

Point: The Changing Nature of Disease *Implications for Health Services*

Barbara Starfield, MD, MPH

The purpose of this commentary is to question the adequacy of characterizing illness disease-by-disease. With rapidly increasing coexistence of multiple diseases within individuals, a disease-by-disease focus is becoming counter-productive to effectiveness, equity, and efficiency of health services.

The sanctity of “disease” prevails in western medicine, despite the fact that diseases were never clearly distinct entities.¹ Most quality of care efforts assume that early identification of risk factors for specific diseases improves health and, thereby, reduces costs, but this approach may not be suitable in meeting future healthcare needs.

Diseases are heterogeneous entities.² Many presumed “diseases,” such as diabetes, hypertension, malaria, breast cancer, chronic obstructive pulmonary disease, prostate cancer, and “heart disease,” are not distinct entities. Many are associated with other diseases. For example, people with hypothyroidism are 4 times more likely to have rheumatoid arthritis and cardiovascular diseases.² Recognition of the heterogeneity of diseases is reflected in planning for the upcoming (11th) revision of the International Classification of Diseases, which recognizes that a disease label masks variability within diseases, including (but not limited to) causal mechanisms, clinical manifestations, and risk factors.³

Many types of prior experiences (including illnesses) predispose to a large variety of subsequent health problems.^{2,4} No risk factor is reliably predictive without consideration of other risk factors.⁵ Moreover, the risks for most common diseases are also risks for other diseases. Chronic and acute diseases share common etiologies; chronic diseases have acute exacerbations and make people vulnerable to acute diseases, and repeated acute diseases can take on the characteristics of chronic illnesses as they recur over time.² The literature does not shed light on the extent to which increased overall vulnerability to diseases of all types is a result of underlying common pathophysiology or an effect of prior illness on decreasing general resilience to illness.

Despite the uncertain predictability of risk factors, their identification is raising the incidence and prevalence of disease and is lowering thresholds for treatment as predisease (disease without symptoms) is being managed as if it were disease. Lowering thresholds for diagnosis of diabetes, hypertension, overweight, and hypercholesterolemia has increased the prevalence of these diseases by 14%, 35%, 42%, and 86%, respectively. Under some proposed guidelines for high blood pressure, high cholesterol, and impaired fasting glucose, virtually the entire population qualifies for a chronic disease diagnosis.⁶

As the frequency of diagnosis of individual diseases increases, so does multimorbidity (the simultaneous presence of different diagnoses and types of diagnoses), which is rapidly becoming more common than morbidity associated with 1 disease. The importance of multimorbidity is highlighted by studies that show its association with exponential increases in rates of hospitalizations for conditions that should be preventable with good primary care, adverse events rates, and, especially, costs of care.⁷

From the Department of Health Policy and Management, Johns Hopkins University, Baltimore, MD.

The author declares no conflict of interest.

Reprints: Professor Barbara Starfield, of Johns Hopkins University, died on June 10, 2011. Reprints can be requested from her assistant, Normalie Barton.

E-mail: nbarton@jhsph.edu.

Copyright © 2011 by Lippincott Williams & Wilkins

ISSN: 0025-7079/11/4911-0971

There is no difference in resource use between people with acute conditions, low-impact chronic conditions, and high impact chronic conditions when analyses are stratified by degree of multimorbidity (ie, number of types of conditions).² It is the degree of comorbidity (measured by the number of different types of conditions) that influences resource use, not the type of condition; the same is likely in the case of risk factors. It even appears that complications of chronic conditions may precede the diagnosis of the conditions themselves, as in the case of diabetes,⁸ thus suggesting an underlying set of multiple interrelated risks. An organ system approach to understanding the nature of ill health no longer serves well. As is the worldwide imperative to address the reorganization of health services to primary health care, so is addressing the interrelationships of risks and of diseases rather than focusing on particular diseases or types of diseases.⁹

In reality, there is no essential difference between acute illness and chronic illness, except for the increased likelihood that most chronic illnesses can be documented as lasting, in original diagnosed form, over a long period of time. In contrast to the concept of “chronic care” (which is equivalent to “primary care” in its focus on care over time, not just in encounters or visits), the concept of chronic disease care is antithetical to primary care because of its focus on diseases rather than on people.² Primary care (the provision of person-focused care over a long period of time) offers the best possibility to observe and manage individual patterns of risk factors as they occur and evolve into a variety of types of illnesses. The benefits of primary care are greatest for young populations (which can benefit most from prevention of future illnesses) and for people with the highest morbidity burdens.^{2,10}

The nature of morbidity is changing. Progressively lowered thresholds for prediagnosis with institution of management strategies runs the risk that any added benefit of early diagnosis is outweighed by side effects of medication in essentially well people, adverse effects of polypharmacy, and diversion of funds from existing illness to individuals who are well and may remain so for a long time.¹¹ The phenomenon of multimorbidity means that patients’ health problems are neither synonymous with their diagnoses nor the sum of their individual diagnoses.

Viewing illness as the interrelationship of coexisting diagnoses also provides a better view of inequity in health across population subgroups because socially vulnerable populations have greater likelihood of multiple diseases; their greater burden of illness is more readily visible through the lens of multimorbidity than it is when individual diseases are the focus of attention.

Preventing and managing morbidity belongs in primary care because of its special features: first contact, person-focused care over time, comprehensiveness, and coordination. The implications of an increase in prevalence (especially of “chronic diseases”) has the potential to change the nature

of the relationship between primary care and specialty referrals. Specialty care might evolve into direct consultation between primary care physicians and specialists rather than referring patients, except when special expertise is required to perform certain procedures. Guidelines for the management of multimorbidity in primary care will have to supplant guidelines for the management of individual diseases, leaving disease-oriented guidelines for specialists. Programs to manage specific diseases have not proven useful, and the promise of the “chronic care model” will not be realized in its current form because most of its implementation is in the context of single illnesses. A major summary of the world focus on “chronic illness management” concluded that there is no evidence of benefit from a focus of health systems or health services on any particular types of diseases, including chronic diseases.¹² The well-known but underappreciated secret of the value of primary care (person-focused) prevention is its focus on people and populations and on the interrelationships of risk factors and illnesses rather than on specific risk factors and diseases.

REFERENCES

- Rosenberg CE. The tyranny of diagnosis: specific entities and individual experience. *Milbank Q.* 2002;80:237–260.
- Starfield B. Chronic illness and primary care (<http://www.cahs-acss.ca/e/pdfs/cdm%20final%20Appendices.pdf>, accessed January 24, 2011). In: Nasmith L, Ballem P, Baxter R, et al., ed. *Transforming Care for Canadians with Chronic Health Conditions: Put People First, Expect the Best, Manage for Results—Appendices*. Ottawa, Ontario, Canada: Canadian Academy of Health Sciences; 2010.
- Will semantic web technologies work for the development of ICD-11? (http://bmir.stanford.edu/publications/view.php/will_semantic_web_technologies_work_for_the_development_of_icd_11, accessed January 24, 2011). In: Tudorache T, Falconer SM, Nyulas CI, Noy NF, Musen MA, ed. *9th International Semantic Web Conference (In-Use track)*, Shanghai, China. New York, NY: Springer; 2010.
- Tucker-Seeley R, Li Y, Sorensen G, et al. Lifecourse socioeconomic circumstances and multimorbidity among older adults (submitted for publication 2011).
- Starfield B. Pathways of influence on equity in health. *Soc Sci Med.* 2007;64:1355–1362.
- Kaplan RM, Ong M. Rationale and public health implications of changing CHD risk factor definitions. *Annu Rev Public Health.* 2007;28:321–344.
- Wolff JL, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. *Arch Intern Med.* 2002;162:2269–2276.
- Ormand BA, Spillman BC, Waldmann TA, et al. Potential national and state medical care savings from primary care disease prevention. *Am J Public Health.* 2011;101:157–164.
- Starfield B. Challenges to primary care from co- and multi-morbidity. *Primary Health Care Res Dev.* 2011;12:1–2.
- Starfield B, Shi L. Policy relevant determinants of health: an international perspective. *Health Policy.* 2002;60:201–218.
- Gervas J, Starfield B, Heath I. Is clinical prevention better than cure? *Lancet.* 2008;372:1997–1999.
- Nolte E, McKee M. *Caring for People With Chronic Conditions*. Maidenhead, UK: Open University Press; 2008.

Counterpoint: Chronic Illness and Primary Care

Edward H. Wagner, MD, MPH

Dr Barbara Starfield's pioneering research and effective advocacy have been pivotal in convincing policy makers in the United States and around the world that a robust primary care sector is the foundation of effective national health care systems. Her thoughtful and provocative commentary in this issue of the journal raises a number of important, interconnected concerns about the changing nature of morbidity and its implications for health care, especially primary care. The concerns emanate from her conviction that "Primary care... (the provision of person-focused care over a long period of time) offers the best possibility to observe and manage individual patterns of risk factors as they occur and evolve into a variety of types of illnesses." On this major point, I am in full agreement. Our work has been rooted in the conviction that chronic-illness care must be person centered¹ and is best delivered in primary care.²

As chronic illnesses often co-occur with other physical, emotional, or social problems, multimorbidity is the rule, not the exception. Dr Starfield's emphasis on multimorbidity is well placed because of its growing prevalence and the clinical challenges associated with a limited evidence base, polypharmacy, and coordinating care among multiple providers. Attention to other sources of risk and morbidity and their interacting effects may be neglected by a focus on a single disease. Studies have shown that this concern is justified,³ but may well be less of a problem when the patient is managed in primary care.² Disease-specific guidelines can be inappropriate in the face of comorbidities because multimorbid patients have often been excluded from the randomized trials from which guidelines emanate.⁴ Guidelines will have to evolve as we conduct more inclusive, pragmatic trials that include multimorbid patients.⁵ In the meantime, wise clinicians will have to create a coherent treatment plan from their knowledge of the patient, his/her health problems, and condition-specific guidelines based on evidence. As adherence to condition-specific guidelines generally improves outcomes, they remain an important starting point for care planning.⁶

But, Dr Starfield sees a threat to primary care—"the concept of chronic-disease care is antithetical to primary care because of its focus on diseases rather than on people." Her concern derives in part from problems with definitions of disease (within-disease heterogeneity and changing diagnosis thresholds), with which I have no disagreement. She appropriately emphasizes risk factors, and one can certainly think of type 2 diabetes as a bundle of risk factors for later morbidity and mortality. But, most chronic illnesses involve both current morbidity as well as future risks of complications and exacerbations, both of which need effective patient management and medical care.

She also questions whether the modifier, chronic illness, conveys any unique information of potential clinical import—"there is no essential difference between acute illness and chronic illness" except that the latter lasts longer. Our research and that of many others trying to improve outcomes of patients with chronic illnesses leads to a different point of view. Individuals with health problems that require ongoing management over years by the patient and their caregivers—our operational definition of a chronic illness—have a somewhat different set of needs than individuals with acute

From the MacColl Institute for Healthcare Innovation, Group Health Research Institute, Seattle, WA.

The author declares no conflict of interest.

Reprints: Edward H. Wagner, MD, MPH, MacColl Institute for Healthcare Innovation, Group Health Research Institute, 1730 Minor Avenue, Suite 1290, Seattle, WA 98101. E-mail: wagner.e@ghc.org.

Copyright © 2011 by Lippincott Williams & Wilkins

ISSN: 0025-7079/11/4911-0973

illness. The Institute of Medicine Committee on the Quality of Health Care in America attributed problems in the quality of care received by Americans with chronic illness to the acute care-oriented design of most delivery systems.⁷ Their study states that “unlike much acute episodic care, the effective care of the chronically ill is a collaborative process, involving the definition of clinical problems in terms that both patients and providers understand; joint development of a care plan with goals, targets, and implementation strategies; provision of self-management training and support services; and active, sustained follow-up” (p. 27).⁷ The Committee’s conclusion was that we need to redesign the organization of care delivery and practice teams and use information technology more effectively to better meet the needs of chronically ill patients.

Holman⁸ has written eloquently about the features of chronic illness that create different challenges to patients and their caregivers than do acute illnesses. He emphasized the undulating nature of chronic illness, variations in illness severity over time, which require competent, often daily decision making and management by patients and their loved ones over time. Certainly effective self-management is relevant for acute illness recovery, but self-management for people with illnesses such as cystic fibrosis, diabetes, depression, or asthma involves ongoing, sometimes lifelong, adjustments to lifestyle, work, medications, use of health care, and so on. Strong evidence now indicates that people with these illnesses can be counseled and supported to become more effective self-managers, and that such support is largely generic—that is, not disease specific. For example, the most thoroughly studied and disseminated self-management program includes patients with any chronic illnesses.^{9,10} Further, the most effective self-management support in primary care involves the use of well-established, general behavior change approaches to set goals, identify barriers, and develop action plans.¹⁰

The waxing and waning of most chronic illnesses puts people with these conditions at risk of morbidity and mortality, which can be mitigated by effective clinical care that increases control of the conditions, improves patient self-management, and detects exacerbations and complications early in their course. Medical care, especially primary care, can reduce the burden and risks of morbidity if it has the capacity to provide evidence-based services routinely over time to patients with ongoing health problems.

I am perplexed by Dr Starfield’s conclusion that “programs to manage specific diseases have not proven useful”, and the promise of the “chronic care model (CCM)” will not be realized in its current form because most of its implementation is in the context of single illnesses. If by programs to manage specific diseases, she is referring to disease management activities that focus on 1 condition, and are external to primary care, I agree that such programs have not proven useful.^{11,12} Some evidence suggests that they have failed because of their remoteness from primary care and their inability to influence it.¹² However, many interventions intended to improve primary care for patients with a specific illness have led to significant improvements in outcomes for patient with that illness.^{12–15} In general,

these interventions consist of fundamental changes to the infrastructure or organization of primary care practice rather than discrete disease-specific programs.

Although the specific changes to the infrastructure and organization of clinical practice tend to be general improvements, most of the research has evaluated the effects of the interventions on the outcomes of people with particular chronic conditions such as hypertension, diabetes, or depression.^{13–15} Although this evaluation decision creates the appearance that these interventions were disease specific in intent, reviews of this research confirmed 2 important findings:

1. Multicomponent interventions were more effective than single ones.^{16,17}
2. A common set of practice changes and interventions seemed to be effective across chronic conditions.¹⁸

These 2 observations provided the foundation for the development of the CCM.

Although the CCM has been largely implemented and evaluated with a focus on single condition patient populations,¹⁹ it was never intended to be disease specific. We and others chose to focus on populations of patients with a specific condition in early implementation and evaluation activities to simplify transformation and measurement for the participating practices, but these single condition populations have always included patients with multiple chronic conditions. For example, the vast majority of people with type 2 diabetes, the most common group studied, has high rates of other conditions such as hypertension, coronary heart disease, and depression. Regardless of condition, mounting evidence suggests that practices that implement the CCM experience improvements in outcomes.¹⁹ Therefore, the evidence, derived from populations with a particular condition, strongly indicates that changes to practice based on evidence improve outcomes for patients with other conditions and multimorbidity.

The more serious question is whether the CCM and the practice changes it includes somehow threaten or mitigate primary care’s focus on the person rather than diseases? The CCM was always intended as a complement to excellent primary care. A significant feature of the CCM is its emphasis on the ongoing relationship and interactions between an informed, activated patient and a prepared, proactive practice team.¹ Therefore, the orientation and goals of the CCM are consonant with the special features of primary care, particularly its focus on patient-centered care over time. This consonance has been recognized in the patient-centered medical home model,²⁰ which combines the CCM and pediatric medical home models. Recently published evaluations of the patient-centered medical home model have not focused on specific condition populations but have shown improvement in the care of chronically ill folks regardless of the nature or number of their chronic illnesses.^{21,22}

No one has contributed more to our understanding of primary care and its vital role in maintaining the health of a nation than Barbara Starfield. She will be sorely missed. Although we may disagree on some finer points, I share Dr Starfield’s conviction that the best care for a patient with

chronic illness will be provided by a primary care team, which knows them as people and treats them as such. But I also believe that effective, patient-centered care requires a practice infrastructure and organization designed to manage these folks effectively, and primary care providers with the training and experience to integrate condition-specific evidence and specialist advice into a coherent, patient-centered management plan. This seems unlikely to happen if we fail to recognize the unique needs of people with chronic illness and the changes to primary care systems that better meet their needs.

ACKNOWLEDGMENTS

The author thanks Katie Coleman and Rob Reid for reviewing earlier drafts.

REFERENCES

1. Wagner EH, Bennett SM, Austin BT, et al. Finding common ground: patient-centeredness and evidence-based chronic illness care. *J Altern Complement Med.* 2005;11(suppl 1):S7–S15.
2. Rothman AA, Wagner EH. Chronic illness management: what is the role of primary care? *Ann Intern Med.* 2003;138:256–261.
3. Redelmeier DA, Tan SH, Booth GL. The treatment of unrelated disorders in patients with chronic medical diseases [see comments]. *N Engl J Med.* 1998;338:1516–1520.
4. Tinetti ME, Bogardus STJ, Agostini JV. Potential pitfalls of disease-specific guidelines for patients with multiple conditions. *N Engl J Med.* 2004;351:2870–2874.
5. Tunis SR, Stryer DB, Clancy CM. Practical clinical trials: increasing the value of clinical research for decision making in clinical and health policy. *JAMA.* 2003;290:1624–1632.
6. Grimshaw JM, Russell IT. Effect of clinical guidelines on medical practice: a systematic review of rigorous evaluations [see comments]. *Lancet.* 1993;342:1317–1322.
7. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, DC: National Academy Press; 2001.
8. Holman H. Chronic disease—the need for a new clinical education. *JAMA.* 2004;292:1057–1059.
9. Lorig KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care.* 1999; 37:5–14.
10. Bodenheimer T, Lorig K, Holman H, et al. Patient self-management of chronic disease in primary care. *JAMA.* 2002;288:2469–2475.
11. Matke S, Seid M, Ma S. Evidence for the effect of disease management: is \$1 billion a year a good investment? *Am J Manag Care.* 2007;13: 670–676.
12. Coleman K, Matke S, Perrault PJ, et al. Untangling practice redesign from disease management: how do we best care for the chronically ill? *Annu Rev Public Health.* 2009;30:385–408.
13. Gilbody S, Whitty P, Grimshaw J, et al. Educational and organizational interventions to improve the management of depression in primary care: a systematic review. *JAMA.* 2003;289:3145–3151.
14. Shojania KG, Ranji SR, McDonald KM, et al. Effects of quality improvement strategies for type 2 diabetes on glycemic control: a meta-regression analysis. *JAMA.* 2006;296:427–440.
15. Walsh JM, McDonald KM, Shojania KG, et al. Quality improvement strategies for hypertension management: a systematic review. *Med Care.* 2006;44:646–657.
16. Renders CM, Valk GD, Griffin SJ, et al. Interventions to improve the management of diabetes in primary care, outpatient, and community settings: a systematic review. *Diabetes Care.* 2001;24:1821–1833.
17. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, Part 2. *JAMA.* 2002;288:1909–1914.
18. Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Q.* 1996;74:511–544.
19. Coleman K, Austin BT, Brach C, et al. Evidence on the chronic care model in the new millennium. *Health Aff (Millwood).* 2009;28:75–85.
20. American Academy of Family Physicians (AAFP), et al. Joint principles of the Patient-Centered Medical Home 2007.
21. Reid RJ, Coleman K, Johnson EA, et al. The group health medical home at year two: cost savings, higher patient satisfaction, and less burnout for providers. *Health Aff (Millwood).* 2010;29:835–843.
22. Gilfillan RJ, Tomcavage J, Rosenthal MB, et al. Value and the medical home: effects of transformed primary care. *Am J Manag Care.* 2010; 16:607–614.

Last Word: Barbara Starfield's Road Map

Lisa I. Iezzoni

“A force of nature” was how one of her former doctoral students described Barbara Starfield to me. The trainee went on to invoke other adjectives—including precise, exacting, and rigorous—shaking her head somewhat ruefully at the recollection. However, Barbara’s former student was clear about 2 critical points: Barbara’s laser-like, concentrated mentorship drew the best intellectual efforts from her students, and Barbara’s own passions inspired others—in this instance, generating a life-long interest in primary care and multimorbidity in her former trainee.

In addition to the forcefulness of her mind and personality, one likely reason that Barbara inspired others was that her passions focused on issues that appeal to the “better angels of our nature”—primary care that recognizes and responds to the diverse forces that determine health for individuals and populations, eliminating inequities in care wherever they occur, giving the youngest and thus most vulnerable among us the best foundation for future health, and ensuring that forgotten populations worldwide have a voice in creating environments within which their health can thrive. It was hard, if not impossible, to argue with Barbara’s broad vision, which was built upon a solid and immutable foundation of social justice.

However, at times, it was also equally impossible not to dispute certain details of Barbara’s assertions and prescriptions for achieving her vision. After agreeing to write this essay—to be the third in the thread initiated by what will be Barbara’s last of many pieces in *Medical Care* and published posthumously¹—I grew increasingly panicky as I read and reread her manuscript. I disagreed with many of her key points, sometimes emphatically. In life, though, I found it difficult to argue with Barbara. I recognized and respected her many years of commitment and toiling in the field, the broad and deep wisdom that she had instilled. More to the point, though, she was a spirited debater, challenging her conversational partners to defend their positions. With Barbara, I generally found it was better to listen and learn. Now, especially, is not the time for me to argue my dissent: I will let Barbara’s essay stand, in my view as “vintage Barbara”—challenging, provocative, perhaps a bit on (or over) the edge, to make her passionately held points.

Barbara’s loss would have been incalculable at any time. However, there is a particular irony in losing her now, just as the nation is focusing anew on primary care and eliminating health-care disparities through provisions of the Patient Protection and Affordable Care Act (ACA). Although she did not write the ACA, Barbara’s fingerprints—or extensions of her research, writings, clinical practice, and advocacy over decades—wend throughout the law. Her signature issue is encapsulated in the leading words of ACA Title V, Subtitle F “Strengthening primary care...” As a dedicated pediatrician, Title II, Subtitle B “Enhanced Support for the Children’s Health Insurance Program” would have won her staunch advocacy. Other selected examples of Barbara’s fingerprints include the following ACA sections:

- Sec. 3502: Establishing community health teams to support patient-centered medical homes.
- Sec. 4206: Demonstration project concerning individualized wellness plan.
- Sec. 4301: Research on optimizing the delivery of public health services.
- Sec. 4302: Understanding health disparities: data collection and analysis.
- Sec. 6301: Patient-centered outcome research.

If Barbara were still here, the admonition to “listen and learn from her” would have carried immediate and forceful weight with policy makers charged with the ACA's implementation. Barbara would have kept policy makers honest—exhorted them to achieve the goals represented by the law's lofty aspirations.

Throughout her decades of research, writing, clinical practice, and service to the health-care and public health fields, Barbara Starfield laid down a road map for others to follow. She stated clearly her ultimate destination: achieving equity in health and health services for individuals across the lifespan and for all populations in their rich diversity.^{2,3} Primary care—care she helped define—offers an evidence-based vehicle for getting there.^{4,5} Policy makers, public health officials, health-care delivery system leaders, and

clinicians should keep her road map close at hand. Barbara's legacy will continue to inform and inspire efforts to improve care, and thus lives, for decades to come, nationally and worldwide.

REFERENCES

1. Starfield B. The changing nature of disease: implications for health services. *Med Care*. 2011;49:971.
2. Starfield B. The hidden inequity in health care. *Int J Equity Health*. 2011;10:15.
3. Furler J, Harris E, Baum F, et al. An international society and journal for equity in health: 10 years on. *Int J Equity Health*. 2011;10:11.
4. World Health Organization. *The World Health Report 2008: Primary Health Care Now More Than Ever*. Geneva: World Health Organization; 2008.
5. Sandy LG, Bodenheimer T, Pawlson LG, et al. The political economy of US primary care. *Health Affairs*. 2009;28:1136–1144.