

Person-Centricity: Promoting Self-Determination and Responsibility in Health and Health Care

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ABSTRACT The transition from a system focused on the delivery of sickness and illness services to one with a heavy focus of helping people become and remain healthier requires a major shift in how we view the patient and person. The health care system attempts to magically transform us from persons to patients in a context of sickness and disease, in need of medical procedures and interventions. Those few hours we spend a year in formal medical and health care contexts do not define us in the broader life space. We contend that “person-centricity” is more reflective of the life space and as such better supports that shift than do models of consumer or patient empowerment, centeredness, engagement, or activation. “Person-centricity” represents the complexity of how individuals make decisions including health and health care decisions, within the broader context of their lives, and accurately addresses the needs and aspirations of people throughout their life journey. This is not simply a shift in semantics, but an entirely new paradigm that frees the individual from assuming and succumbing to the passive and subservient patient role and dramatically changes the way in which we view ourselves and interact with the health care system. The changes required to create a healthier America and affect costs associated with lifestyle-related diseases need to happen on a personal level, coupled with a supportive infrastructure and public policies to promote and sustain them. This shift is critical to our transition from health care to a healthier way of living and of controlling avoidable costs.

INTRODUCTION

Each person defines him/herself by their past, their values, preferences, and aspirations; they decide what personal truths to keep private, and which truths to share with others. The term “patient” is defined variously as a sufferer; one who suffers from bodily disease; one who is subjected to supervision, care, or treatment or correction; one who is under medical treatment; or merely one who waits.¹ The transition from person to patient has been fueled by the complexity of the system, which for the most part excludes the person from the process of decision-making. Patients are constructs imposed on the person and at best are but one restricted persona of any individual person. Health plans and policy experts routinely lament that the patient is not vested enough in the program. Yet the same experts have not provided meaningful pathways for the person to own their own role in the decision-making process. Our focus needs to shift from passive patients to active persons. Person-centricity² is an ongoing, continuous, dynamic process in which all constructs and actions revolve around the person and his/her decisions. It profoundly transforms how our decisions including

health-related and health care decisions are made and who has the authority and ability to make them. More broadly, a person makes changes to promote, improve, maintain, and sustain their health and lives they lead as persons.³ Such a paradigmatic shift views the individual as a “regulating fulcrum” managing information and requires a supportive infrastructure to help evaluate and filter the information in a way that is consistent with his/her values, priorities, preferences, beliefs and aspirations.⁴ We contend that self-determination expressed through “person-centricity” better supports that shift than do models of consumer or patient empowerment, centeredness, engagement, activation, shared decision-making, patient-centered care, and other efforts to engage individuals, and adjudicates many experiential pathways of health and wellness, including experiences within the health care infrastructure, as a component of people’s broader life experiences.

The relationship between the notion of person-centricity and the transition from health care to health is symbiotic. The concept of person-centricity functions as both the missing link and the common thread that weaves together the needs, choices, and aspirations of people throughout their health journey and is absolutely crucial in addressing the mind, body and spirit triad required to support and inspire all individuals to reach higher levels of health, self-actualization, resilience, and well-being. The policy implications for supporting people in their pursuit of health require a change of mindset away from that of either “patient” or “consumer” and are indeed life-changing.

Our current health care system is illness- and disease-based, with cost centers promoting procedures to manage disease states. The shift from health care to health should increase person awareness, compliance, and cost savings. As

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centric-persons we wish to stay healthy and not “get” sick, but most of our current efforts at prevention are limited to, and targeted toward, sickness/disease prevention rather than a broader sense of health and health promotion. A more expansive view of prevention would be based upon the person’s readiness, resilience, and endurance. Readiness prepares or readies a person to respond to potential or actual events, while resilience refers to the ability to recoil and regain one’s homeostasis pursuant to an event. Resilience varies over time and can be affected by stress, job, relationships, or financial concerns. The systematic resilience and readiness of both the individual and their larger community must drive our thinking toward maximizing health, and supersede our entrenched views of “prevention,” with its narrow focus on disease avoidance.

Compared with prevention, health is a continuous and dynamic process; it involves the “capacity of an individual and community to adapt and self-manage”⁵ in the face of social, physical, and emotional challenges. And whether health improves or deteriorates is strongly influenced by our choices, actions, and behaviors. So, if we are to be successful in our efforts to solve the nation’s health crisis, our person-centricity approach needs to focus on more than prevention; it must focus on health.

It is also time, we take a fresh look at our traditional approach to health care and decide if we are prepared to continue to finance an unsustainable system. We must move from a procedure-driven to a health-value-driven system. And we need to change the belief that the person’s only stake in the path to health is through the “waiting room” as a “patient.” The system must serve the person and their community to support and promote healthy behaviors and guide the individual toward a state of well-being.

This new system of care is grounded in behavioral change and utilizes low-cost alternatives to our current “episodic care” approach. In his provocative article, Steven Brill suggests a “systemic overhaul.”⁶ That is consistent with our concept of person-centricity; many of our health care woes evaporate if we can remain outside of the “system” as much as possible, and we can best achieve that by staying healthy. Patients seek treatment for relief from maladies; persons seek both treatment and sustainable health.

Moreover, “prevention is an investment to be leveraged rather than a cost to be justified.”⁷ To facilitate and optimize the impact of person-centricity, we need to go beyond the individual person and target an entire community for health improvements, not just an insured life or member or a caregiver’s panel of “patients.” On a community, systemic and national level, we need to be true to the spirit of our missions. Health plans and providers must be charged with planning for health and truly managing care rather than premium dollars. Communities must step up with infrastructure and safety net protections to support those in greatest need and peril. Promoting and sustaining health must be rewarded. For example, we suggest consideration of the development

of policy to allow a new health insurer to bill the prior health insurer for closing all evidence-based gaps in prevention (e.g., immunizations, colon cancer screening, etc.) that were warranted while under the care of the previous insurer. This approach will incentivize ALL health plans to improve preventive care and plan for health, despite rapid turnover of members. This allows for a fairer distribution of the burden of cost and compliance that needs to be reinforced. We need to move from excuses to solutions.

SHARED RESPONSIBILITY

Person-centricity requires that each person be vested with the responsibility for his or her health. However, we must be vigilant not to abandon the person in self-determining their health and health care by shifting responsibility to the person without tools or an adequate infrastructure to support them; there is a balance. Person-centricity is most effective when there is synergy among the payor, community, health professionals, and government to create the requisite infrastructure to invest the person with more say and control in their lives and health. This is far from excusing anyone, be they person, payor, community, or government, to avoid responsibility; there is a balance and shared responsibility between what systems provide people and what they themselves need to take responsibility for. Person-centricity is a mandate to support the person to become a more active agent in the course of their lives rather than a passive victim to the decision and choices of someone other than themselves. In addition, person-centricity acknowledges that in this construct individuals have a responsibility to their communities for their health.

This paper presents a shift in the way we currently think about health, health care, and personal responsibility as applied to the person, and describes some of the parameters that we and our nation needs to consider for implementing and supporting such a shift.

DEFINING THE ROLE OF SELF-DETERMINATION IN PERSON-CENTRICITY

Self-determination (autonomy), transparency, and health literacy create a substrate as well as serve as a catalyst whereby the person can choose or not choose to be part of an accessible collaborative interaction with health and sickness providers. This does not shift accountability and responsibility to individuals alone, but it does make them part of the equation as the person, community and the system working collaboratively to fuel needed change and correct systemic inequities.

For example, consider a person who has been asked by his physician to undergo a routine screening that will provide only limited or conflicting evidence. The physician may offer the option of the test simply because it is considered the standard of care in the geographic region in which they practice. On the other hand, and more often, the physician

might instead focus on the individual as a person and begin a dialog leading to a shared decision.

In this second scenario, the person will consider the evidence for performing the test in the context of their personal risk for developing the condition and desires for treatment. Such a collaborative model needs not be limited to such a narrow range of decisions but can be extended across the spectrum of health and health care-related interactions and policies.

In the person-centricity model, people are not subservient to the will of their providers, health teams, or anyone else. This is a significant departure from the “captain of the ship” mentality where the provider decides. Health care professionals will need to accommodate this difference, beginning with early professional education processes. In practical terms, we need never again think of the woman in Room 215 as a broken hip with congestive heart failure; she will be a person with these conditions that have come to us for help, guidance, and peace of mind.

The person-centricity approach then encourages the person to become more expert on him/herself in assessing the impact of any treatment or option. In health care contexts, the provider may offer advice on the recommended treatment regimen and, in concert with the person, optimize the desired outcome. This approach is enhanced and strengthened when the appropriate support infrastructure exists, such as a composite of insight and defined knowledge that people can consider, gained from population profiles through evidence-based comparative effectiveness studies.

CREATING AN APPROPRIATE SUPPORT STRUCTURE FOR SELF-DETERMINATION

Federal and state governments have a role to protect the less fortunate and ensure that market forces do not unethically “game the system.” Local government has an obligation to secure funding needed to address the unique needs of local communities to ensure effective infrastructure and coordination of services. Local non-government organizations need to participate and help to coordinate ancillary services for the disadvantaged and tackle locally problematic health issues. And local industry leaders need to drive healthy communities where their employees live by investing in the creation of health-promoting infrastructures that ultimately reduce health care outlays. When communities and local leaders work together in mutually supportive ways, the relationship enhances the overall goals of the community at large as well as the individuals within them. These efforts need to be established to support the needs of the individual, and in turn the role of the individual is to fully exploit healthy opportunities within their communities consistent with the concept of person-centricity.

In 2003, the World Health Organization (WHO) published an influential document, “The Solid Facts” on the social determinants of health. It points out that “poor social

and economic circumstances affect health throughout life. People further down the social ladder usually run at least twice the risk of serious illness and premature death as those near the top...The longer people live in stressful economic and social circumstances, the greater the physiological wear and tear they suffer, and the less likely they are to enjoy a healthy old age.”⁸ This is meant to help us understand what we need to do to affect change across the population, not to serve as an excuse to maintain the status quo or to excuse people, the community and the system from doing whatever they can to make a difference. Each of us can do something to improve our lives and health, and public health efforts need to address the health implications of social and environmental factors that will successfully effect change across populations. Even small changes collectively can make huge differences! This is a significant benefit of the person-centric concept.

While person-centricity relies on some fundamental changes in policy and infrastructure within the health care system, there are many changes outside the conventional health care system that must be addressed in support of the of entire communities.

Many of the health components to support person-centricity need to be community-based. These include systematic support for exercise and healthy eating K-12, the elimination of nutritional deserts of inner cities, programs to create safe parks and sidewalks, engagement of the spiritual community to support local health and homebound persons, and leveraging mobile apps for health that have a demonstrated evidence base for success. It requires improving the safety of social media for health, primarily through stronger privacy policy supporting transparency into “who has my data and what are they doing with it?” and sanctions for unauthorized uses.⁹ And coordination of community health services, especially mental and behavioral health, and better engagement of personal social support networks for healthier behaviors. Finally, it involves avoiding extremes of excess and deficiency and seeking balance in our lives regardless of our age, socio-economic status or current state of health. And, of course, it is critical that patients believe in themselves and have confidence in their ability to take control of their own health; belief and confidence in one’s self is foundational to the notion of person-centricity.

Furthermore, we need metrics and challenges for community-based programs that provide an evidence basis for what works in which context (e.g., a rural Appalachian town needs very different solutions than inner-city New York for narrowing health disparities).

LEVERAGING HEALTH INFORMATION TECHNOLOGY AND MOBILITY TO REINTEGRATE HEALTH INTO OUR LIVES AND BEND THE SICKNESS CURVE

Our system has matured to allow us to align the advances of information technology, mobility, and advanced technologies

to allow us to recapture both the concept of person and health back into the framework of living in order to improve the health of the person, the community of persons, and the nation as a whole.

We have improved tools at our disposal to engage the community and support person-centric decision-making through mobile health solutions, genomics, and comparative effectiveness. We need a venue in which these elements can be integrated for the person, which can be best achieved through increased health literacy. Such a re-integration is consistent with those elements of self-determination, prudence, good judgment, and personal and social responsibility that typify the American spirit and tradition.

Mobile technology, through high-speed networks and smartphones, has transformed the ways we work, learn, communicate, and play. Instant access to information on the World Wide Web and the ability to contact anyone wherever they may be have changed the world forever. But as serious as our national health crisis is, the evolution of the ecosystem for mobile apps for wellness will need to include tools that address that small but significant cohort vulnerable to “wellness anxiety.” In a paradigm of sickness and disease, there are those who fear they are too sick; in a paradigm of health and wellness, there are those who will now fear they are not well enough. Health professionals will need to recognize and address this condition.

Mobile technology can help address this issue through easily-accessible, real-time, continuous data for current status updates. Improving our health by using a smartphone collecting a broad set of physiological data from sensors that use Bluetooth Low Energy are already hitting the market. These data are sent to caregivers and even to expert systems that will analyze the information and provide actionable feedback that allows us to modify our behavior.

While technology is not a panacea for all of our nation’s ills – the negative impacts of technology on our society are only now becoming all too apparent – health information technology, properly integrated with clinical practice, has significant potential to help address some of our most intractable health issues as a society.

HARNESSING THE POWER OF GENOMICS AND EXPOSOMICS TO PROVIDE PERSONALIZED CARE

Genomics will play an increasing role in both personalized medicine and in self-determined healthy living through which the individual can use their genomic information to guide decisions for health, disease prevention, and disease management. These include personalizing dietary habits based on genetic profiles, reducing drug side effects by use of genomics and personalized medicine, as well as monitoring and mitigating personalized risk of genetic predispositions.

The CDC says that “one of the promises of the human genome project was that it could revolutionize our understanding of the underlying causes of disease and aid in the

development of preventions and cures for more diseases. Unfortunately, genetics has been found to account for only about 10% of diseases, and the remaining causes appear to be from environmental causes. So, to understand the prevention of disease, environmental causes need to be studied.” What that means to us is that the social determinants of health play a far more significant role in a person’s health than do genetics.¹⁰

In most cases, disease results from a combination of multiple genes, variation in the level of expression of those genes, and the environmental influences on how those genes and their products interact. Individuals at higher risk should be more vigilant about healthy lifestyle choices with exercise, diet and sleep habits, which will postpone or prevent the onset of these conditions.

The role of genetically guided therapies in clinical care is growing rapidly, with an ever-growing list of genetically targeted cancer therapeutics, such as breast cancer, that have become standards of care. The number of conditions for which genetically based drug selection and dosing is relevant is also growing and includes large classes of drugs such as anti-coagulants, anti-depressants, lipid-lowering agents, anticonvulsants, and others. The value of knowing an individual’s genetic profile includes guiding therapeutic options for initial drug selection, drug dosing, and for minimizing drug–drug interactions, and conditions related to potential adverse reactions.

CAPITALIZING ON THE INSIGHTS OF COMPARATIVE EFFECTIVENESS RESEARCH

In addition to genomics, we can also support people making better decisions through access to knowledge and dissemination of studies designed for comparative effectiveness research (CER). CER uses large data sets to compare different drugs, devices, surgical interventions, behaviors, and delivery strategies head to head in real-world settings to determine the most effective approach to a given illness or condition. CER rises above historical preference, loyalty to a specialty, and perceived value to help us move from eminence-based practice to evidence-based practice, generating better outcomes and to help individuals strengthen their autonomy.

OPTIMIZING PERSON-CENTRICITY THROUGH IMPROVED HEALTH LITERACY

The autonomy that is so critical to person-centricity is further enhanced by improved health literacy. Improving health literacy skills promotes autonomy. Health literacy is the ability to obtain, process and understand basic health information that is required to make health decisions, and apply these skills in evaluating options and weighing alternatives and costs to determine best choices. Decision-making often requires support and we must be cognizant of that reality that acting on new information can create a potential overload.

Imagine a person seeking advice from a family physician, orthopedist, and rheumatologist for treatment related to a vertebral compression fracture. She will likely get three different answers with conflicting information in respect to best options and cost. Making the best choice requires leveling the playing field by outfitting that person with better tools to evaluate evidence-based treatment options that are personalized for the individual.

Decision-making should pivot on what the person determines is best rather than who or where care or services are sought. However, given the current reality, having a trusted source is critical in helping to identify the most appropriate site and clinician for that care, service, or procedure. Health literacy and a supporting infrastructure are critical to optimizing person-centricity.

Conversations with providers are only one source of patient information; there are many others, including quality websites, social media accounts, and community resources that can supplement the information a patient receives from his or her provider. In addition, medical professions will need additional skills training in becoming better educators.

INTEGRATING PERSON-CENTRICITY WITH END-OF-LIFE AUTONOMY ISSUES

Self-determination expresses itself in all facets of our lives, including at the end of our lives when we are most vulnerable to have our wishes and intent disenfranchised. Our self-determination can be assured through advance directives; appointments of durable agents; videos that clarify intents and wishes; and frank discussions with loved ones, trusted friends, a trusted physician, and clergy. One might even specifically state that a primary reason for choosing and designating that durable agent is to insulate against a family member(s) whose opinions or unresolved grief may force decisions inconsistent with the person's wishes when they become incapacitated and unable to speak for themselves and thereby avert the risk of challenges to self-determination.

Knowing and listening to what the person wants is critical, as is the manner in which medical professionals respond. When the oncologist deals with a person rather than a patient the outcome can be dramatically different, and overcome various perversities of the system such as those spawned by an exaggerated perception of legal liability in end-of-life scenarios mandating an "everything must be done mentality" so contrary to good care.

Instead, an honest and frank discussion saying, "Your disease has progressed to a point beyond which there is nothing more than I can do for you medically to change its course. My care for you should now be oriented toward palliative measures to keep you comfortable, alert, manage your pain, and other symptoms so as to maximize your remaining existence. That will better allow you to savor your precious remaining time with your family." It also will allow them help to integrate loss into life. That typifies dealing with a

person rather than a patient. It minimizes undignified last-ditch, medically futile interventions and saves both emotional pain and dollars wasted on futility. We need to better educate health care professionals regarding their legal duties and their exaggerated concern about potential lawsuits and the risk of liability.¹¹

Many fears of legal liability are based on misunderstanding of the legal concepts of duty, negligence, and injury, and arise more from misperception than reality. A better understanding of these concepts can be accomplished with changes in medical education and exposure to concepts of health law and torts so these concepts and principles are understood. Moreover, the major reason for negligence cases and provider malpractice claims has centered on failure to adequately inform or disclose material information. The legal test for whether consent has occurred pivots on materiality – that which involves a reasonable person understanding and appreciating the significance of information afforded. Person-centricity is a fundamental step toward tort reform involving "reasonable divulgence"¹² we should clearly embrace.

REPLACING LEARNED HELPLESSNESS WITH TRANSPARENCY

Transparency is the core element of person-centricity, without which the person will be at a disadvantage to make a decision in their best interest.¹³ They also need to know treatment options, risks and benefits, probable outcomes, and the implications of not availing themselves of any of these options. In formal institutionalized settings (e.g., hospitals and long-term care facilities), persons should not be passive recipients – or, worse yet, mere bill payers – of services and bills after the fact. They will need to have more input and transparency in these types of decisions and charges and disclosure of charges in advance of services being provided. A person wants to know what things cost.

Similarly, the culture of our hospitals should replace loss of autonomy, and eroding confidence on the part of the person through learned helplessness, with self-determination-promoting missions, visions, and values. Learned helplessness is a consequence of the current system that in the past defined the subjugated patient as the antithesis of person-centricity.

CONCLUSION

"Person-centricity" is a new concept meant to give individuals more authority, autonomy, education, responsibility, and accountability for pursuing health and health care. The goal is for a health-oriented lifestyle to replace the current disease-focused approach and for the person to be the key participant in their own health outcomes. The changes required to create a healthier America and reduce costs associated with lifestyle-related conditions need to happen on a personal level, coupled with a supportive infrastructure and public policy to promote and sustain this new approach. We have presented a shift in the way we currently think of

health, health care, and personal responsibility as applied to the person, and described some of the parameters to consider for implementing and supporting that shift. We have presented opportunities for enhanced self-determination with the advent of new tools of comparative effectiveness, genomics, and mobile health. We addressed socio-economic, cultural and environmental challenges and the implications related to the social determinants of health. Addressing these problems and challenges requires collaboration, sharing and communication at the federal, state, and local levels, with a clear understanding of unique issues and needs at the community level. We must identify impediments and enlist our creative energies in addressing these issues in order to create a healthier America. We must work to make being healthy not a daunting, unpleasant, or insurmountable task, but to make the “healthy choice, the easy choice” for an improved quality of our health and lives. The concept of person-centricity provides a rationale and an infrastructure to significantly alter and improve the direction of health in America.

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