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Full Length Research Paper

Integrating a web-based, patient-administered assessment into primary care for HIV-infected adults

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Providers routinely under diagnose at risk behaviors and outcomes, including depression, suicidal ideation, substance abuse, and poor medication adherence. To address this, we developed a web-based, self-administered patient-reported assessment tool and integrated it into routine primary care for HIV-infected adults. Printed results were delivered to providers and social workers immediately prior to patient appointments. The assessment included brief, validated instruments measuring clinically relevant domains including depression, substance use, medication adherence, and HIV transmission risk behaviors. Utilizing the Institute for Healthcare Improvement's Plan-Do-Study-Act (PDSA) approach to quality improvement, we addressed issues with clinic flow, technology, scheduling, and delivery of assessment results with the support of all levels of clinic staff. We found web-based patient-reported assessments to be a feasible tool that can be integrated into a busy multi-provider HIV primary care clinic. These assessments may improve provider recognition of key patient behaviors and outcomes. Critical factors for successful integration of such assessments into clinical care include: strong top-level support from clinic management, provider understanding of patient-reported assessments as a valuable clinical tool, tailoring the assessment to meet provider needs, communication among clinic staff to address flow issues, timeliness of delivery, and sound technological resources.

Key words: Patient-reported outcomes, quality improvement, HIV-infection, patient-provider communication, plan-do-study-act (PDSA) cycle.

INTRODUCTION

Busy HIV care clinicians may underestimate the severity of clinically relevant issues, such as depression and suicidal ideation (Fredericksen et al., 2011; Lowe et al., 2003; Staab et al., 2001), substance use (Conigliaro et al., 2003; Hawkins et al., 2007; Messiah et al., 2001), and adherence to medication regimens (Bangsberg et al., 2001; Gross et al., 2002; Paterson et al., 2000). Providers may also underestimate the clinical importance of these issues, probing in a superficial or inefficient manner (Marvel et al., 1999). Several provider- and patient-related factors may contribute to the failure to address these issues. Providers may find it difficult to fully assess patients presenting with a large number of symptoms and/or adverse health behaviors, given time constraints (Ostbye et al., 2005; Yarnall et al., 2003).

Patients may also contribute to these communication gaps by not prioritizing important topics for discussion (White et al., 1994) or simply forgetting to bring up issues altogether. Social desirability bias may cause patients to

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underreport behaviors or symptoms they think will reduce their providers' opinions of them such as sexual risk behavior or substance abuse (Kissinger et al., 1999). Additionally, patients may lack language skills to accurately convey their feelings or symptoms (Williams et al., 2002). Linguistic and cultural barriers may further inhibit open, effective communication (Narayan, 2010).

To bridge these communication gaps, investigators have developed a variety of patient-reported measures, often also referred to in the medical literature as patient-reported outcomes. A patient-reported measure (PRM) is generated directly from patients and describes their symptoms, behaviors, or function or feelings in relation to a health condition and its treatment (U.S. Department of Health and Human Services, 2006). Collecting PRMs has many benefits for clinical care including increased focus on patient concerns (Fung and Hays, 2008; Noel et al., 2005), enhanced detection and management of conditions and treatments (Dobscha et al., 2001; Marshall et al., 2006; Valderas et al., 2008), greater satisfaction with care (Wasson et al., 1999), and improved patient-provider communication (Brown et al., 2001; Detmar et al., 2002; Taenzer et al., 2000; Velikova et al., 2004). These benefits may be particularly advantageous for HIV-infected patients who must often manage symptoms from multiple medical conditions in the setting of complex psychosocial issues, and increased rates of maladaptive health behaviors. PRM assessments that are well integrated into routine clinical care with real time feedback of results to providers incorporate several aspects of Chronic Care and Patient-Centered Medical Home Models, including clinical information systems, delivery system design, and decision support (Bodenheimer et al., 2002; Wagner, 1998; Wagner et al., 2001a; Wagner et al., 1996).

Historically, while the integration of PRMs into clinical care has increased detection of patient problems (Greenhalgh and Meadows, 1999), it has demonstrated only minimal impact on patient outcomes (Valderas et al., 2008). A number of reasons have likely contributed to the underwhelming impact of PRMs in clinical care in the past. First, PRM collection efforts to date have often been research-driven, rather than clinician-driven (Valderas et al., 2008), with a focus on domains that may be difficult to address in the setting of clinical care, and which may have led to low clinician utilization of PRMs. To remedy this, in the development of the PRM assessment for this study, we met with key informants among clinic leadership in order to choose domains valued and clinically relevant to clinicians and patients. We developed and modified a web-based assessment of clinically relevant PRMs that are self-administered on-site by HIV-infected patients prior to primary care visits. This electronic assessment is printed and delivered to providers in "real time", immediately prior to the visit.

Recent technological advances may help overcome some of the factors that have likely contributed to the minimal impact of PRMs on clinical outcomes in the past as well as the limited feasibility for routine administration in some clinical care settings. Touch-screen technology can facilitate data collection by decreasing staff burden for scoring and data-entry and allowing results to be immediately available for use by providers to improve care. Electronic collection allows patients to feel more at ease reporting socially undesirable behaviors reducing social desirability bias (Kissinger et al., 1999). The inclusion of skip patterns dramatically reduces patient burden and allows easier integration into busy clinics. Patient information can be immediately scored, displayed, and printed for use in clinical care in real-time.

This paper describes the design of our PRM assessment and its successful implementation and integration into routine primary care in a large, multi-disciplinary HIV outpatient clinic.

MATERIALS AND METHODS

Setting

The UW HIV clinic is the largest single provider of medical care to HIV-infected individuals in the northwestern U.S. It is staffed by 49 physicians, 10 fellows and 4 psychiatrists; 3 part-time ANRPs, 6 RNs, 1 LPN, 2 medical assistants, 15 social workers, a health educator, and a half-time dietician. Many of the physicians including the fellows are in clinic one half day per week. The HIV clinic provides primary continuity care, on-site specialty care, social case management, and pharmacy services; it also coordinates inpatient, home health, and residential care for individuals from diverse demographic and socioeconomic backgrounds regardless of their ability to pay.

System

We used a web-based survey software application, developed for PRMs (Crane et al., 2007). Patients used tablet PCs with touch screens to answer questions displayed in large, easy to read type, with clearly labeled radio buttons to indicate responses. Automated skip patterns are incorporated into the programming. For example, if a patient indicates never having used marijuana, related follow-up questions such as the frequency of marijuana use in the last 3 months are skipped.

Instruments

We considered instrument validity, reliability, responsiveness, efficiency (in terms of patient burden), and interpretability when choosing specific instruments (Scientific Advisory Committee of the Medical Outcomes Trust, 2002). The number of questions in the assessment ranged between 43 and 99 depending on patient responses and skip patterns. Patients could choose not to answer any question. After patients completed the assessment, a provider feedback form (Figure 1) summarizing patient responses was automatically printed and delivered to the appropriate provider before the clinic visit. Not shown, but included in the provider feedback form, are results from a symptom inventory printed on the reverse of the form, and a list of clinic-specific resources to address problems identified by the assessment.

The current version of the assessment includes the following

Patient-Based Measures Provider Feedback

Name:
Date Completed:

Instrument	Interpretation
PHQ-9 Overall depression score last 2 weeks	
23	Severe depression (20-27)
PHQ-9 Suicidal ideation score last 2 weeks	
4	Nearly every day
Substance use within last 3 months	
Cocaine/Crack	
Amphetamines	
Marijuana	
Tobacco use: Currently	
Less than half a pack a day	
Alcohol Score (AUDIT-C)	
0	Not at-risk alcohol consumption (<5)
Antiretroviral adherence	
Adherence in the past 4 weeks	Very good
Last missed	Within the last week
High risk behavior-last 6 months	
Anal sex condom use: Never	
Vaginal sex condom use: had vaginal sex with 0 people in the last 6 months	
Sharing needles or injection equipment: A few times or less	

Figure 1. PRM feedback format.

instruments:

1. Depression and anxiety: 9-item depression and 5-item anxiety instruments from the Patient-Health Questionnaire (PHQ) from the Primary Care Evaluation of Mental Disorders (PRIME-MD) (Kroenke et al., 2001; Spitzer et al., 1999).
2. Antiretroviral medication adherence: 4-item Adult AIDS Clinical Trial Group (AACTG) instrument (Chesney et al., 2000), a rating scale item (Lu et al., 2008), and a visual analogue scale item (Giordano et al., 2004; Kalichman et al., 2005; Walsh et al., 2002).
3. Detailed tobacco use history and pack-years of tobacco exposure.
4. Alcohol use: Alcohol Use Disorders Identification consumption questions (AUDIT-C) (Bradley et al., 2003; Bush et al., 1998).
5. Drug use: Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST); patients are also asked items about injection drug use and drug/alcohol treatment (Newcombe et al., 2005; WHO ASSIST Working Group, 2002).
6. HIV transmission risk behaviors: HIV Risk Assessment for Positives (HRAP).
7. Symptoms: HIV Symptom Index which addresses presence and impact of HIV-related symptoms (Justice et al., 2001).

Pilot study of discrepancies between PRMs and same-day provider documentation

We reviewed HIV provider clinic notes from the same day patients completed the PRM assessment for patients identified as at-risk from the clinical assessment. We completed this study before we implemented feedback of PRM results to providers to assess the need, if any, for the PRM feedback results. At-risk patients were those reporting severe depression (defined as PHQ-9 scores ≥20), moderately severe depression (defined as PHQ-9 scores ≥10), current substance use (use of illicit drugs excluding marijuana in the prior 3 months), or very poor adherence (missing multiple doses of their antiretroviral medications in the prior 4 days). We determined whether at-risk behaviors or symptoms (depression, current substance use, inadequate adherence) were identified by the provider and if it was addressed by any related actions initiated by the provider based on the provider documentation for that day. All medical record reviews were performed by a chart reviewer blinded to the primary goals of the study. This study was approved by the University of Washington Human Subjects Division.

Clinical assessment design and implementation methods

We formatively evaluated initial assessment data and implementation experience with a focus on clinical improvement. We used the Breakthrough Series of the Institute for Healthcare Improvement (IHI) framework to guide our work, which makes extensive use of plan-do-study-act (PDSA) cycles. In this framework, small amounts of data collection are used to inform iterative and incremental systematic change to both the design of the intervention and its implementation (Kilo, 1998; Wagner et al., 2001b), including

domain selection, integrating PRMs into clinic flow, the need for PRM feedback to providers, and ongoing check-ins to assess provider satisfaction.

RESULTS

Pilot phase

The PRM assessment was first introduced in September 2005 as a computer-based survey for research purposes. Informed consent was sought from patients by a part-time research assistant. Patients were invited to complete the assessment in a private area of the clinic waiting room without compensation. Patients were informed that their responses would be anonymous and confidential, except in the event of reports of intent to self-harm, which triggered pagers alerting appropriate clinic staff. During this early research and evaluation stage of implementation, providers did not receive PRM feedback results. Two portable computer tablets were used, allowing two patients to take the survey simultaneously. Depending on patient responses, the clinical assessment took patients a median of 6 min 12 s (inter-quartile range (IQR) 4 min 49 s to 7 m 42 s). However, over time, the assessment proved to be a useful platform for both clinical research studies as well as other clinically relevant data collection. Additional items were rotated into the assessment, resulting in increased median completion times, typically between 7 and 10 min, depending on current instrument lists.

We reviewed provider chart documentation from the same day patients completed the PRM assessment and found remarkable discrepancies between PRMs and provider documentation. Among the first 300 patients completing the assessment, a chart review of the 20 patients reporting severe depression symptoms on the assessment revealed no mention of depression by providers for 9 of these patients (45%). Of the 11 of 20 visits (55%) where depression was acknowledged, only 7 of the 20 (35%) had it addressed in any way (medication initiated, dose increased, psychiatry or case worker referral, etc.). Among the 68 patients who reported current use of illicit drugs (excluding marijuana), providers either failed to document the issue altogether or of even greater concern reported no substance use for 31 (46%) patients. Providers documented addressing substance abuse in any way (including even a discussion encouraging a patient not use) for only 22 of 68 patients reporting current substance use (32%).

Among the initial 300 patients who completed the assessment, 238 were currently receiving antiretroviral medications, of which 62 self-reported very poor adherence (missing multiple doses of their antiretroviral medications in the prior 4 days). Of these, providers documented inadequate adherence for only 17 (27%), did not comment on adherence for 25 (40%) patients, and, most concerning of all, reported good adherence (examples included “missed no doses,” “>95% adherence,” and “perfect adherence”) for 20 (32%) of these patients. Furthermore, among the 17 patients for whom the provider did acknowledge poor adherence, 5 of 17 (29%) had moderate to severe depression that was not acknowledged, 4 of 17 (24%) had current substance abuse that was not acknowledged,and 2 of the patients [12%] had both unacknowledged depression and substance abuse disorders.

Implementation of expanded PRM assessment

We presented findings of missed depression, substance use, or inadequate adherence by providers to our clinic providers, staff, medical director, and heads of nursing and program operations, who therefore supported the implementation and expansion of the PRM assessment from a small research study into standard clinic practice with PRM results delivered to providers prior to clinic visits. This top-level support was key to the successful integration of the assessment into the “care” model in several ways. First, clinic management supported the creation of eight 15 min time slots per hour for the assessment prior to patient appointments by modifying the clinic’s existing electronic clinic visit scheduling framework. Second, clinic management furnished a work station for the PRM assessment coordinator near the nursing triage desk. This physical proximity proved essential to facilitate fluid communication with clinic staff regarding which patients were checking in, their whereabouts, and the feasibility of administering the assessment given patients’ arrival times and scheduled appointment times. Third, nurses were familiarized with the content and purpose of the assessment, and were instructed to regard it as another “vital sign”, a required element to be completed prior to provider visits. Fourth, clinic staff supported the placement of tablets into examination rooms.

Next steps included the purchase of 2 additional PC tablets, bringing the total to 4, and patients who were eligible to complete the assessment at their next visit were given an appointment time 15 min prior to the scheduled provider appointment. Consenting patients were informed that their responses would be reviewed by their provider as possible points for discussion during the visit, and were given the option of refusing the assessment.

The Head of Nursing, Assistant Director of Support Services, and PRM assessment coordinators met formally several times during the first two weeks and communicated informally throughout the day to troubleshoot flow issues. As flow improved, we expanded the number of appointment time slots from 2 to 4 per 15 min period, totaling sixteen 15 min time slots per hour. We also purchased 7 additional tablets, bringing the total to 11, to accommodate simultaneous administration of

assessments in all ten examination rooms, with one in reserve in case of technical problems. Tablets were locked to patient chairs, and removed twice daily for battery recharging, cleaning, maintenance, and evening storage. We decreased eligibility intervals from 6 months to 75 days, to target assessment completion on average at least every 4 to 6 months. To meet the needs of the clinic's large Spanish-speaking population, the assessment was translated into Spanish, giving patients the option of self-administering the assessment in Spanish or English. We hired an additional half-time research assistant to help administer the assessment to the increased number of patients. Staff time for overseeing assessment administration consisted of the equivalent of one full-time position.

Current assessment administration

After several PDSA cycles, we arrived at an optimized system for integrating the assessment into patient flow: 1) Patients check-in with front desk staff upon arrival in the clinic. 2) Nurses and medical assistants then obtain vital signs and alert a PRM assessment coordinator to administer the assessment. 3) The coordinator asks the patient to complete the assessment using a computer tablet. 4) If patients are unable to complete the assessment due to cognitive impairment or language issues, it is deferred and/or the patient's name is added to a list of those not to be scheduled for the assessment in the future. 5) Each patient's progress toward completion is viewable as "progress bars" on a secure website from a desktop computer monitored by the PRM coordinator, and 6) upon completion, coordinators alert the triage nurse that the patient is ready to see the provider, and hand-deliver the printed assessment feedback form to the patient's primary care provider and their designated social worker.

The PRM assessment has now been integrated into clinical care. The assessment has been completed 3,583 times by 1,475 unique patients (for demographic profile; Table 1), with nearly two-thirds of these assessments completed since integrating the instrument into routine clinical care in January 2009. Since then, the assessment has been completed by an average of 97 patients per month, with an extremely low patient refusal rate (1%, n=36). The most commonly stated reason for refusal is feeling too ill. In 97% of instances, the feedback report has been successfully delivered to the primary physician at the time of patient visits.

DISCUSSION

We found that a PRM assessment could identify a substantial proportion of HIV-infected patients with depression, adherence, and substance use that was not detected by providers. We have demonstrated that a clinically relevant PRM assessment can be successfully integrated into routine primary care in a large, multi-disciplinary HIV outpatient clinic.

The results of the pilot study of discrepancies between PRM results and provider documentation demonstrate how poor providers are at identifying and addressing substance use and depression and particularly at estimating patient adherence, as has been documented previously (Bangsberg et al., 2001; Conigliaro et al., 2003; Gross et al., 2002; Haubrich et al., 1999; Lowe et al., 2003; Messiah et al., 2001; Paterson et al., 2000; Staab et al., 2001; Starace et al., 2002). These findings suggest that provider feedback may benefit 83% of patients with inadequate adherence (40% in whom the provider does not acknowledge adherence, 32% in whom the provider mistakenly thinks adherence is excellent, and 11% in whom inadequate adherence is acknowledged but concurrent depression and substance use are not). During the implementation process, we addressed several challenges:

Determining patient eligibility

Determining which patients should be asked to complete an assessment prior to any particular clinic appointment required knowing the date of the last assessment, or if they were ineligible due to a language barrier, cognitive impairment or a prior refusal. Several separate lists of ineligible patients had to be cross-referenced and updated daily: one list of patients who spoke languages other than English or Spanish, another list of patients who had taken the assessment within the window period (currently 75 days), and a "do not approach" list of patients who had permanently refused the assessment or were severely cognitively impaired. We addressed this obstacle by training PRM coordinators to operate the appointment-scheduling program, using duplication elimination software to cross-reference and merge eligibility lists, and by consolidating information into the assessment database. These steps have relieved front desk staff from the burden of determining eligibility and scheduling patients for the assessment.

Encroachment onto provider appointment time

To accommodate the varying time periods needed to complete the assessment and to avoid encroaching on provider appointment times, several adjustments in scheduling were made. 1) We expanded the time slots scheduled for completion of the assessment to 20 min. 2) We developed a protocol to forego the assessment when patients arrived to the clinic more than 10 minutes late for their scheduled time with the assessment. 3) To take advantage of the occasions when providers run late,

Table 1. Demographic and clinical characteristics of patients who completed the PRM (N=1475, unless otherwise noted).

Characteristic	N	%
Sex		
Male	1252	85
Female	223	15
Race		
White	875	59
Black	310	21
Hispanic	183	13
Other/Unknown	107	7
Age (years)		
<30	122	8
30-39	305	21
40-49	660	45
≥ 50	338	26
Risk factor for HIV transmission		
Male sex-with-male	809	55
Injection drug use	381	26
Heterosexual	280	19
Other/unknown	5	<1
CD4$^+$ cell count nadir (cells/mm^3)		
≤350	1193	81
351-500	279	12
≥501	103	7
Currently receiving HAART		
Yes	1137	78
No	338	22
Depression (PHQ-9 score) (N=1406)		
None (≤ 4)	613	44
Mild (5-9)	345	25
Moderate (10-19)	354	25
Severe (≥ 20)	94	7
Current substance use (prior 3 months)		
Cocaine/crack	171	12
Amphetamine/speed	187	13
Opiates/heroin	50	3
Marijuana	437	30
At-risk alcohol use (N=1416)		
Yes	399	28
No	1017	72

Table 1. Contd.

Smoking status		
Never	453	31
Prior	381	26
Current	641	43

PRM coordinators confer with the triage nurse to determine whether to administer to late-arriving patients.

Clinic staff routinely tracks patient flow through the clinic on a dry-erase white board that lists patient name, room, provider name, appointment time, and whether and when the provider has been notified that the patient is ready to be seen. The triage nurse is stationed near the board and is continually apprised of updates. Constant, brief verbal communication between clinic staff and PRM coordinators help coordinators to know when patients may be available to complete an assessment. These carefully planned and modified steps minimize impact upon provider appointment time, staff time, and interruptions to patient flow.

Varying relevance across provider types

An independent qualitative evaluation and observational workflow study conducted among UW Madison Clinic providers as part of the PDSA process found PRMs to be very useful in clinical practice (Tufano et al., 2010). However, clinic psychiatrists found the assessment to be less useful for their purposes. Psychiatrists cited the reasons for this were the lack of depth for the depression and anxiety PRM screening instruments, and lack of relevance of other assessment domains to their practice. In contrast, shortly after integration, social workers/case managers expressed strong interest in receiving the PRM assessment feedback report. Social workers receive feedback reports for patients deemed "high risk", meaning any indication of suicidal ideation or moderate-to-severe depression symptoms; anything less than perfect adherence to HIV medication regimens in the past month; current substance abuse of any type or frequency; and at-risk sexual behavior. Since 6/2009, the platform has been programmed to automatically print a second copy of the feedback report to be delivered to the social worker if any of the at-risk criteria are met. Since then, over two-thirds of administered assessments have identified at least one at-risk behavior or symptom. The feedback report has been successfully delivered to a social worker in every one of these instances.

Language barriers

At present, the assessment is administered exclusively to English and Spanish speakers. Future plans include translating the assessment into additional languages. In our clinic, common languages besides English and Spanish include Vietnamese, French, Amharic, and Somali.

Generalizability

The generalizability of these findings is limited to patients that are willing and able to self-administer the PRM assessment, and to patients able to arrive at their scheduled appointment times. This limitation may exclude patients with ongoing or severe medical, cognitive, psychiatric, or social issues. However, even among patients who often arrive late, they frequently still complete the assessment if their provider is also running behind schedule. The generalizability of these findings may also be limited to clinic settings with sufficient infrastructure and commitment to support PRM administration and delivery.

Future steps

Several next steps have been planned or are in progress as we continue to employ PDSA cycles to improve our patient care. Right after implementation, an independent evaluation of the PRM assessment's integration and utility, consisting of an observational workflow study and provider, staff, and patient interviews, overwhelmingly indicated that the PRM assessment is well-accepted by patients, valued by providers, and minimally disruptive to clinic flow (Tufano et al., 2010). Now that it has been established longer, we are formally re-assessing patient and provider satisfaction with the assessment, and seeking provider input to iteratively improve the utility of the feedback report. In addition, we will evaluate the impact of PRM assessment integration on provider behaviors and clinical outcomes for the domains of adherence, depression, substance use, and HIV transmission risk behavior. We have added other domains to the assessment and plan to introduce new domains, including cognitive functioning in the future.

To date, the PRM assessment has been static; its only variation between patients has been accomplished by differences in skip patterns. In order to tailor the assessment to more closely reflect the needs of individual patients, we are extending the features of the web-based survey software to incorporate computerized

adaptive testing (CAT), which uses prior patient responses to facilitate precise measurement of a domain while minimizing patient burden (Cella et al., 2007; Gershon, 2005; Revicki and Cella., 1997). In addition, we are exploring other ways of refining PRM collection for example; alternating certain domains at each visit, such as body morphology and cognitive functioning, so that relatively stable domains are assessed with appropriate frequency and patient burden is minimized.

Conclusions

Integrating web-based point-of-care PRM assessments into primary care for HIV-infected patients is feasible. This methodology is especially useful for identifying conditions and risk behaviors that often are under-reported or under-assessed. Key features facilitating successful implementation included careful selection of domains deemed clinically useful by patients and providers, top-level support from clinic management, early involvement in the planning process across diverse provider types to ensure buy-in, careful planning of the roll-out with opportunities for modifications, strong moment-to-moment communication between clinic staff and PRM assessment coordinators, timeliness of feedback report delivery, and sound technological resources. PDSA cycles inspired by the IHI Breakthrough Series provided a useful tool to facilitate successful initial steps toward routine PRM collection and reporting in our clinic. As the implementation of patient-centered medical home models evolve, integrating routine, real-time PRM assessment into outpatient care has great potential to improve the quality of care for HIV-infected patients, as well as other clinic populations.

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