



*Navigating a Changing Health Care System:
How Consumers, Clinicians and Policymakers Can Make
Sense of Shared Decision Making and Information Therapy*

Joshua Seidman, PhD
President
Center for Information Therapy

Karen Sepucha, PhD
Senior Scientist, Health Decision Research Unit
Massachusetts General Hospital/Harvard Medical School
Medical Editor
Foundation for Informed Medical Decision Making

March 19, 2008

Imagine...

Imagine a world in which clinicians delivered just the right information to their patients at precisely the right moment. Imagine that clinicians were able to focus their limited time helping well-prepared patients to put that information into perspective for their particular situations, guiding them to a decision that balances the best available scientific evidence with what matters most to them. Imagine that the collaboration continues over time, with clinicians delivering tailored information at the right time to help people consistently make informed choices and do their right things for themselves.

You may say that we're dreamers, but we're not the only ones...

Funding

Funding for this study was provided by the Foundation for Informed Medical Decision Making, Boston, Massachusetts.

Acknowledgment

We gratefully acknowledge valuable input provided by Annette O'Connor, MScN, PhD, University of Ottawa, Canada, and Susan Edgman-Levitan, Massachusetts General Hospital. The quotes were edited from transcripts of the interviews to enhance readability.

Other White Papers Published by the Center for Information Therapy

- **Improving Population Care and Disease Management Using Ix Principles**
by Joshua Seidman, PhD, and Paul Wallace, MD
Simply stretching today's "sick-care" system is no longer feasible to effectively manage chronic care. A new model of care is needed—one that places the locus of control with individuals and that supports all health decisions with targeted information prescriptions.
- **Turning on the Light: Illuminating the Care Experience Through a New Consumer Paradigm for Quality Measurement**
by Joshua Seidman, PhD; and Margaret E. O'Kane
Consumers are often "in the dark" when it comes to understanding the quality of care delivered by providers and health plans. The little information about provider quality that does exist is hard to understand, and it's frequently not clear how the ratings were calculated. Opening the "black box" of health care performance measurement will require a consumer focus, innovative thinking, provider commitment, and an investment of scientific and practical resources.
- **The Arrival of 21st-Century Health Care: Group Health Cooperative Reengineers Its Delivery System Around Information Therapy and Patient-Centered Informatics**
by Joshua Seidman, PhD
This best practices paper reveals how Group Health Cooperative is revolutionizing care delivery by using information therapy and patient-centered informatics as key strategies. Members can have anytime, anywhere access to personalized health information and immediate connections to clinical support.
- **The Mysterious Maze of the World Wide Web: What Makes Internet Health Information High Quality?**
by Joshua Seidman, PhD; Donald Steinwachs, PhD; and Haya R. Rubin, MD, PhD
Existing tools designed to help consumers find credible Internet health information focus almost exclusively on proxy measures of quality, such characteristics of the site sponsors and whether the site lists its sources. This paper presents results from the review of 90 sites with diabetes information and lays out an alternative strategy to help consumers find accurate, comprehensive health information online.
- **The Ix Evidence Base: Using Information Therapy to Cross the Quality Chasm**
by Bianca R. Gwinn, MS, and Joshua Seidman, PhD
This white paper pulls together the empirical evidence that demonstrates how information therapy (Ix) responds to the call to action issued by the Institute of Medicine (IOM). Specifically, self-care, self-management, shared decision making, and other Ix-related initiatives improve patient knowledge, self-efficacy, clinical quality, patient experience with care, and cost-effectiveness.

Visit www.ixcenter.org to download other white papers or to contact the Center for Information Therapy.

Introduction

The world is changing. The world has moved from information scarcity to information abundance, forcing fundamental changes in the way clinicians and patients interact and make decisions about care. In addition, health care purchasers and plans have offered consumers far more opportunities but also have mandated they assume a heavier burden for owning their own health care universe. Regardless of the virtues or drawbacks of the “consumer-driven” paradigm, new strategies and tools are needed to make the best of that world for the average consumer.

There is a growing consensus that ensuring high-quality care requires getting the right information to the right person at the right time and engaging consumers as active partners in care management and decision making. However, considerable divergence of opinion exists in how to best do this, and about what this means for traditional roles and responsibilities. Creating the right infrastructure for informed consumer choices and collaborative communication between clinicians and their patients requires more than granting access to information and establishing new models of financial accountability. Consumers and clinicians need new tools and resources to match information to individual needs and structure the way they think about health care choices and communicate about them.

In order to assess how these changes are unfolding across North America, we interviewed two experts who are leading efforts to implement shared decision making and decision aids into clinical practice. Susan Edgman-Levitan is the Director of the Stoeckle Center for Primary Care at Massachusetts General Hospital and Dr. Annette O'Connor is the Canada Research Chair in Health Care Consumer Decision Support, a Professor at the University of Ottawa, and Senior Scientist at the Ottawa Health Research Institute. We asked both experts a series of questions regarding challenges they have encountered in

presenting these concepts to various audiences, and some of the more effective strategies they have used to connect with patients, consumers, providers, administrators and payers. In this viewpoint, we summarize their views and highlight some key themes and issues for those interested in getting these types of interventions implemented.

Finding the Right Words

Confusion and misinterpretation result from the use of the many different terms to describe engaging and informing patients in decisions (such as shared decision making (SDM), information therapy (Ix[®]), informed consent, informed choice, etc.).

Edgman-Levitan: “In my experience, talking with clinicians whether they're primary care or specialty clinicians, about shared decision-making and information therapy...they find the terms off-putting. I usually get lots of follow up questions like, “Well, are you really talking about just patient education materials? Are you talking about the informed consent process?

Are you talking about things that we need to be concerned about in terms of risk management? What do you really mean by these terms?... What I run into frequently with patients when we talk about shared decision-making, is they get really nervous that we're expecting them to be their own doctors.”

The confusion goes both ways, as they attempt to understand the language used by administrators and insurers.

O'Connor: “The language changes wherever you are, talking to the hospital administrators, I didn't understand their language, the committees are even labeled differently, they talk about RVUs [relative value units], business case, roll-out, big picture, and we were talking about shared decision making, informed choice, and preferences. With clinicians, what matters most to them is health outcomes and efficiency.”

Perhaps most surprising, the confusion is not limited to the big labels and technical terms, like utilities and equipoise, but includes some of the seemingly innocuous ones, like “values and preferences” because the terms have different connotations for different people.

Edgman-Levitan: One of the questions on the CAHPS instrument that didn't do well was, "Does your doctor know your values and preferences?" Not only did patients not like it, they actually were pissed off.

They said, "It's none of my doctor's business what my values and preferences are!" So we said, "Wait a second, can we talk about this a little bit more?" They said, "Well, I don't care if my doctor knows whether I'm a Republican or a Democrat or what I think about guns." They had all these very concrete examples, none of which had anything to do, almost nothing to do with health care. They really thought it was an invasion of their privacy to even use those phrases. So I think talking about what's important to you, we've got to come up with better words to convey what that really means to people.

In many cases, the language we use in research reports and publications becomes more of a barrier than a tool in talking with consumers, administrators, and health care providers. New plain language is needed to communicate with a broad audience about ways to involve patients and caregivers in decision making.

Communication Pitfalls Associated with Common Terms

Many times consumers, clinicians or administrators will use a term like informed consent or patient education to describe the content of decision aid interventions. Although it is tempting to relate these to familiar concepts, there are some potential pitfalls in this approach because of the specific meaning already associated with them.

Edgman-Levitan: I actually think that we have to do a lot more work directly with

patients and consumers about this because, by and large, people think patient education is a pretty negative term because what that evokes is brochures that have been Xeroxed five million times.

O'Connor: "For naïve audiences, I often start with informed consent but then am quick to differentiate between informed choice and informed consent. I use lots of examples for clinical audiences, talking about VBAC [vaginal birth after caesarean] that has a big consent form, and describe how the decision aid helps with good informed consent"

SEL: "I would stay as far away as possible [from informed consent] because that has a very, very, very clear, concise meaning to clinicians and to many patients, and that is a form that one signs before you have certain procedures done...most people do not think that that is in any way, shape or form an information sharing process."

Seeing Is Believing

In this new era of information abundance, consumers have to sort through a plethora of information—some inaccurate, conflicting, incomprehensible, and much of it not relevant to the individual's particular needs at that specific time. Just like medications, information can be life-saving but it can also produce dangerous side effects or people can overdose on it. Unorganized or unfiltered information likely has limited value; in fact, in certain circumstances, it may create negative consequences. Information overload may make consumers feel overwhelmed and confused, and incomplete or inaccurate information may mislead consumers into making bad decisions.

People want their doctors to prescribe them information. For example, 49.5 percent of cancer patients reported that their physicians would be the first preference for information [4]. Despite that desire, only 10.9 percent of those who sought cancer information reported having gone to a

physician as the first source of information, whereas 48.6 percent went to the Internet first. The independent, unconnected and parallel information tracks create inefficiencies and lost opportunities.

The popular media has seized on the problems of information overload, but often has misdiagnosed the problem. For example, in a *New York Times* piece, "Awash in Information, Patients Face a Lonely, Uncertain Road," [5] Jan Hoffman describes how an overload of generic or unspecific health information available often does not meet the needs of patients or caregivers facing serious health issues. However, the solution is not cutting off the information flow, or over protecting patients from information, rather it is developing more thoughtful strategies for directing consumers to the right information at the right time. Interventions that engage patients with information and skill building have been shown to increase adherence, attainment of goals, and improve outcomes [10-11]. Engaging patients in meaningful ways in management of chronic disease also has efficiency implications, with patients having fewer hospitalizations and less resource utilization [11]. Not only is engaging and informing patients the right thing to do, but it may also lead to greater efficiency in the system.

If these tools really are different from what is out there, and really can provide a benefit, then how do we get the message across? The experts agreed on two main strategies: first, getting people to actually review the decision aids; and then framing the "solution" to their problems.

O'Connor: "To get buy-in you really need to show [clinicians] what the difference is in the consultation, what does it look like, and what will it do."

Edgman-Levitan: When our doctors saw the colorectal cancer screening decision aid, several of them commented that if they had days to spend with their patients..., they

could never do as good a job.

What will it take to get these used more widely? Different groups have different perspectives on the benefits, and care needs to be taken to match the "solution" to the problem.

O'Connor: With clinicians, health outcomes are what they care about, orthopedic surgeons can't get colleagues excited about this [because] the only thing they care about is did I get the knee straight and if the X-rays look fine, then they did their job. We need to convince them that this will make their lives easier. That it will save time.

Edgman-Levitan: I think there [with clinicians] we really focus on the time-saving and the risk management, emphasizing that when you begin to use these decision support tools, whether a video or a questionnaire or just information that you give people, you're saving yourself time and you're protecting yourself because you can't begin to convey all of this information verbally to someone in an office visit. So that's what we focus on.

O'Connor: Hospital administrators worry about effect on bottom line, worry about business case, and need incentives – if you prevent one lawsuit you have saved a lot of money (although not much data exists on decision aids and malpractice). The only thing that got them [administrators] excited was changing the RVU and reimbursement.

Administrators at another hospital were having problems managing referrals for ADHD [attention deficit/hyperactivity disorder]. And there were huge inefficiencies in that parents showed up who under no circumstances would use medication, so in essence they didn't need to be there. In this situation, we presented decision aids as a way to more efficiently manage the referral process.

Before any of this will happen on a broad scale, we need to better understand how to

communicate with key audiences. We need to conduct empirical research through focus groups, interviews, and surveys with consumers, clinicians, administrators and purchasers to test out new language. We need to connect the tools to results that are meaningful to each stakeholder.

These movements will not succeed if individual consumers and clinicians have to do things by themselves. An increasing number of health care systems have committed to patient-centered care and have made fundamental changes in the way they interact with patients, share information and make clinical decisions. For example, the Center for Shared Decision Making at Dartmouth Hitchcock Medical Center contains an extensive library of decision aids and has trained staff in decision coaching. Several clinical specialties throughout the hospital, most notably the Breast Program and the Spine Center, have systematically integrated tailored decision support materials into the flow of patients through their clinics [14-15]. Patients are more informed, more engaged in decisions, and more satisfied with their care. The providers also see benefits; the tools have elevated the quality of their discussions, making patient consults more interesting and engaging.

Conclusion: Will the Future of Health Care Be Driven by Doctors or “Dr. Google”?

More people in the US now get health information on a typical day from the Internet than visit their doctors, [16] what Susannah Fox of the Pew Internet Project terms the “Dr. Google phenomenon.” Change is coming to medicine, and the question is how to take advantage of the democratization of information and harness its potential to improve the quality of health care. A recent *BMJ* (“How Google is Changing Medicine”) article [17] documents the various search engines that brought visitors to their Web site. PubMed and other clinical search engines represented about 25,000 hits whereas Google and Google Scholar generated close to 500,000. The way information is created, exchanged, and shared is compounding exponentially, raising the importance of new tools to sort,

search, organize and synthesize it. Methods to deliver the right information to the right patient at the right time are critical. If those within health care do not step up and support the design of these systems, external entities will drive the future.

To succeed in the coming decades, the health care environment needs to foster relationships based on trust, clear communication, and informed choices. Consumers will bear an increasing burden of decision making and cost. Clinicians will need to synthesize a growing amount of information and will need tools to individualize risk assessments and project treatment benefits. Purchasers will need to manage costs while improving quality. If we can meet the challenge of providing the right information to the right person at the right time in this future care delivery setting, consumers will have greater sense of confidence and control, leading to a better overall health care experience.

References

1. Crawford, L., et al. (2003). When medical error becomes medical malpractice: The victims and the circumstances. *Archives of Surgery*. 138(4); 447-454.
2. Hickson, G., Federspiel, C., Pichet, J., Miller, C., Gauld-Jaeger, J., & Bost, P. (June 12, 2002). Patient complaints and malpractice risk. *JAMA*, 287(22), 2951-2957.
3. Levinson, W., Roter, D., Mullooly, J., Dull, J., & Frankel, R. (Feb. 19, 1997). Physician-patient communication: The relationship with malpractice claims among primary care physicians and surgeons. *JAMA*, 277(7), 553-559.
4. Hesse, BW, Nelson DE, Kreps GL, et al. (2005) Trust and sources of health information. The impact of the Internet and its implications for health care providers: Findings from the first health information national trends survey. *Archives of Internal Medicine*. 165:2618-2624.
5. Hoffman J. Awash in information, patients face a lonely, uncertain road. *New York Times*, Aug. 14, 2005:1.
6. Eiser, J. Richard, ed. (1982) *Social Psychology and Behavioral Medicine*. Chichester: John Wiley & Sons.
7. Seidman J (2004). The arrival of 21st-century health care: Group Health Cooperative reengineers its delivery system around information therapy and patient-centered informatics. Available: <http://www.ixcenter.org/whitepapers/index.cfm>. Accessed August 10, 2006.
8. Barry M, Fowler FJ, Mulley AJ, Henderson JJ, Wennberg J. (1995) Patient reactions to a program designed to facilitate patient participation in treatment decisions for benign prostatic hyperplasia. *Med Care*. 33(8):771-82.
9. Christensen CM, Bohmer R, Kenagy J. (2000) Will disruptive innovations cure health care? *Harv Bus Rev*. Sep-Oct;78(5):102-12.
10. Bodenheimer T, Lorig K, Holman H, Grumbach K. (2002) Patient self-management of chronic disease in primary care. *JAMA*. Nov 20;288(19):2469-75.
11. Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, et al. (2001) Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Med Care*. Nov;39(11):1217-23.
12. Frosch DL, Kaplan RM, Felitti V. (2001) The evaluation of two methods to facilitate shared decision making for men considering the prostate-specific antigen test. *J Gen Intern Med*. Jun;16(6):391-8.
13. O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, et al. Decision aids for people facing health treatment or screening decisions (Cochrane Review). (2004) In: *The Cochrane Library*; Issue 1. Chichester, UK: John Wiley & Sons, Ltd.
14. Kearing S, O'Connor AM, Collins ED, Clay KF, Moore CP, et al. (2005) Integrated Decision Support in Clinical Care: Decision Making in a Cohort of Early Stage Breast Cancer Patients. Society for Medical Decision Making Annual Meeting (abstract).
15. Center for Shared Decision Making website: http://www.dhmc.org/webpage.cfm?site_id=2&org_id=108&qsec_id=0&sec_id=0&item_id=2486. Accessed August 2, 2006.
16. Fox, S. (2004) Today's e-patients: Hunters and gatherers of health information online. Pew Internet & American Life Project website: http://www.pewinternet.org/PPF/r/27/presentation_display.asp. Accessed February 26, 2007.
17. Giustini D. (2005) How Google is changing medicine. *BMJ*. 331:1487-1488 (24 December).