The Whatcom County Experience: A Patient-centered System

by Mary Minniti

"Never doubt a small group of committed citizens can change the world. In fact, it is the only thing that ever has."
Margaret Mead

"We must be the change we wish to see..."
Gandhi

Without much effort, you can find many articles highlighting the challenges in the current state of healthcare delivery in America from the New York Times to the New England Journal of Medicine (NEJM). Numerous studies have cited the high cost, poor quality and lack of access to basic healthcare for many citizens. In the June 2003 NEJM, a study by Elizabeth A. McGlynn, PhD, Associate Director of RAND Health, reported that the quality of care varied substantially across medical conditions. For instance, patients with alcohol dependence received recommended care only 11 percent of the time while older patients with cataracts received the recommended care 79 percent of the time. Overall, people seeking care from their doctor's office received recommended care for common conditions only 50 percent of the time. More startling was that underuse of care was greater than overuse—according to the study, patients failed to receive recommended care 46 percent of the time. Eleven percent of the time, patients in the study received care that was not recommended and potentially harmful.

Chronic conditions, like asthma, diabetes, and heart failure, are a huge and growing problem and are the leading cause of illness, disability, and death. Chronic illness is responsible for at least 70 percent of all healthcare expenditures in the United States and is expected to impact 157 million people by 2020.

All of us will be impacted, directly or indirectly, by one or all of these statistics. Many policy makers and healthcare professionals debate about what can be done. A small project in Whatcom County, Washington may have found some answers by organizing as a community.

Whatcom County

Whatcom County is a fairly typical Pacific Northwest, semi-rural county of 170,000 residents 90 miles north of Seattle on Interstate 5, close to the US/Canadian border. It has a community hospital, independent physicians' practices, and a nonprofit community health center providing care to the underserved.

In 1996, local healthcare stakeholders formed a coalition called the Community Health Improvement Consortium (CHIC). Currently, it comprises the large organized medical groups, public health department, hospital, major local payors, and a representative from the City of Bellingham. CHIC's mission is to improve healthcare outcomes in the community by working on problems that require cooperation, have high clinical impact, and are measurable. Its members have worked on clinical improvement projects like tobacco cessation, diabetes management, and immunizations.

CHIC was formed because these healthcare professionals perceived that only working in the silos of individual organizations would fail to produce system-wide changes in clinical outcomes.

St. Joseph Hospital, one of 5 hospitals in the PeaceHealth system, and Whatcom Northwest Medical Bureau, a local payor, provided start-up funding to create HInet, a Regional Health Information Organization (RHIO). HInet provided electronic connectivity between the physicians, hospital and payors in the county. It also provided each site with a computer and a secured intranet highway facilitating the flow of health information and communication among participants. With the capacity of email, access to lab results, the Worldwide Web, payor information, and clinical information in the hospital's electronic medical record, this RHIO has been self-supporting since 1999. Plans are underway to expand the connectivity to ancillary providers, including nursing homes and pharmacies.

In 2001, St. Joseph Hospital, on behalf of CHIC, was one of 12 recipients among 326 applicants to receive a small planning grant ($50,000) from the Robert Wood Johnson Foundation (RWJF). RWJF was seeking organizations that would propose effective ways to transform the system of care with the intent of improving all aspects of healthcare delivery. The 12 recipients produced grant applications that, if successful, would implement their innovations as part of a $20.9 million RJWF campaign called Pursuing Perfection.

So—inspired primarily by patients—two new innovative concepts emerged from the early design stages of the project.

The Robert Wood Johnson Foundation's challenge to Whatcom County and other planning grant

The Cost of Buying into Reform

One stakeholder in Whatcom County, a large multi-specialty practice providing primary care services to over 40 percent of patients, chose not to participate in the initial implementation of the Pursuing Perfection Program. While they agreed with the vision of the program and the need for change in managing both heart disease and diabetes, they cited economic short-term concerns as their reason to decline participation. This was an important message for P2 leadership and the primary funder of the program, The Robert Wood Johnson Foundation, to hear.

The reluctance of a major stakeholder to participate was not taken as a statement about the futility of starting the transformation of services in Whatcom County. Rather, it was an important statement about the issues of payment realignment; short-term winners and losers in a system when an entire community adopts an effective chronic care management system—even when there are clear benefits to the community as whole. In this case, System Dynamics modeling by Jack Homer and Gary Hirsch confirmed that the initial investment in improved services fell on physicians who were not compensated by health insurance. Additionally, the hospital's reduced revenue could have a negative financial impact as charity care burdens on hospitals increased. Because the modeling showed that the initial economic beneficiaries were Medicare and the pharmaceutical industry, early and ongoing conversations have occurred with these stakeholders. Overall, modeling emphasized that investment in a community's capacity to create an effective chronic care management system is, in the long term, in the interest of stakeholders outside the community.

recipients was based upon recommendations from the Institute of Medicine's report "Crossing the Quality Chasm." The Foundation sought to identify organizations capable of building a system that achieved the six aims of the report. These aims were to create a patient-centered, equitable, efficient, timely, evidence-based, and safe system of care.

Listening to the Stakeholders

In response, healthcare stakeholders of Whatcom County formed a planning team to develop the ideas and methods by which to transform the care experience—with an eye for better clinical outcomes and lower costs. Diabetes and heart failure were identified as two areas of focus for the project.

In their first meeting, someone asked a critically important question: "When creating a patient-centered system, how could we proceed without patients at the table as equal partners?" Patients were invited as design partners to share how they lived daily with heart failure and diabetes. They gave a realistic picture of how often the current delivery system fell short of their needs. Patients, in turn, listened to the experiences of overburdened healthcare professionals who spent their time working in a system of misaligned incentives that created roadblocks to improving care.

All stakeholders in the group shared what they valued about healthcare and how best to achieve remarkably better outcomes. Together, we studied what was known as "best practices" in chronic care.

Three gaps in care were identified by patients and family members as critically important to achieve perfect care:

- Access to information
- Appropriate, cost-effective interventions that prevented hospitalization
- Timely communication between patients and the care team as changes occur

The Clinical Care Specialist

Frequently, patients with chronic conditions receive care from more than one physician, and often, each has different information about changes made in the patient's treatment and/or medications. Ways to address this problem did not emerge from the literature review of best practice.

➤So—inspired primarily by patients—two new innovative concepts emerged from the early design stages of the project. The first was a new job within the healthcare profession to be performed by a nurse or social worker—a navigator, guide, and coach for developing patient self-management skills and expediting access to care when it was needed. We called the new role a clinical care specialist (CCS). And we expected them to function more effectively and at a lower cost than a physician could.

Our patient-centered model aligned the CCS primarily with the patient, who received the services of a CCS regardless of economics, employment, or organizational affiliation. In other words, we organized care around the patient's needs rather than the needs of insurers, physician's offices, and other payment structures. Diabetes and heart-failure patients whose clinical outcomes were not being effectively addressed by the system were referred to the CCS by participating physicians. This partnership with traditional healthcare organizations continues to be critical to the project.

We also began to understand that patients experience a complex social and professional support system we called a "virtual care team." The professional and non-professional members of this team, who were often geographically dispersed, needed timely access to information from all sources to make effective decisions that promoted their patient's health and avoided unneeded and costly services.

The Shared Care Plan™: A Personal Health Record

The second innovative concept created by our collaboration with patients was The Shared Care Plan™ (SCP). Designed to be a personal health record, this web based communication and self-management tool was owned by patients and was shared seamlessly with their care team members.

Unlike a traditional, organization-specific, electronic medical record that is not generally accessible to patients or other care providers outside a particular organization, the web-based SCP allows key information—like current medications, allergies, diagnoses, self-management goals, and personal preferences—to be accessed by any person authorized by the patient, regardless of location. The virtual team can include family members, physicians, and others in professional roles that support the

patient's continuing care.

While electronic medical records are important to care delivery within an individual setting, they do not necessarily facilitate care across the continuum of a patient's support network or solve all problems patients described. In meetings, our patients kept reminding us that they lived in communities, not within one healthcare organization. Information flow across a community was a necessity for the future. In respect for patient preferences, both a paper SCP and a web-based SCP (HIPAA-compliant) were developed. As patients with their SCP in hand began to interact with their care team, the nature of the interactions began to change for the better. As one patient noted, "my doctor's appointment was more focused, and the quality of the visit improved." Universally, doctors who were unaware of the project, after having a SCP available during the patient's appointment, would comment they wished all their patients had a SCP.

The cost of these two innovations was less than the cost of the solutions originally imagined by the professional healthcare stakeholders. The cost of programming staff to design and build the web-based Shared Care Plan in the first year was less than $150,000. In contrast, the cost to implement an electronic medical record for a large primary care practice is often over a million dollars; the cost of connecting such systems of medical records across a community using interface technology can be prohibitive.

In addition to these innovations, we designed a blueprint for the transformation of healthcare delivery across organizational boundaries and within each participating organization. The blueprint included clinical redesign of chronic care services and ongoing organizational development to promote a team culture and transparency in clinics and hospital settings. These changes to infrastructure created a capacity to respond to any chronic condition and were not limited to our initial selection of heart failure or diabetes.

A leadership board composed of the chief executive officers of the participating organizations and patients was established. Their role was to guide and advocate for the changes proposed within their organizations as well as in the wider community. Having patients on design and implementation teams became the norm.

➤A web-based, electronic health record captured the imagination and interest of a diverse population in Whatcom County and beyond.

The P2 Application

Whatcom County CHIC was the only community in the nation to receive the prestigious RWJF Pursuing Perfection (P2) Grant. The other six grants were awarded to single organizations whose focus was on changes inside their own organizations. The $1.9 million P2 grant was supplemented with the in-kind and monetary support of the participating organizations. Implementation of the innovations designed for the P2 grant began in June 2002 with the hiring of staff to provide support to participating organizations.

Achievements and Learning: Improved Outcomes, Reduced Costs

The P2 program implementation has been underway for over 2 years in Whatcom County. As we hoped, the services of CCS have produced clinical improvements for patients. These patients are periodically assessed for physical function ability, health-related quality of life, and depression. Generally, many of these patients would have experienced declines in these measures. With the program, the majority of patients improved or maintained their physical functioning (59 percent) and health-related quality of life (65 percent). A majority (62 percent) experienced a decrease or maintained their level of depression. Of patients with CCS, 98.5 percent report their lives have improved since a CCS has been part of their care.

In addition to measuring improved functioning and patient satisfaction, we tracked costs saved or harm prevented because of CCS intervention, such as prevented or corrected medication errors, prevention of inappropriate emergency department visits, 911 calls, outpatient visits, and/or inpatient hospitalizations. The estimated one-year savings for the 69 patients was $349,000, or a net savings of approximately $3420 per patient.

➤From the beginning, the concept and the reality of a web-based, electronic health record captured the imagination and interest of a diverse population in Whatcom County and beyond. The use of the SCP, initially started with a small group, is now in use with over 650 patients.

A survey of these patients was completed in the winter of 2005. Most notably:

- 75% reported that having a SCP helped them use the healthcare system more effectively;
- 82% believed it helped them keep their healthcare information organized;
- 71% were more confident in interacting with the healthcare system;
- 74% reported the SCP helped in communication with their healthcare team;
- 73% believed they made more informed and better decisions regarding their health; and
- 71% felt more confident in their ability to problem solve unexpected healthcare changes.

Show Me the Money and the Uses of Modeling

The P2 cost of new care designs for improved clinical outcomes involved specific interventions in areas of personnel, electronic information systems, and healthcare costs. Clinical intervention components of the P2 program included screening and prevention education for diabetes, risk management for heart failure, and disease management for both conditions as well as self-management support. The costs of a transformational support team and the time needed from healthcare professionals to implement change were factored into the cost of healthcare delivery.
As we moved toward implementing the program, upfront costs were perceived as a major barrier to key stakeholders. There were real concerns about investing in infrastructure changes without expectations of economic benefit (please see the sidebar *Buying into the Costs of Reform*).

Systems Dynamics modelers Jack Homer and Gary Hirsch were hired to help the traditional stakeholders understand the true costs and benefits of delivering care more reliably and effectively in the current payment system. Could the physicians' practices afford to invest in the infrastructure changes required to transform improvements in chronic care? Who would the financial winners and losers be in the current compensation system of third-party payors—both private and Medicare?

The answer to these questions affected the long-term adoption of P2 interventions by all healthcare organizations. So, we performed an extensive analysis of historical financial and outcomes data for the

Implications for Oregon

Many people—doctors, caregivers, administrators, and patients—agree: Healthcare is in need of change. There exists a chasm between the quality of care possible and the actual day-to-day delivery of care. There are barriers to change, challenges in collaboration, and roadblocks to new and improved ways of working. Despite all this, many people across the country are actively engaged in the challenge of bridging the chasm.

In most cases, these efforts are narrow, bringing together similar organizations within disciplines or domains. Examples are hospitals that combine cardiovascular services and technology to better serve a specific group of patients. I believe the partnerships that cross organizational, discipline-specific, and professional boundaries are more likely to succeed.

There are local Oregon communities, similar to Whatcom County, who are seeking their own answers through conversations and coalition building. I am aware of two Oregon community-wide examples of stakeholders coming together to make paradigmatic changes to providing healthcare to their communities.

Currently, United Way of Lane County is taking a leadership role in addressing the unmet needs of healthcare access and medication affordability by building a coalition whose aim isto improve community health. A similar effort is occurring in Jackson County, Oregon led by the Health Alliance of Southern Oregon. Both groups are learning from the expertise of Kristen West and a national coalition called Communities Joined in Action.

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These efforts are promoting action that builds on the collective assets found among the people and organizations who care about the health of their communities. Such action can have an immediate positive impact on real people. The stories of these changes create hope and momentum as diverse stakeholders work through the complex and difficult conversations that are required to make transformational change.

Mary Minniti

healthcare providers, the hospital, patients, and insurers to quantify the cost of diabetes and heart failure to the community. Using complex software that looked at over 200 variables, projected costs were modeled for 20 years to show the escalating costs of status quo operations. These costs were presented in constant 2001-dollar terms, excluding inflation in the general economy and healthcare.

Diabetes-related costs were projected to grow from $50 million to nearly $100 million, in Whatcom County alone. Broken into four categories of Provider Revenue and Ancillary, Pharmacy, Employer Loss, and Social Loss; the largest cost category was Provider Revenue and Ancillary. In that category, 74 percent of the total cost was hospital costs. Unmanaged diabetes results in frequent hospitalization as a patient's health declines with organ disease and post organ failure.

In contrast, when we modeled full adoption of the P2 interventions for the same 20 years, the result for diabetes was $6 million per year in net savings to the system, or 7 percent of the status quo costs. The savings included a $4 million per year reduction in disability losses.

Additional modeling focused on the program's impacts over the shorter term—the first 6 years of program implementation. The results of the modeling helped each organization see how they might be affected and helped convince stakeholders that the cost of the program was worthwhile, even if one ignored disability savings and long-term benefits. *(A more detailed article on this modeling process can be found in the System Dynamics Review Vol. 20 no. 3, Fall 2004 -Ed.)*

In the current payment structure, savings from P2 for at least the first several years of the program fall unevenly among those paying for care. Medicare is likely to be the biggest "winner" because of the immediate savings from costly and unnecessary hospitalizations. Commercial insurers, on the other hand, would actually pay out more under P2 relative to the status quo for 6 years, after which they too start to realize net savings, due to the accumulated achievements of primary prevention under the program. Other winners are employers in the community and the community-at-large. This occurs because of the reduction of disability losses resulting from diabetes and heart failure. Another big winner is the pharmaceutical industry. In a reliable system, patients who would benefit from pharmaceutical therapies to improve clinical outcomes and prevent organ failure or disease would receive these therapies far more often.

However, in our current healthcare financing model, economic losers are created when an effective chronic care system such as P2 produces better health across a community. Those experiencing the losses will be the hospital and physicians (particularly specialists), who will likely see reductions in net income as complications from chronic conditions diminish.

While the loss of revenue to hospitals and specialists in the modeling can be seen as a downside, it is possible that a community hospital could use the excess capacity to provide services that might otherwise be lacking as the population ages. In Whatcom County, there is both a shortage of primary care physicians and tremendous pressure on cardiologists, whose practices have doubled in the last 4 years. The use of a CCS could reduce pressure on individual physicians and stabilize their practices.

The system modeling improved everyone's ability to understand the effect of the program on the entire system of healthcare and piqued the interest of self-insured employers. St. Joseph Hospital is conducting a pilot program to provide its employees and their dependents the services of a CCS. These services are not currently covered by medical insurance or as an employee benefit. Because the

Hard Numbers for Diabetes Care

Most diabetic control recommendations are based on HgbA1c. A HgbA1c value under 7 shows good blood sugar control. When blood sugar is not controlled, patients with diabetes may develop complications such as heart failure, organ damage, blindness, and kidney failure. In any population with diabetes, a large proportion of patients are likely to have HgbA1c values considerably above 7. Improving outcomes for these patients in a 24-month time period thus also involves being able to move patients with very high HgbA1c levels closer to 7. Because changing HgbA1c values takes patient-initiated behavioral changes, including changes in diet, exercise, blood-sugar monitoring, and adjustments in medication type and timing, the lag in improving results is expected even with effective interventions.

During the first two years of P2 Implementation, P2 clinics focused on changing their chronic care delivery model and tested the changes with diabetes patients. Some of their changes included offering group medical visits, redesigning healthcare roles and functions in the clinics, and instituting effective follow-up support to patients. These clinics also used the Clinical Care Specialist and supported the use of the personal health record, web-based Shared Care Plan. Improvements in HgbA1c values were tracked over time at both P2 sites and other clinics in the community. At P2 sites, results ranged from 30.7 percent to 50 percent improvement in measures of blood sugar level control over the baseline (2002) rate, while during the same period non-P2 sites improved by 19.3 percent.

Systems Dynamics modeling showed benefit to employers in the reduction of lost productivity and disability costs, this pilot benefit could be adopted by other self-insured employers and would be an investment in the workforce and the community.

The System Dynamics modeling has also drawn the interest of policy advisors and planners who have a broader view, including representatives from Medicare and the pharmaceutical industry. Medicare has expressed interest in a demonstration grant for P2—when we began our implementation, it was difficult to gain their interest.

Today and Tomorrow

In Whatcom County, more and more organizations and groups are adopting the use of SCP. This tool is being piloted in Eugene and Florence, Oregon as part of an Agency on Healthcare Research and Quality grant to improve medication safety. SCP has generated intense interest among many others interested in chronic-care interventions. In British Columbia, a chronic-care program has built its own paper version, modeled after Whatcom County's. Through Whatcom County's networking with other P2 sites, the National Health Services in the United Kingdom featured one of our CCS staff as a best practice strategy in their work to address chronic-care problems in their country.

Starting with a vision of patient-centered care, we made changes one patient at a time and learned from the experience, then scaled the learning up. This approach continues today in Whatcom County.

Mary Minniti, BS, CPHQ*, has been a quality improvement professional and community organizer for over 20 years; the last 10 years specializing in healthcare. Since 2001, she has worked as the Project Director for the Whatcom County Pursuing Perfection Program and currently serves as Special Project Consultant to this innovative effort. Her passion is bringing patients, family, and the community into the conversations about healthcare transformation because of the positive and powerful impact it creates for all stakeholders. She lives in Eugene, Oregon with her husband and dogs on 48 beautiful acres.

*Certified Professional in Healthcare Quality

For more information on The Shared Care Plan™ (SCP), the personal electronic health record, go to www.sharedcareplan.org For general information on self-management and chronic care information go to www.patientpowered.org, a site designed by patients in Whatcom County. Healthcare professionals interested in chronic care research, programs, and resources go to www.improvingchroniccare.org. For more information on the Pursuing Perfection Project go to www.ihi.org.