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Managing Chronic Disease

Technology and Community Offer New Hope

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A Community-Based Solution to Complex, Chronic Health Needs

MARCUS PIERSON

SUMMARY • The challenge of chronic care resides in the complexity of the care, not in the duration of the illness. It is complex care that creates an urgent call for community cooperation, above the fray of competition, for the sake of our patients, our organizations, our communities, and ourselves. This article is not a manual or a recipe; it calls for a shift of mind, a slightly different view of the world. It is an invitation to join in the journey toward healthy communities.

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COMMUNITY SOLUTION

Complex care may be the biggest health challenge and opportunity facing healthcare professionals, hospitals, and payers in this country today. Patients with complex medical needs make up a small percentage of the population, yet they require a disproportionately large amount of the resources available for healthcare—about 10 to 20 times that of the less complex and healthier population. I suggest that the solution is to be found in communities—the places people meet their caregivers and interact with healthcare organizations and agencies.

Optimal care for these patients must fit the way they interact with healthcare. We providers must look beyond our situation and understand these patients' experiences. Complex patients' needs cross, rather than follow, our lines of service.

The choice is simple: Hospitals and physicians can cooperate with other healthcare organizations for the sake of the patients' health, or we can arm ourselves for competitive combat within our own communities.

Communities are composed of relationships among individuals and relationships among organizations. A prior CEO here liked to say, "The primary currency of healthcare is relationship, not money." The choice is simple: Hospitals and physicians can cooperate with other healthcare organizations for the sake of the patients' health, or we can arm ourselves for competitive combat within our own communities. Which would our patients prefer? They desperately hope we choose the former.

The common social and business mythos of America works against cooperation, against our communities, against our organizations, and against our patients. Our business approach is often imbued with a cowboy, only-winning-counts mindset. If my thesis is correct, if the community is the right domain for healthcare cooperation, and if W. Edwards Deming (1994) was right about competition, then the real winners will be those who manage to cooperate within their communities and the losers will be those who cannot or will not.

Deming (1994, 66) was clear about what results from competition between the components of a system: "Result: The system is destroyed, causing loss of unknowable magnitude." Given that, of the six most industrialized nations in the world, the United States has the poorest quality of care at the highest cost, the magnitude of the loss to which Deming referred may well be known (Davis et al. 2007).

Whether we acknowledge it or not, healthcare in a community is a system—what happens in one part impacts the other parts. Deming (1994, 55) wrote, "The boundary of the system . . . may be drawn around a single company, or around an industry, or as in Japan in 1950 around a whole country. The bigger the coverage, the bigger the possible benefits, but the more difficult to manage."

This is the challenge for healthcare—to increase the size and benefit of the system of care and to successfully manage it. Healthcare in a community is a complex system. We can only manage such a system through cooperation. Since Deming's time, much has been learned about the theory and practice of managing under conditions of social complexity. My favorite practitioner of social complexity is David Snowden. I encourage you to read his *Harvard Business Review* article (Snowden and Boone 2007). And then reread Deming's *The New Economics* several times. Together they provide the practical basis for large system management through cooperation.

Cooperating in this context is not simply being nice to one another, or responding to problematic situations together. I am talking about envisioning a system of services that meets the needs of those with complex health problems. I am talking about cooperatively designing and managing a system of services that supports this special population.

My organization, St. Joseph Hospital in Whatcom County, Washington, is part of PeaceHealth, a Catholic healthcare system. The PeaceHealth mission statement calls for "community collaboration" and our values statement calls for "social justice." Most of our hospitals are in one-hospital communities. Our circumstances probably more easily align with the points of view I espouse here than the circumstances many other healthcare leaders find themselves in. In fact these values are what attracted me to PeaceHealth. Community cooperation will pose very difficult challenges for some organizations; I understand that. However, the inescapable fact is that we all exist within a complex system and those who know how to cooperate will have an advantage.

I am suggesting, as Deming did, that there is competitive advantage in cooperating at the right level, the largest level that can be managed. There is an understanding of managing that includes complexity and even chaos. Managing within the space of complexity allows businesses to consider cooperating and building systems that include whole communities.

Outside the context of complex and chronic care another opportunity for community cooperation exists. Far upstream of acute care lie the key health choices, lifestyle and prevention. These choices are best addressed by the whole community, not just the doctor's office and hospital. Among the biggest opportunities for patient-centric cost reduction is enabling end-of-life care to occur in the home or elsewhere outside of acute care hospitals whenever appropriate and possible.

WHAT WE'VE DONE

The challenge in "chronic care" is the complexity of care more than the chronicity of illness. Things get complex when patient circumstances require services from several entities.

In 1996 PeaceHealth and Whatcom County created a wide area network (Whatcom Health Information Network) to which every provider is connected. We share clinical information across sites as HIPAA covered entities. Lab results, images, and hospital and emergency records are available on a need-to-know basis across the whole community of providers. Our community has not been fatally poisoned with the belief that adversarial competition is the best way to deliver healthcare.

In another act of cooperation, PeaceHealth physicians, nurses, and administrators joined together with our non-PeaceHealth peers to improve the management of diabetes. We used team-based quality improvement, shared clinical information systems, and shared intranet. We also created disease registries and joined collaboratives. We worked together with leaders in Family Care Network (FCN), a separate organization of about 40 family practitioners. Together we adapted our information systems to the needs of a community disease registry.

But diabetes is only one chronic condition. In 2001, we were admitted into the Robert Wood Johnson Foundation Pursuing Perfection (P2) program. In this program we learned how to provide efficient, high-quality, cost-effective care for the community population of complex patients by managing our own cooperation.

Mary Minniti was the Whatcom County P2 project director. At the start Mary asked, "One of the IOM's six aims is patient centeredness, so we will invite patients to be on all or our project teams, right?" Her request made sense. These patients and their voices changed everything. Having patients present in design activities, as well as governance, changed the tone and content of our meetings. Most important, having patients as partners allowed us to learn from them (Homer et al. 2004).

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Many of the patients in the P2 project had complex health circumstances and chronic multiple conditions. Quite a few were "train wrecks," whose needs outstripped the capability of individual healthcare providers. These patients were a blessing! Since these complex patients were in the program, we had to figure out how to improve their care, how to keep them from falling through the cracks, how to improve the handoffs between the parts of the system, and how to keep these patients safe. In short, we had to create equitable care for this population of patients, who are discriminated against by the fact that their care needs are not well aligned with the existing capabilities of the system. Providers were not discriminating against these patients. They were trying their best. The system itself is the cause of inequity—it is designed for less complex care than these patients need. It leaves them out.

We can choose to lead our systems so that the system can provide effective, high-quality, and lower-cost care for complex patients or we can turn our eyes away.

We asked many of these complex patients what "perfect care" would look like to them. Their answers were simple, unexpected, and transformative. We learned that these patients were not as helpless or as dependent upon us as we had imagined. They wanted support that was attuned to their current and often changing ability to care for themselves. They wanted a greater voice—not to make our lives difficult, but to help us improve outcomes and quality and lower costs.

As they told the stories of their experiences with healthcare, the failings of the system became abundantly evident. But rather than taking an adversarial stance, these patients wanted a partnership with us. We began to recognize that the patients, not the healthcare professionals, are actually the center of the situation. Recognizing that would lead us down the path to improved quality, lower costs, and better outcomes.

Patient Navigator

These patients asked us to create a role that was missing: a patient-biased, cross-organizational "navigator and coach." They wrote the job description for this position they called a Clinical Care Specialist (CCS). This was an RN or social worker with the ability to listen and understand what barriers were blocking the professional, the patient, and the laypeople who were supporting their care.

Part of the CCS role is simply assisting and teaching the patient how one navigates the system. Part of it is facilitating communication between healthcare professionals and the patient, since these two parties often have very different worldviews and do not share the same language. We equip the CCSs with tools such as the Patient Activation Measure. This 13-item measure is a key to affordably meeting the challenge of complex care. It provides the CCS with a precise understanding of each patient's current self-management capability, and it suggests ways to increase their self-management behavior. During P2 we learned that of all the components of the system, CCS has the largest influence on outcomes. In a virtual model (Homer, 2004) of our system that we created, too few CCSs led to poor health and economic results. The right number of CCSs led to overall savings in life and dollars.

The CCSs in our P2 project work seamlessly with complex patients, their Shared Care Plans, their small social networks of friends and family, and all the community's healthcare providers. The result has been dramatic improvements in the lives of these patients, lower costs, fewer medication errors, and a decrease in admissions to the emergency department and hospital. While we did some data collection which supports these claims, I would refer you to CareOregon, which has provided similar care for its complex patients and has kept much better records of the savings—five to six thousand dollars per person per year for the 3 percent of their patients who require 30 percent of their resources.

Personal Health Record

Our P2 patients also asked us to create a peculiar kind of medical record. Rather than accepting access to the physicians' and hospital's medical records (which we thought was a generous offer), patients asked for their own personal health record (PHR). With grant support, these patients designed one that would work for them. They designed a record that supports both their self-management and their communication with healthcare professionals.

I learned that many of these complex patients have their own unique support systems—people who truly care for them, people who do their best to help. So when the patients asked for their own health record they did not mean an isolated "personal" health record, but a *shared care plan*. It was envisioned as a place for their small social network to share information and support the patient. This was a virtual place for all of an individual's chosen care network members, including healthcare professionals, to participate in the individual's health decisions and behaviors and have ready access to vital information. They inverted the professional paradigm. Their circumstances required this inversion—their lives depended upon it.

Through the experience of seeing this patient-centered PHR develop I began to understand that with the Internet we could provision a patient's home with vital information, and that this could facilitate improved health outcomes for whole communities. Conversations between our activated patients and Peter Neupert at Microsoft influenced the creation of Microsoft's HealthVault platform. Microsoft is creating an ecosystem for personal health support applications. It is critical that allopathic healthcare understand this shift toward direct patient involvement.

Health Information

The patient group also requested help finding the information they needed to properly manage their care, including written material, websites, educational forums, and peer meetings.

These three things—the Clinical Care Specialist, the shared patient care record, and assistance in finding health information—were and still are the patients' definition of "patient-centered." These three things are the exact redesign of American healthcare our complex patients are asking for.

FUNDING ISSUES

Finances matter. During the P2 program we came to understand that personal meaning, individual choices, and behavior change are the real issues. But as soon as the grant expired, our funding dried up. Ultimately one needs to develop the business case for this kind of program and then fund it from the savings that accrue.

No one doubts that patients with complex situations and illness require a high proportion of the health resources. The question is what to do with this fact.

My hope is that we or others will create community health plans that use local care managers who support all the patients and providers. The questions are who will perform the role, who will fund the role, and who will benefit. It is likely that the skilled nurses from the Area Agencies on Aging could extend their services to the community's complex care. Their fees would be covered from the savings that occur.

In Whatcom County, we learned that the economic winners in a whole community system of chronic care are the pharmaceutical companies and Medicare. The rest of the system does the work and at best breaks even—not the best incentive for investment unless you are cooperating together as a system to improve outcomes, reduce costs, and share the benefits (Homer, 2004).

Considering the economic dynamics of complex care, there is an important role for enlightened payers. The governance of payment is critical to supporting cooperation and alignment. I am suggesting a local payer presence with flexibility to participate locally, community by community, in the ongoing design of systems for health. When providers and patients begin cooperating, payers will be selected for their ability to cooperate. We cannot wait for the tail to wag this dog.

A good starting point is to begin working with payers who are incentivized to cooperate locally for the care of complex patients. That would be state Medicaid organizations. When the bugs are worked out there I predict Medicare will be willing to copy the successes. Then other payers will join the community.

ASSESSMENT

No one doubts that patients with complex situations and illnesses require a high proportion of the health resources. The question is what to do with this fact.

The solution for complex care can only be found in the community. The frontline healthcare workers—social workers and nurses who craft temporary fixes patient-by-patient—know that solutions are found by knitting together community resources, healthcare and otherwise. We leaders should help them build better systems in our communities and support the efforts of existing small social-care networks of family and friends. These little care networks need to be enabled. They want to be enabled. Let's not discount this powerful force by pointing out that there are some patients who have no networks and low activation. Innovative communities will figure out ways to build neighborhood-based networks of caregiving.

HOW IS IT DONE?

So if you have read this far you may be asking, "How?" Peter Block (2003) wrote a simple little book titled, *The Answer to How Is Yes*. He was suggesting that we act into knowing rather than overanalyze challenges that require innovation. Complex social issues do not yield to solutions that are mechanical, programmatic, or classically manageable with precisely predictable outcomes. The good news is that we all are already pretty good in these spaces. We may be leaving them at home when we come to work.

There is a lot of literature on complexity. My favorite thinker and practitioner is David Snowden (Snowden and Boone 2007). Other interesting authors on sense making and complexity are Karl Weick (1979, 1995), and Ralph Stacey (1992). These reflective thinkers point out that in dynamic and rapidly changing environments the chief leadership competency is navigating uncertainty, complexity, and even chaos. We can all hire wonderful experts and practitioners for managing the day-to-day, process-based, analytical side of the business. Successful approaches to complex situations are fundamentally different, and actually simpler. They require leadership and sense making. This work is more like gardening or getting along with your family.

For all the books and articles written on complexity, the simple concept is talking with the players, being truly interested, focusing on what *they* care about, and finding openings for personal and organizational commitments to a shared and co-designed future. Messy, human, and simple! America's leaders are smart and capable, but we may be looking under the lamppost for the keys. We are comfortable looking for solutions that are predictable and controllable. The keys may be in the grass to the side of that light—in a socially complex space.

The future leader must have an ability to make sense of the situation and its possibilities in perpetual uncertainty and occasional chaos. Leaders will have to hone their abilities to find the best solutions with others who are not under their control, including some important solutions beyond the security of analytical solutions.

We need to be open to the possibility that the solutions to complex medical care are available right in our communities. Let's help the solutions emerge through cooperation. Let's pick up the human tools appropriate for complex situations: curiosity, convening, asking, listening, attracting, and limiting. Ultimately, it is community gardening—planting, watering, fertilizing, and pruning. Most hospital leaders have the tools for gardening. Most have the skill. What is lacking is the understanding of the necessity and the opportunity.

Cooperating with "competitors" is a pretty big mindset shift. An even bigger shift is believing that patients and their friends can make a big difference, that they can be the actual center. I now understand that a key part of the solution to complex care is empowering and enabling all willing patients and their small social networks.

So, what specific suggestions or insights do I have to offer? Only what our patients taught us and what we learned from others.

INSIGHTS

- Patients are more competent within their own social circles than they may appear to us in our part of the system.
- Complexity and uncertainty are the key domains for leadership for the future.
- Leaders will be master gardeners rather than commanders or mechanics.
- Communities are a key domain for cooperation in healthcare.

RECOMMENDATIONS

- Provide patient-centered, community-focused system navigators with care coordination and coaching roles.

Jönköping County – Doing it Right

One place, Jönköping County in Sweden, often occupies my mind when I think about community-based health. In Jönköping County they manage the health of 350,000 people with extraordinary results. (Bodenheimer, Bojestig, and Henriks 2007 and Boel and Neuhauser 2007)

Fifteen years ago they were like us. There are three hospitals and 34 clinics in the county. These were internally as competitive and uncooperative with each other as we are in our communities. Today, they are the model of community cooperation in care; a model that sets the standard for access, high quality, low cost, and equity.

How did they do this? At the risk of oversimplifying, I will say that they are serious learners, and serious system thinkers, and they understand the development of relationships among players and teams over long time periods. No external agent led or forced them to change. They learned how to be a community that improves its own whole system of care.

They chose to cooperate, and hired leaders who intended to do so. One of the leaders is an army officer, another a national basketball coach, and another is a physician with a knack for teaching others. It has taken, as Deming would say, persistence of vision and longevity of leadership—each leader has been in his role for well beyond a decade. They have built relationships and systems based on cooperation rather than competition.

In Jönköping, all funds for healthcare are generated from taxes. Local elected officials from each community have oversight of the funds. One of the more visible parts of the system is the development department of the county, called Qulturum. Qulturum is housed in an inviting building where dialogue, learning, collaboration, and research take place. It was organized in 1998 and I think it is here that the community gradually came to see itself as a whole.

The Jönköping model is my preferred model—a whole community locally managing the systems of care, the risk and the costs. Does it sound American or anti-American to you? What have we become? What will we become? We have choices. Some of us can show the way. These changes started in only one county in Sweden. Their approach is now spreading to surrounding counties. Complex solutions are never installed, they emerge and adapt.

- Provide access to personal health information that we currently control.
- Provide access to knowledge sources that enhance personal decision making.
- Use the Patient Activation Measure (PAM) to tailor support and care to the individual's current capacity for self-management. This 13-item measure may be the single most cost-effective segmentation tool to guide resource allocation (Hibbard et al 2004, 2005). When one matches the expensive support to the individual patient's activation level, one has a much higher chance of obtaining the desired outcome.
- Move at the speed of relationships. Make your business plans match relationships.

If you have plans without relationships, create the relationships.

Promise yourself right now that you are going to make whatever mindshifts you need to make to succeed. Read Donella Meadows' (1999) article, "Leverage Points: Places to Intervene in a System," which puts into perspective the importance of mindshifts compared with manipulating parameters. We all tend to fiddle with parameters while Rome burns. Try to find the time to read this brief article.

Forward-thinking communites should apply for the Healthcare Baldrige Award.

Finally, we should convene with each other. Those who are working and those who want to work on community-based cooperation for complex care could come together virtually or face to face to learn and share. Those in the Whatcom, Jönköping, CareOregon, and Alaska's SouthCentral Foundation experiments would gladly share with others the lessons they have learned and that we could all learn from each other.

In closing, we have to face the fact that disruptive change is occurring. The World Wide Web is finally beginning to change the foundation of healthcare. The customers, and particularly the baby boomers, are going to change the game. If we providers don't cooperate to support patients locally (locality being our obvious advantage), the globalization of information, travel, and competition will surely displace us.

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Response from a Feature Author

MARCUS PIERSON

I would like to acknowledge the debt of gratitude that I have to Intermountain HealthCare and University of Michigan Health System. Ellen J. Gaucher's book about the quality journey at Michigan, *Total Quality in Health Care: From Theory to Practice*, was a very strong influence on me. IHC's information systems and their Advanced Training Program (ATP) have had an enormous influence on my community as well as PeaceHealth. Before I was an employee of PeaceHealth, the hospital CEO, John Hayward, partnered with the community and supported the attendance of 13 community members and two hospital leaders at Intermountain Healthcare's Advanced Training Program in the mid-1990s.This common background was the basis for cooperation in clinical quality at the community level. PeaceHealth has recently partnered with IHC to create a local version of the ATP, and we continue to include community physicians in the quality training programs.

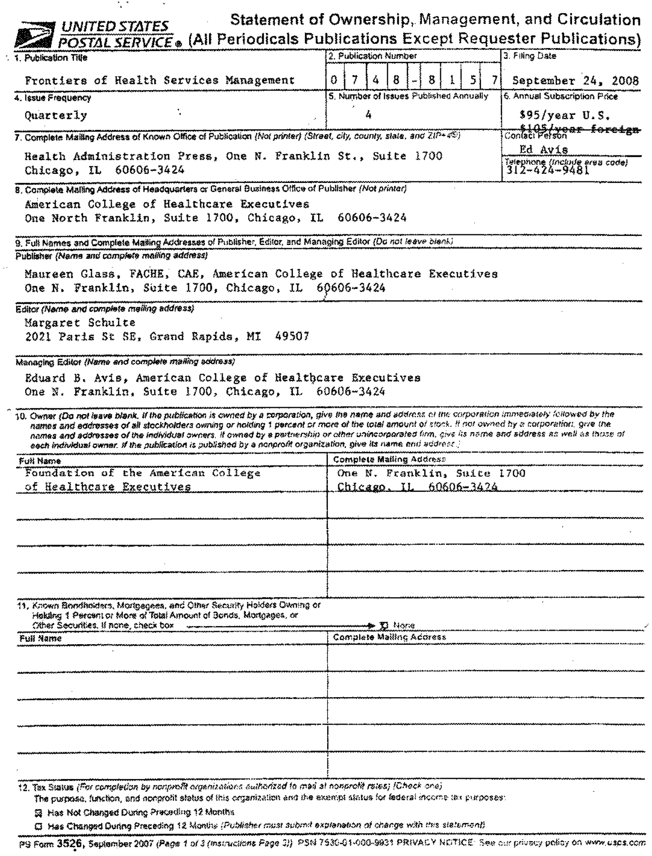
I completely agree with and endorse Dr. Bernstein's call to critically assess the effectiveness of our programs and to examine our assumptions. The reviewers and the feature authors seem to share an urgent interest in learning about what works in the space of complex and chronic care. There is a real opportunity for continued sharing and accelerated learning (as the reviewers suggested) if these organizations are able to begin proactively communicating. If we were to include a few more organizations with formal research infrastructures, much could be learned in time to support the demographic bulge that has begun to outpace our ability to provide the care people deserve. Jönköping County, Sweden, certainly should be considered in any learning and research association.

Dr. Bernstein refers to the necessity of a multifaceted approach. Whatcom and others could focus research on the often-missing facet of patient engagement—in the patient's actual home—as well as community engagement—

churches, schools, grocery stores, clubs, etc. In Whatcom County a collaboration between PeaceHealth Whatcom Region and Western Washington University has formed the Critical Junctures Institute to lead action research in this domain. Our initial focus is on how to enhance the relationships and coordination of care with electronic (and paper) personal health records which interoperate across the community, including with business medical records.

The word "panacea" was used without clear reference. I just want to be on record as not expecting to find any panacea. Instead, in complex systems there can generally be found points of high leverage that are counterintuitive before they are discovered (see Jay Forrester's ideas on the dynamics of nonlinear systems). We believe that patient involvement, clinical care specialists, and cooperation across organizational boundaries are such high-leverage points, but certainly not panaceas. We could all look toward the CDC's Syndemics Prevention Network (www.cdc.gov/syndemics/monograph/index.htm) for ideas and methods that match the dynamic complexity of health in our communities.

I hope that this is not the end of the discussion but rather the beginning.



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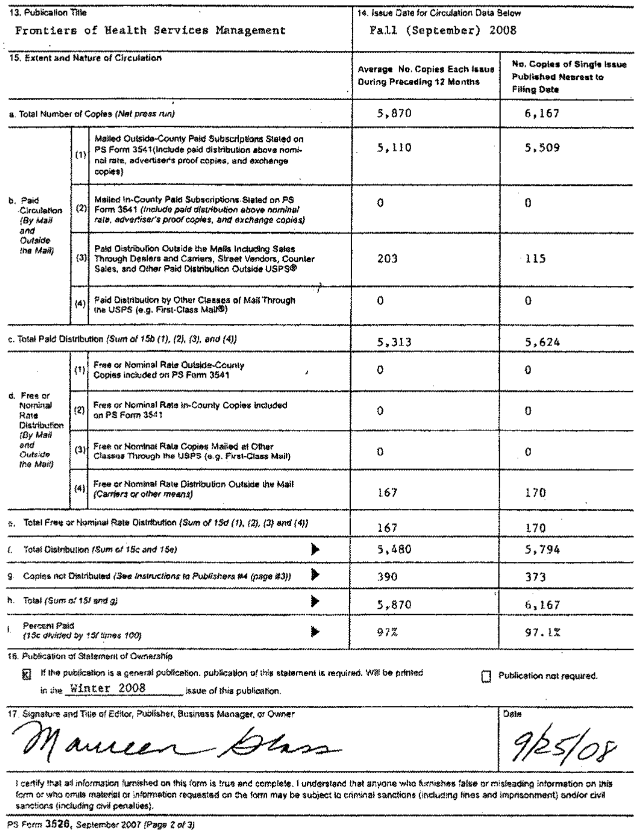

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