
⁵ Proportions may not add to 100% due to rounding