Future Directions in Chronic Illness Care

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> *We always overestimate the change that will occur in the next two years and underestimate the change that will occur in the next ten. Don't let yourself be lulled into inaction.* Bill Gates

Envisioning the Future State of Chronic Illness Care

The demographic trends of an aging population are ongoing, and a greater burden of chronic illness will continue to be part of the patient experience and the ways in which we care for them. People are living longer with diseases and conditions that, in previous times, would have limited life expectancy and function [1, 2]. The average number of illnesses per person is increasing [3], but a growing array of medical treatments and technologies will promote better functional status and prolong life. Multimorbidity will be the common denominator in this future state, and integration of care across multiple diseases will become more complex. Unfortunately, competing economic demands and global inequity will lead to more constrained resources [4], effects that will create a demand for clearer articulation of trade-offs between treatment benefit and burden.

In such a future state, chronic care delivery will evolve toward goal-directed care and underscore the need for clear and ongoing communication about patient values and goals, directly contributing to more nuanced decision-making about what it means to have "optimal therapy [5, 6]." Patients and clinical care teams will focus on goals and discuss known evidence about how each treatment helps or hinders those goals and what resource constraints may limit choices. These are predominantly cognitive skills and services that will require empathetic providers who can communicate effectively with patients and synthesize the anticipated effects of multiple treatments across a range of outcomes.

There are generally multiple treatment options for specific chronic diseases, and those range of options will continue to expand [7]. To facilitate a higher order of chronic illness care, cognitive specialties – particularly primary care – will need to have usable, clear decision support that integrates the outcomes and consequences of treatment and illness across multiple morbidities [8]. In this way of thinking, single disease guidelines will become secondary sources of information, and integrated approaches to treatment decisions will become primary. Patients will be able to connect their selected treatments and behaviors with their desired health outcomes. As a result, treatments and therapies (e.g., exercise, nutrition, mindfulness) that can simultaneously address multiple illnesses will become predominant [9, 10].

The sites of chronic illness care will move outside of the medical exam room. Because of the inconvenience and time inefficiencies of clinical encounter-based care, patients will have scheduled, focused visits with care team members that can occur over video conference or telephone. Non-urgent and other minor patient concerns will be addressed through asynchronous electronic communication. As a result, the business model of ambulatory care will shift further toward personnel and away from capital costs (e.g., infrastructure, bricks, and mortar) [11, 12]. Chronic illness care reimbursement will no longer be transaction based since fee-for-service does not align with a philosophy of care that is ongoing, relational, spontaneous, and routine.

Practices will care for patients through population-based payments that are risk adjusted, based on the complexity and comprehensiveness of care needed [13, 14]. Both government and commercial payers will streamline their reimbursement strategies in order to reduce the administrative complexity of managing multiple fee-for-service arrangements. Payment will be tied to the evaluation of the quality of care delivered, aligning evidence-based, cost-effective care with the patient care experience, away from fixed targets set by individual disease group guidelines [13]. However,

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this framework will substantially challenge data collection strategies for performance measurement in real-world practice settings, potentially impacting both patient and provider sensibilities about optimal care delivery.

Patients will continue to struggle with the complexity of health-care delivery and behavior change, and integrated health-care systems will need to focus on reducing the complexity of navigating health services and promoting access to care. Community-based organizations will also be a part of the landscape and will provide a larger perspective to help understand the patient's goals and provide complimentary support for navigating complexity and promoting behavior change. Ideally, community-based organizations will be able to communicate directly with health-care systems and have access to patients' overall care plans in the health record.

Bridging the Gap and Getting to the Future State

There are several key areas of development that are necessary to achieve this vision of chronic illness care: workforce, attention to social and behavioral determinants of health, care redesign, patient and family engagement, evaluation and research, and business models.

Workforce

The current health-care workforce is not prepared for the knowledge and skills which will be necessary to care for an aging, chronically ill population [12]. These gaps cut across nurses, physicians, social workers, and other health-care professionals. Current training programs need to better reflect the anticipated needs in managing an aging population, and there may be a need to create new health-care professions altogether. It will be important to view workforce redesign through the lens of a team, with the patient as the captain. If the patient is the most important member of the team, training in disease self-management skills will be needed. Although health-care systems such as the Veterans Administration (VA) have promoted disease self-management skills in their patients, a majority of patients do not have ready access to this type of training from their health-care system or community-based organizations [15].

Team-based care is another skill set that the workforce will need in order to meet the needs of patients [16]. Team members will need to have clear and defined roles and expectations for their performance and communication. Clearly defined policies and buy-in from team members will allow each person on the team to do the tasks they are best equipped to do and communicate to others the tasks that they cannot carry out. The lack of role definition and buy-in can create uncertainty and frustration among team members and impede patient care. The colocation of team members is one approach that can help facilitate communication among members [17].

Within the team-based domain, identified and selected team members will need training in behavior change techniques, such as motivational interviewing, to help modify risks of substance use, depression, smoking, and poor dietary habits. In addition to medication management (e.g., drug-drug interactions and drug-disease interactions), clinical pharmacists can be tapped to provide chronic disease management across more conditions [18]. Both medical assistants and social work-prepared personnel must be encouraged to practice to the full scope of their license and have capacity to facilitate behavior change and address social determinants of health, such as trauma, and poverty, which impact chronic disease management and outcomes [19]. Trauma-informed care, for example, is an emerging competency, since childhood trauma is associated with the risk of multiple chronic illnesses later in life [20–27].

Physicians will need an enhanced educational framework and targeted training in order to treat patients with multiple complex chronic illnesses. Undergraduate medical education will need to move beyond paradigms that focus on acute disease states and chronic conditions, to a more integrated approach, such as the health system science framework that is emerging in some schools [28]. Both medical students and residents will need skill sets to function as effective members on interprofessional teams, including the capacity to listen and learn from the expertise of related disciplines [29]. Other competencies will include the recognition and management of polypharmacy, goal setting, group visits, and team communication. Clinical teaching sites and educators will need to be highly functional so that students, residents, and other learners are exposed to care models and mentors in practice.

A population health specialist may be representative of the new type of provider in the emerging health-care ecosystem [30]. This person may have skills in epidemiology, as well data management and analysis, and would primarily manage and analyze clinical data at the individual patient, practice, and population level. Data from multiple sources, such as claims, wearable devices that record biomarkers (e.g., pulse, blood pressure), patient-reported outcomes, and clinical encounters, will be integral to managing the health of chronically ill patients. The population health specialist can assist the care team to plan the highest yield interventions for their population at the individual or community level.

Attention to Social and Behavioral Determinants of Health

There has been increased interest in addressing social and behavioral determinants of health. Providers feel ill equipped, and health-care systems have largely not been accountable for these factors [31]. As a result, it is challenging to develop and implement care plans in chronically ill patients without fully tackling the underlying social and behavioral factors that impact their lives [19]. The health-care system, for example, will need to improve social support to meaningfully see improvement in chronic disease management.

Many health-care systems utilize social workers in clinical settings to better assess and manage social and behavioral barriers to care [32]. Complex chronic diseases require a high degree of engagement, coordination, travel, and communication, and clinics and hospitals are finding that social workers are effective at addressing several barriers that can impede high-quality care, including the ability to pay for medications, travel to appointments or pharmacies, and linkages with providers [32]. Transportation is a key barrier for many patients, and new models are focusing on ways to provide home-based care [33]. Pharmacies are also recognizing the need to bring the care to the patients. Care systems will need creative strategies to help patients maximize the care they need when they need to visit clinics.

Coordinating with behavioral health resources is critical in helping patients manage chronic disease. More primary care practices are seeing the value of colocated social workers or psychologists in meeting the behavioral health needs of their patients [34]. Clinics that are small or in rural locations may collaborate to share these resources or bridge with community-based behavioral health organizations to streamline and facilitate transitions of care to the community [35]. Adding services for substance use disorders, such as specialists in tobacco control, alcohol, and medication-assisted treatment for opioid use, can also mitigate the future risks for chronic disease in vulnerable patient populations. These key drivers of poor health, health-care utilization, and poor chronic disease control are modifiable, and an understanding of substance abuse as a chronic disease will greatly improve the health of the individuals with these conditions [36, 37]. Finally, telemedicine is another model that has potential to help expand the reach of behavioral health care. In general, policy and reimbursement changes are needed to support the increased integration of physical and mental health [38].

Health-care policy and reimbursement are starting to shift toward supporting behavioral health improvements [39, 40]. In 2017, Medicare expanded payment for collaborative care for depressive disorders between specialty and primary care [39]. This new payment structure allows payment for care coordination between specialties and outreach and follow-up for enrolled patients. While the structure of the payment program does reinforce an evidence-based collaborative care model [41], the specific requirements for payment may not allow clinics to be nimble in meeting the behavioral needs of their patients.

Care Redesign

The redesign of chronic illness care begins by recognizing that current ambulatory approaches are marked by multiple sites of care (i.e., primary and specialty care) that frequently result in dislocating patients out of their communities and their jobs to spend time in clinical settings. Patients with multiple chronic illnesses will need to receive care that is seamless between home, community-based locations, and clinical settings. Clinical teams will need to move out of their practice silos into the communities they serve to better learn about and meet the needs of patients and families.

In some aspects of care redesign, there has been great movement to the chronic illness care paradigm of the future; in others, there is lot of work to do. For example, most clinicians appreciate the complexity of multiple chronic illnesses, but usually lack evidence-based information on the best therapies and interventions for comorbid conditions [42]. The majority of chronic illness care is provided through office-based visits with little focus directed to non-transactional care [43]. There has been an increase in disease management and case management programs, which have demonstrated modest improvements in outcomes by filling some care gaps between traditional visits. More advanced practices often provide embedded care management but can have difficulty finding fiscal models that support the costs involved [44, 45].

Better guidelines are another component to care redesign. Unfortunately, guidelines are predominantly developed for disease states, not patients, which have resulted in conflicting recommendations that often do not promote optimal care in preventive services, diagnostic testing, and therapeutic interventions [46]. For example, individual disease guidelines generally focus on process or intermediate outcomes, such as blood pressure, hemoglobin A1C levels, or specific medication therapies [47]. In chronically ill patients with comorbid conditions, it is unclear how to adjudicate these intermediate outcomes, or the additional burdens created with competing guidelines, or the strategies to help patients reach their goals.

Clinical guidelines and decision support need to be applicable across comorbid diseases. For example, an analysis of drug-disease interactions and drug-drug interactions for common chronic diseases in the National Institute for Health and Care Excellence (NICE) clinical guidelines found that many potential drug-disease interactions and drug-drug interactions were not highlighted in UK national guidelines [48]. Future guidelines should seek to incorporate common conditions, such as arthritis, chronic kidney disease, and hearing or vision impairments in chronically ill patients, and highlight approaches to navigate comorbidities.

Health information technology (HIT) and electronic health records (EHR) that incorporate decision support tools have the potential to assist with guideline implementation [49]. A recent systematic review, for example, noted the under-investigation of decision support tools for multimorbidity [8]. Patients and providers need better information to inform the highest priorities for an individual's care and should have the ability to modify EHR reminders for a particular patient to meet that patient's needs and priorities. In addition to decision support, EHRs can also identify important drug-drug interaction and drug-disease interaction concerns for chronically ill patients [50, 51].

In addition to EHR's, HIT applications can further facilitate chronic disease management by making the work easier, more streamlined, and less duplicative. Software applications and devices can interface with clinical care to allow information exchanges between patients and the care team [52]. There will be a great need to expand the capacity of smartphones and other devices to connect the patient and team by video, email, and text. Existing communication processes that include sending and receiving faxes, paging and returning pages, and telephone messaging will continue to limit the capacity for effective care redesign. Patient-centered communication approaches will be multi-model and driven by their preferences, which will require building a more robust HIT infrastructure.

As practice settings move into team-based care designs, the overall structure of care provision must be reconsidered, and a culture of shared responsibility will be the hallmark. The alignment of inpatient, outpatient, and community-based care has the potential to bring the right care to the patient, in the most convenient location, at the right time. New care redesign models will need to move from health centers that are medically based to centers of health which are community-based. Although acute hospital care is a key component in care redesign, these settings will need to also manage multiple chronic illnesses, sustain the care plans set in the communities and clinics, and communicate with the outpatient care team.

Finally, care redesign will need to rebalance primary and specialty care. This will require recruiting and training the next generation of clinicians into primary care. Primary care will need to work with specialty care partners to build out medical neighborhoods, where care pathways clearly delineate primary care responsibilities and the contributions of specialists in care plans. Emerging integrated models, such as robust eConsult services from the University of California, San Francisco, can provide technical information and assist in decision support for issues that come up in primary care without requiring the patient to see a different provider [53]. New care models of integrated care delivery will require a rethinking of payment models that can reimburse and incent primary care for high-quality, cost-effective, patient-centered care.

Patient and Family Engagement

To make chronic illness care truly patient-centered, patients and their families must be engaged in decision-making about their care, integrated into quality improvement in the practice, and engaged in policy and research about their conditions [54]. Patient and family members need to be included in all levels of health-care delivery. The Southcentral Foundation's Nuka System of Care in Anchorage, Alaska, is an example of a care delivery system that was transformed by changing to a patient engagement model [55]. Nuka had been a bureaucratic health system centrally controlled by the Indian Health Service with low performance in health-care outcomes [55]. Several regulatory changes allowed the Alaskan Native people to become the operators, owners, employees, and patients, effectively driving a complete care redesign of the Nuka system. They were able to change the health-care system to meet their needs: focusing on physical, mental, emotional, and spiritual wellness. The patient owners changed the health-care system from an example of bureaucratic low-quality care to the current state of a Nuka that is viewed as a model of patient and community engagement, population health, quality improvement, and clinical quality [55].

Quality improvement teams in clinical settings will need to shift their engagement strategies from consulting with patients and families to approaches where patients are at the forefront of driving the quality improvement [56]. The work of health-care improvement often occurs in silos, without understanding how service lines interface and impact patient care. At the health-care leadership and administrative levels, patient and family voices can richly inform quality improvement. For example, the Medical College of Georgia Health System in Augusta has invited and placed patient and family advisors on system and practice-level councils and committees. During this time, clinical quality has improved and litigation has gone down [57].

Evaluation and Research

Chronic illness care of the future will be informed by data and dependent upon robust evaluation strategies. Unfortunately, existing quality metrics and initiatives do not often reflect real-world patient care. Improvement efforts are often indexed to care that is demarcated by single biomarkers, such as blood pressure and hemoglobin A1c, or process compliance measures [46]. Promoting the uptake of beta-blocker usage in heart disease or retinopathy screening in diabetes are valid quality improvement targets, but they may not be focused on what patients value most. Alternate patient-centered measures may include a functional status that allows full-time work or the number of work hours that are missed for doctor visits or diagnostic testing. Patients, policy makers, and clinicians will need to work together to identify new metrics that determine the degree of care that is aligned with a patient's values and takes into account the benefits and risks of the treatment options across chronic illness.

Some have argued that the growing climate of measurement and quality improvement has contributed to provider burnout [58]. Physicians and other providers still value autonomy, mastery, and purpose, attributes that can be threatened by attempts to measure and incent well-developed outcomes [59]. Some health-care organizations have used an alternative approach through the use of "true north metrics," which define global, practice-wide goals, and encourage providers and care staff to provide input about how they will achieve these goals [60]. Figuring out the balance of incenting quality care without burning out the workforce will be critical in coming years.

Research in chronic disease management will need to become more applied and implementation and dissemination activities more nimble and timely. Currently it takes many years between the development of a research idea to reach practice implementation, which leads to research findings that can be outdated or unable to be adapted due to shifting practice. This type of research will need to be conducted across disciplines and disease states, with a focus on patients with multimorbidity who are often on multiple medications [61]. In the rapidly changing world of chronic disease management, the research to application pipeline must become quicker. In addition, traditional health services and clinical trial research, with its narrow inclusion and exclusion criteria, are often not applicable to real-world practice. Chronic illness care will benefit from an increase in pragmatic trials that can better inform care in clinical settings.

Finally, research priorities need to emphasize new models of care for patients with chronic disease. For example, eConsult is increasingly being piloted to see its impact on helping primary care providers manage patients without face-to-face visits by multiple different specialists [53, 62, 63]. Emerging care delivery models will need to determine risks and benefits versus usual care, and the growing disciplines of implementation science, health systems science, and data analytics will be foundation fields in chronic care research and evaluation. A workforce of well-trained researchers, specializing in studying health delivery models, will be critical to help produce the evidence base for new care models [64].

Business Models

The current fee-for-service payment structure creates disincentives for the effective integration of care that is required for patients with chronic illness. Health-care payment reform is moving toward bundled payments and population-based payments, strategies that will help to incentivize coordinated care across the continuum. For example, the Medicare Access and CHIP Reauthorization Act (MACRA) set forth strong incentives for providers to enter into alternative payment models – beyond fee-for-service – that reward quality and efficiency. These new payment models are designed to support care that has the highest value, limiting incentives to perform as many procedures as possible.

New payment models will also expand the accountability for the health of populations. For example, the Center for Medicare and Medicaid Services is testing the Accountable Health Communities model, an initiative that broadens an understanding of care to include social determinants, and encourages health-care system-community partnerships that would be accountable for health outcomes in a defined population of patients [65]. Health systems must now begin to consider social factors of care that contribute to patient outcomes, such as providing housing for a homeless patient.

As we pursue the system of the future, incentives will need to be used wisely. Quality metrics will need to encourage value-based change while not threatening providers' motivations for care. This will involve organizations looking inward at how they use quality metrics and incentives to reward high-quality care. Many health-care systems introduce fiscal incentives for physicians and other health-care workers that are based on these metrics and/or productivity [66]. Although attractive, a body of evidence now suggests that this approach may decrease intrinsic motivation to improve and provide high-quality care [59, 67].

Final Comments

There are rapid changes ongoing in health care, and we will arrive at the future state before we know it. Communities and health-care systems that have invested in rapid improvement and change will be poised to lead this change. Health-care systems that include patients in meaningful ways in their improvement efforts will be able to more easily design the improvements that patients want and need. By training a new workforce of health-care providers with needed skills, the culture of health care has the potential to shift to one that is patient-centered, accountable, and value-driven. It will take a tremendous investment of time and capital by many stakeholders to reach the care system of the future that is responsive to the needs of chronically ill patients. This is a social movement, and our best chance of success lies in focusing on the patient, simplifying the payment system, and designing care systems for multimorbidity.

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