Encouragement of Patient Self-management and Adherence through Use of a Computerized Tracking System for Cervical and Colon Cancer Screening

Despite high rates of Papanicolaou smear (Pap) screening in the United States (more than 90%), nonadherence to follow-up recommendations is common, ranging from below 10% to more than 40%.[1–3] Ensuring completion of appropriate follow-up of abnormal Paps can be a significant clinical challenge, especially in medically underserved populations.[4,5] For colon cancer, screening rates are much lower and unfortunately management of abnormals varies.[6,7] Tracking systems designed to ensure regular screening and acceptable follow-up should improve both patient and provider adherence.[7,8] We designed a computerized follow-up tracking system for testing done in an urban community health center that serves mainly low-income minorities. In this study, we present our results and important lessons learned in over 6 years of its use. Data reported here provide a comparative numerical reference for others in primary care who, in their clinical practice, may implement recommendations given in medical literature.

Database Structure and Workflow

We developed a Microsoft Access database to track and enhance follow-up of numerous laboratory and pathology tests. We used this database mainly to track Paps and fecal occult blood tests (FOBTs). It served as our "registry" for the Bureau of Primary Health Care National Health Disparities Collaborative in which we have participated since 2002.[9] The database keeps track of laboratory and pathology results, produces letters to patients informing them of their results (whether normal or abnormal), and sends appointment reminder and recall letters as an efficient way to encourage patients to follow good health maintenance schedules.[7] It serves as the center of case management.

Our workflow is as follows. The laboratory technicians assure that all test specimens sent out lead to an actual formal report. They keep a copy of each requisition until the report comes back. Data enters the database directly by appropriate automated interfaces, or the coordinating nurse enters them. This nurse follows our institution's protocols to decide what follow-up is needed in each case, consulting the patient's provider when necessary. A positive FOBT requires colonoscopy. For Paps, we receive reports under the Bethesda system,[10] and then use standard algorithms for follow-up.[11] The nurse then has the database print out the appropriate letters for mailing. Whenever we use the database to generate a batch of letters, the built-in programming automatically selects the appropriate cases for each type of letter. This removes the need for any manual review or manual selection of cases for letters. A copy of every letter goes into the patient's medical record.

In addition to helping us notify patients of their results and recommended follow-up, the database also facilitates quality management. Using programmed macros, we can print provider-specific lists and clinic statistics to show trends in testing and follow-up for the entire clinic, and to identify potential problems within the clinic or larger system (for example, no-shows, or cases without a referral appointment). We can also identify problems outside the clinic (eg, we detected an inability to get follow-up diagnostic testing done in a timely fashion for positive FOBTs, and that step is now much easier).

Our successive letters go out, even if people never or only periodically come to our clinic—these people are at highest risk for poor outcomes.[12,13] For coordination, all our comments and ongoing decision-making notes appear together in the memo section of each case's database form, rather than spread through a medical record, or not existing at all. We can print them for the chart at any time.

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Table 1. Patient Adherence to Pap Follow-up Recommendations

	2003	2004	2005
Colposcopy completed within 1 year:			
All ages: n/N (%)	79/112 (71%)	44/70 (63%)	62/111 (56%)
Age ≥21: n/N (%)	69/94 (73%)	38/63 (60%)	57/99 (57%)
Age <21: n/N (%)	10/18 (56%)	6/7 (86%)	5/12 (42%)
Colposcopy completed within 90 days:			
All ages: n/N (%)	51/112 (46%)	32/70 (46%)	39/111 (35%)
Age ≥21: n/N (%)	44/94 (47%)	26/63 (41%)	36/99 (36%)
Age <21: n/N (%)	7/18 (39%)	6/7 (86%)	3/12 (25%)
Gynecological treatment of CIN II-III:			
Ever completed: n/N (%)	6/12 (50%)	2/5 (40%)	0/0*
Completed within 90 Days: n/N (%)	4/12 (33%)	1/5 (20%)	0/0*
Cases seemingly lost to follow-up:			
Cases within the 1 calendar year: n/N (%)	491/3551 (14%)	478/5072 (9%)	570/6161 (9%)
Since October 1999, of nonpurged cases (in 50-, 62-, and 74-month periods respectively): n/N (%)	569/3551 (16%)	948/5072 (19%)	1376/6161 (22%)
Completion of a follow-up Pap or a colposcopy within subsequent 3 years:			
All patients included, no exclusions: n/N (%)	Unavailable†	173/203 (85%)	570/625 (91%)
Excluding patients verified lost‡ from DH's Community Health-FQHC system: n/N (%)	Unavailable†	173/175 (99%)	570/576 (99%)

*We first had HPV high-risk reflex testing available to us in March 2005.
†Unavailable under our older database versions.
‡Patients considered "lost" are those not seen anywhere in Denver Health's Hospital and Clinic system after the date targeted for their follow-up.

Clinical Outcomes

We reviewed the number of Paps and FOBTs done in our clinic and the number of abnormal results for 3 calendar years (2003 to 2005). Nearly all patients (98%, 98%, 100%) got notification of FOBT results within 30 days, but fewer (65% to 74%) received Papanicolaou test results within 30 days because of reporting delays (data not shown).

We did 1152 to 1583 screening tests annually on 982 to 1389 patients per year (including 132 to 331 eligible patients getting an FOBT each calendar year). A total of 2082 women had at least 1 Papanicolaou test in 3 years. Approximately 10% of Paps needed colposcopy per protocol,[11,14] resulting in 12, 5, and then zero CIN II-III cases per year—the zero being in 2005, when we started doing reflex HPV testing. We found 2 cervical cancers.

Table 1 shows patient adherence to recommended Papanicolaou follow-up. Adherence rates for rescreening were better than those for follow-up of abnormals. However, many of the colposcopy candidates elected a follow-up Papanicolaou test instead, leading to actual follow-through rates of 85% (2004) to 91% (2005). Excluding patients totally lost to our entire multiple clinic system, we achieved 99% ultimate completion rates both years. In an independent HPV study on a small subpopulation (266 cases) from these same patients, over the same 3 years, we found high-risk HPV in 19% (51 cases), of which 35% (18) had a squamous intraepithelial lesion (SIL) on Papanicolaou. Five percent of all Paps had atypia, and 17% (2) of these atypias showed high-risk HPV. However, for the 28 Paps with SIL, 68% (19) had high-risk HPV.

Looking at our FOBTs, we now have a cumulative total of 76 positives. After we got easier and more rapid access to colonoscopy services, our colonoscopy completion rate increased from 42% to 65%. We found 2 cancers (4% of colonoscopies). Although our measured rate of positive FOBTs (13% to 14%) remains above expectations,[15] only 9% of colonoscopies have been entirely normal, whereas 77% have shown some type of polypoid lesion (2 with dysplasia).

Discussion

We learned many lessons about optimizing the design and management of follow-up tracking sys-

tems for screening. Any tracking database should be designed to import as much information as possible from labs, electronic medical records, and scheduling systems. This automation reduces the need for staff time, which is important because lack of dedicated personnel can contribute to the failure of many customer relationship management applications, including those with reminder systems.[16]

After showing advanced lesions on Papanicolaou smear, we had many women fail numerous appointments for colposcopic procedures. We ultimately got only repeat Paps on many of them. Although this does not meet national recommendations,[11,14] most lesions regressed. For both Paps and FOBTs, the test sensitivity is such that that the power of screening is achieved only after years of serial testing.[13,15,17] Once positive, Paps with low-grade and high-grade SIL progress at rates of 0.15% and 1.44% (respectively) to invasive cervical cancer at 2 years after the Papanicolaou.[18] Given all this, there is divergence of expert opinion on management.[14,17,19] Getting a follow-up completed is the major task. Patient involvement and patient self-management represent personalized care,[17] and may prevail. The largest risks are in never- or rarely screened people, and in the patients whose positives are not followed at all.[8,17] Our approach is to persist until we have some testing and follow-up done, even if what we get is not the optimal choice in everyone's view. In some cases, the best goal may be simply getting done what testing and serial follow-up we can achieve without losing the patient.

Conclusions

Our patients attached a surprising significance to our letters. Patient adherence to recommendations was slow but usually eventually occurred. We feel that our continued efforts to remind our high-risk patients saved many lives and sidelined much morbidity. A reminder system, such as the one we developed, can be accepted, sustainable, and successful in both therapeutic and screening programs. It will be more successful if it functions automatically. It can remind patients (and providers alike) of what needs to be done and when. We remember, though, that there will always be a manual component to medicine. There is no way to program for every possible eventuality. For these additional situations, the more sophisticated checking and prompting the program does, the better. However, as a minimum, such programs should proceed on their own if dedicated time somehow escapes clinic staff, even if they send unnecessary reminders. Those letters still serve an educational purpose.

(Note: Our complete report, with more specific information on our database itself, is available from GWB.)

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