How Patient-Centered Medical Homes Can Bring Meaning to Health Care: A Call for Person-Centered Care

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ABSTRACT

The development of patient-centered medical homes in the United States was, among other things, an attempt to improve patients' experiences of care. This and other improvement strategies, however, have failed to confront a major barrier, our disease-oriented medical model. Focusing on diseases has contributed to subspecialization and reductionism, which, for patients, has increased medical complexity and made it more difficult to engage in collaborative decision making. The progressive uncoupling of disease prevention and management from other outcomes that may matter more to patients has contributed to the dehumanization of care. An alternative approach, person-centered care, focuses clinical care directly on the aspirations of those seeking assistance, rather than assuming that these aspirations will be achieved if the person's medical problems can be resolved. We recommend the adoption of 2 complementary person-centered approaches, narrative medicine and goal-oriented care, both of which view health problems as obstacles, challenges, and often opportunities for a longer, more fulfilling life. The transformation of primary care practices into patient-centered medical homes has been an important step forward. The next step will require those patient-centered medical homes to become person centered.

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INTRODUCTION

The creation of patient-centered medical homes (PCMHs) in the United States was an attempt to address 3 meaningful patient-oriented concerns: reductionism, paternalism, and medical complexity. Although substantial progress has been made, improvement strategies have failed to address a root cause of these problems, our disease-oriented medical model. The successes of disease-oriented care have too often overshadowed the actual person-centered goals of health care, namely, helping people live longer, more fulfilling lives.

Building PCMHs that can deliver person-centered care will require a fundamental change in the way we—clinicians, patients, policy makers, payers, and administrators—think. The assumption that prevention and management of disease will result in personally meaningful outcomes is valid only in those unusual circumstances when context is unimportant. Until we learn to focus more directly on the outcomes important to each person, care will not actually be patient centered. In this article, we discuss some of the challenges that PCMHs have addressed and then propose 2 complementary approaches that can guide us toward truly person-centered care.

HISTORICAL CONTEXT

As a natural consequence of our efforts to eradicate disease, medical care has become increasingly subspecialized and dispersed across multiple clinicians and settings. That shift has made the health care system increasingly impersonal and hard to navigate. It has also created a power differential whereby patients are dependent on the medical knowledge of clinicians and subject to the complex policies and procedures of the health care delivery system. In an effort to address those concerns, clinicians, policy makers, and payers have embraced the concept of patient-centered care, although the idea is far from new.

As early as 1899, Sir William Osler proclaimed, "Care more particularly for the individual patient than for the special features of the disease."[1] In a 1927 *Journal of the American Medical Association* article, Francis Peabody wrote, "The treatment of

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a disease may be entirely impersonal; the care of a patient must be completely personal."[2] In 1948, the World Health Organization insisted that health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity,"[3] and in 1969, the British psychoanalyst Enid Balint and colleagues[4] coauthored an article entitled "Training Medical Students in Patient-Centered Medicine." In 1967, the American Academy of Pediatrics introduced the concept of medical homes to coordinate the care of children with special health care needs.[5] Two years later, the specialty of family medicine was founded to "rescue a fragmented health care system, put it together again, and return it to the people."[6]

The term *patient centeredness* reappeared in the Institute of Medicine's 2001 *Envisioning the National Health Care Quality Report*.[7] It was defined as "health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they require to make decisions and participate in their own care." Since then, US health systems have implemented a variety of processes, tools, and professionals to enhance patient-centeredness, including open-access scheduling, patient portals, postvisit summaries, coaches, care coordinators, patient navigators, and patient advisory committees. Patient-solicited feedback is now routine, and clinicians who score poorly receive additional training. The Patient Protection and Affordable Care Act of 2010 established the Patient-Centered Outcomes Research Institute to engage patients in research.

PATIENT-CENTERED TYPOLOGIES

In 2015, Tanenbaum[8] reviewed the literature and identified 3 typologies of patient-centered care based on the problems they were designed to address. The first type attempts to combat reductionism, viewing people as the sum of their parts. The quest is whole-person care. Strategies have included implementation of the biopsychosocial model and integration of physical and mental health services.[9] A major policy objective has been recruitment, training, and support of primary care clinicians.

The objective of the second type of patient-centered care is to elevate the status and influence of patients. Approaches have included shared decision-making tools, postvisit summaries, patient-reported outcome measures, and patient involvement in quality improvement and research. At the policy level, advocates have encouraged value-based reimbursement, whereby value is derived, in part, from patient-reported outcome measures.

The intent of the third type of patient-centered care is to make the health care system more user friendly. Its methods include systems reengineering to improve patient experiences, patient portals, new team members (eg, care coordinators and patient navigators), and economic innovations such as accountable care organizations to improve care coordination and comprehensiveness.

Although each approach addresses a problem patients have had with the health care system, none of them addresses the underlying cause of those problems. When the focus is on diseases, subspecialization and reductionism are natural consequences. Subspecialization increases the numbers of clinical interactions, record systems, care locations, and recommendations, complicating coordination and continuity and patients' ability to access and navigate the system. It is difficult for patients to meaningfully contribute to clinical decision making when they know so much less about diseases and the organization of the health care system than their clinicians.

In 2007, thought leaders in primary care resurrected and adopted the term *patient-centered medical home* (PCMH). All of the allopathic and osteopathic primary care professional associations subsequently endorsed 7 structural principles of PCMHs: (1) every patient should have a personal physician; (2) practices should be physician directed; (3) care should focus on the whole person; (4) care should be well coordinated and fully integrated; (5) quality and safety should be emphasized; (6) access to care should be optimized; and (7) the payment system should be reformed.[10] The principles further stated, "Practices advocate for their patients to support the attainment of optimal, patient-centered outcomes that are defined by a care planning process driven by a compassionate, robust partnership between physicians, patients, and the patient's family" and "Patients actively participate in decision-making, and feedback is sought to ensure patients' expectations are being met." These PCMH principles and functions encompass all of the 3 patient-centered care typologies that Tanenbaum[8] identified.

The clinical methods required to provide patient-centered care within the PCMH structure have been articulated by Stewart and colleagues.[11] There are 6 components: (1) exploring both the disease and the illness experience; (2) understanding the whole person; (3) finding common ground; (4) incorporating prevention and health promotion; (5) enhancing the patient-physician relationship; and (6) being realistic. Their conceptualization is an attempt to resolve the tension between patient-centered care and the traditional disease-oriented approach.

PERSON-CENTERED CARE

Tanenbaum[8] identified a fourth typology that she called person-centered care, which has been defined by Miles and Mezzich[12] as "a medicine of the person (of the totality of the person's health, including its ill and positive aspects), for the person (promoting the fulfillment of the person's life project), by the person (with clinicians extending themselves as full human beings, well grounded in science and with high ethical aspirations), and with the person (working respectfully in collaboration and in an empowering manner through

a partnership of patient, family, and clinician)." Coincident with Tanenbaum's article on typologies, an American Geriatrics Society panel[13] published the following definition: "Person-centered care means that individuals' values, preferences, goals, and priorities are elicited and once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires."

In this fourth type of patient-centeredness, the focus is on each person's life project. The clinician's concern shifts from, "What's the matter with you?" to "What matters to you?" Health problems are viewed not as undesirable abnormalities, but as obstacles, challenges, and opportunities to achieve major life goals. Health status is gauged by personal successes over time rather than population-derived measures of normality. Two approaches to person-centered care have been described: narrative medicine and goal-oriented care.

Narrative medicine is based on the importance of personal stories and clinicians' ability to "absorb, interpret, and respond to them."[14] The premise is that "along with scientific ability, physicians need to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf." The skills required are not unlike those used to analyze and comprehend works of literature, including point of view, setting, characters, plot, important events, conflicts, language, metaphors, and themes. Also acknowledged is the value to the patient of constructing their narrative, which can give "shape to and control over the chaos of illness."[14]

Goal-oriented care is based on the conceptualization of life as a journey filled with challenges and opportunities, and health as the ability to derive as much benefit—joy, meaning, growth, fulfillment—as possible from the experience. The purpose of health care then is to help each individual live a long and meaningful life, optimize personal growth and development, and experience a good death. Those goals, as understood and prioritized by individuals seeking assistance, drive and shape cocreated plans of care.[15,16]

Whereas disease-oriented care assumes that eradication of diseases will ensure that patients will experience longer, more rewarding lives, goal-oriented care focuses directly on the desired outcomes and the values underlying them. Patient-centered care engages in the prevention and treatment of health problems while taking into account the background, values, preferences, and goals of the person affected. Person-centered care aspires to help individuals have long and fulfilling lives by helping them reduce risk, face challenges, and capitalize on opportunities for personal growth and development. That shift in mindset and focus expands the range of therapeutic options, provides a basis for prioritization, and supports interdisciplinary teamwork. It should be noted that focusing on outcomes in no way diminishes the importance of clinical knowledge and skills. In fact, individualizing and prioritizing care requires even greater clinical expertise.

In Table 1, we illustrate the differences between patient-centered care, narrative medicine, and goal-oriented care using prototypical clinical questions. It should be noted that although narrative medicine emphasizes the development of additional clinical knowledge and skills, goal-oriented care provides a rational framework within which clinical knowledge and skills can be applied. The 2 approaches are therefore complementary.

That complementarity extends to the value of these approaches for transforming practices and health care systems. Proponents of narrative medicine point out the importance of the narratives shared between colleagues, and the narratives explaining relationships between clinicians and the larger society. By creating a collaborative process focused on those seeking assistance, goal-oriented care provides a practical framework for clinical, professional, organizational, and system-level integration of services.[17]

In the past 50 years, a desire for person-centered care has driven a number of changes in health care. The development of birthing centers in the 1970s was driven by women who objected to overmedicalized obstetric care. Palliative care grew out of a desire for better quality of life and healing relationships at the end of life. Athletes were largely responsible for the development of sports medicine. The high rates of nonadherence to clinical guidelines by both patients and clinicians and the rates of clinician dissatisfaction and burnout suggest that neither patients nor clinicians are satisfied with our current approach to care.[18]

THE CHALLENGE AHEAD

Although health care has become somewhat more patient centric, parallel efforts to improve quality and reduce variability have reinforced the disease-oriented approach. Standardization has affected the design of medical records, decision-support strategies, population management systems, and coding and billing processes, and although efforts to improve quality are laudable, many believe they have amplified a transactional approach to care that will make further progress toward person-centered care more difficult.[19]

The good news is that substantial groundwork for a person-centered approach has been laid. Many medical schools offer narrative medicine courses, and centers of excellence, textbooks, and curricula are available. Examples of goal-oriented care also exist within and outside of the health care system. Occupational therapists, orthopedists, palliative care clinicians, mental health professionals, social workers, some geriatricians, as well as teachers, financial planners, lawyers, and personal trainers all use goal-oriented approaches. The emerging literature includes relevant research, books, and online instructional materials for clinicians and patients, and demonstration sites are being developed in the United States and several other countries.[17,20-24]

Table 1. Primary Focus and Prototypical Clinician Questions Illustrating 3 Approaches to Care

Aspect	Patient-Centered Care	Narrative Medicine	Goal-Oriented Care
Primary focus	Health problems (symptoms, diseases)	Person's life story (actual, imagined)	Desired outcomes (goals, priorities)
Meaningful life goals			
Prevention of premature death	Now that you have turned 45, you should begin to get screened for colon cancer. Knowing how you feel about invasive procedures, would yearly stool tests be preferable to colonoscopy?	What would you like to see and do before you die? What do you think you could do to increase the chance that you will live long enough to experience those things?	What do you think you are most likely to die from? Have you thought about how to keep that from happening?
Good current quality of life	What level of pain are you experiencing? What troubles you most about it? What have you done to try to handle it? How much is the medicine I gave you helping? How has the pain affected your marriage?	How has the pain affected the life you had imagined for yourself? How would your life be different now had you not developed this painful condition? What adjustments have you had to make?	What do you want to be able to do that you can't do now? Why are those activities important to you? How much has the pain interfered? What options have you considered?
Growth and development (physiologic, psychological, and spiritual)	Can you tell me about your childhood? How far did you go in school? What jobs have you held? Tell me about your marriage and other important relationships. What challenges have you faced?	What would you like for me to know about you? How would you say your life has gone to this point? What does the future look like? What challenges have you faced and what challenges do you anticipate?	What challenges are you facing? How have you coped with similar challenges in the past? What opportunities do they present for you? How can I help?
Good death	Have you thought about your end-of-life wishes? Have you completed advance directive documents? Have you discussed them with your family?	How long do you expect to live? How would you like to spend your final days? What steps have you taken to try to help things turn out that way?	What conditions in life would be worse for you than death? What have you done to make sure that when you die, you have a good death as you define it?

NEXT STEPS

The creation of PCMHs has led to important advances in the structures and processes required to deliver patient-centered care, and in the types of quality improvement assistance practices need. Primary health care has become more holistic, collaborative, and coordinated; however, there is more to be done. Designing PCMHs that can deliver person-centered care will require a fundamental change in how we think about health and health care. Health is the ability to participate in and derive meaning from activities and relationships for as long as possible, not a list of problems to eliminate. We have been so focused on clinical strategies that we have lost track of the goals of care. Once that realization reaches a critical mass of early adopters, necessary changes in structures and processes of care will follow. Given that people are even more complex than diseases, primary care teams will be expanded to include allied, social, and mental health expertise. Person-centered decision-making tools, curricula for students and residents, training programs for practicing clinicians, demonstration sites, and implementation guides will be implemented. We can do this, and we should.

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Key words: patient-centered care; patient-centered medical home; person-centered care; goal-oriented care; narrative medicine; primary care; disease-oriented medical model; organizational innovation; delivery of health care; professional practice

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Corrections

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An abstract in the NAPCRG 49th Annual Meeting – Abstracts of Completed Research 2021 contains incorrect author attribution. The authors of this abstract are Karl Nadolsky, Donna R. Cryer, Amy Articolo, Travis Fisher, Jennifer Schneider, and Mary Rinella. Elizabeth Tanner is not an author. The authors regret the error.

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In: Orrego C, Perestelo-Pérez L, González-González A, et al. A virtual community of practice to improve primary health care professionals' attitudes towards patient empowerment (e-MPODERA): a cluster randomized trial. *Ann Fam Med*. 2022;20(3):204-210, the affiliations for one of the authors, Carlos Bermejo-Caja, MSc, were listed incorrectly. The author's affiliations are Unidad de Apoyo Técnico, Gerencia Asistencial de Atención Primaria, Servicio Madrileño de Salud, Madrid, Spain and Departamento Enfermería, Universidad Autónoma de Madrid, Spain (not Universitat Autònoma de Barcelona, Barcelona, Spain). The authors regret the error. The article has been corrected online.