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Diabetes And The Fragmented State Of US Health Care And Policy

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Abstract

Progress in the prevention and treatment of type 2 diabetes—the dominant form of diabetes—appears to have stalled in the US over the past decade, and diabetes-related morbidity has increased nationally. The most geographically and socioeconomically disadvantaged segments of the population have been especially hard hit, and interventions that reduce the risk for diabetes have not reached these populations. In this overview article we lay out how fragmentation in health policy and governance, payers and reimbursement design, and service delivery in the US has contributed to low accountability and coordination, and thus stagnation and persistent inequities. We also review the evidence regarding past, ongoing, and new reforms that may help address fragmentation, lower diabetes burdens, and narrow disparities.

Diabetes is a common and debilitating chronic condition. Increasingly, it is emblematic of the declining health and high health care costs experienced by many people in the United States. At the physiological level, diabetes is a metabolic disorder, but at the population level, it is a symptom of larger societal problems, where the most socioeconomically vulnerable people experience the biggest disease burden.[1] Type 2 diabetes (hereafter referred to as diabetes) accounts for 90–95 percent of all diabetes cases and is a multifactorial disease; the outcomes associated with diabetes thus are influenced by policies across multiple sectors, including education, health care, transportation, housing, and agriculture. In the spheres of health care and related policy, there have been important advances in the science of preventing and managing diabetes, many of which were chronicled in a special issue of *Health Affairs* in 2012.[2] Despite these advances, however, the rapid growth of diabetes is outpacing the US' ability to care for those affected.

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Epidemiologic analyses also demonstrate recent stagnation in diabetes prevention and control. There are currently an estimated 37.3 million Americans living with diabetes,[3] more than a 40 percent increase from a decade ago (25.8 million) and twenty-three-fold higher than in 1960 (1.6 million).[4] Historical and current factors (for example, chattel slavery, Jim Crow, segregation, warfare, assimilation policies, and systemic racism),[5,6] socioeconomic exposures (for example, housing and neighborhood characteristics, food environments, pollutants, media, and crime),[7,8] and inequities in access to health care and preventive services have contributed to substantial disparities in the burden of diabetes.[9,10] Black, Hispanic, and American Indian/Alaska Native adults are approximately 1.5 to 2 times as likely to develop diabetes[11,12] and significantly more likely to die from the disease as compared with non-Hispanic White adults.[13]

Further, pharmacological and behavioral interventions that reduce the risk for diabetes have not been implemented equitably,[14] contributing to disparities by race and ethnicity, age, socioeconomic status, and especially health insurance status. State-level data show variability in the prevalence of diagnosed diabetes in the US. For example, from 2004 to 2019 the prevalence ranges of diagnosed diabetes increased and widened, from 5.8–7.9 percent in 2004 to 6.9–11.3 percent in 2019. With time, increases in prevalence have been regionally concentrated, with marked growth in southern states (exhibit 1). Despite evidence that control of glucose, blood pressure, and cholesterol prevents the microvascular and macrovascular complications of diabetes, progress from the early 1990s to 2010 has stalled,[15–17] and glycemic, blood pressure, and cholesterol control in US adults with diabetes has also leveled off or declined.[18]

Not unlike the disease itself, failure to bend the curve on diabetes growth, morbidity, and mortality in the US is multifactorial and related to various demographic, socioeconomic, and behavioral factors. In addition, these failures are rooted, at least partially, in the lack of emphasis on and resources for population health interventions for people who are at risk for or have diabetes.

In this article we consider the role of fragmentation in health policy and governance, payers and reimbursement design, and service delivery in stalled efforts to curb increasing burdens and disparities imposed by diabetes. Since there are varied definitions of *fragmentation*, we broadly define it as siloed or heterogenous health services that occur because of the lack of unified goals, policies, incentives, and information across stakeholders. Fragmentation results in uncoordinated and highly variable care that deviates from evidence-based recommendations, thereby undermining population health goals and equity.[19] Using this working definition, we consider some major past, present, and ongoing reforms that are particularly relevant to reducing fragmentation and their implications for diabetes prevention and management.

Fragmentation

Fragmentation is rooted in how health services evolved in the US. During and after the Civil War, health services were delivered by physicians on a fee-for-service basis at the point of care. At the turn of the twentieth century, third-party insurance payment mechanisms were established to expand access to health services for all Americans. Over time, US health care evolved into a quasi-private-public system that still largely uses fee-for-service arrangements between third-party payers and health care delivery systems. As a result, Americans have autonomy and responsibility over their own health, but there is very little focus on population health and equity.[20] Below, based on our working definition that fragmentation is rooted in the lack of unified goals, policies, incentives, and information across stakeholders, we discuss how fragmentation in these domains, in the context of a hybrid system, results in suboptimal focus on population health and equity with respect to diabetes prevention and management.

Health Policy And Governance

There is fragmentation in and across health policies related to diabetes in the US. Fragmentation occurs across vertical levels of government (federal, state, county, and local) and, consequently, affects the associated policies that influence risk for and management of diabetes. For example, Medicare is a federal program, while state governments have significant influence over Medicaid program design and implementation. Even federal policy implemented across states can produce heterogeneous results. For instance, the availability of payers operating across local individual health insurance exchanges (included in the passage of the Affordable Care Act in 2010 and implemented in 2014) varies. The number and types of plans affect premiums, benefit generosity, and provider networks available to people at risk for or with diabetes who rely on the exchanges for insurance coverage. Fragmentation in policies operating at different levels diminishes accountability and coordination, both of which are necessary to prevent and manage diabetes.

Payers And Reimbursement Design

Payers or insurers for health services in the US segment the population by age, income, disability, immigration status, and employment. Since household circumstances or, if applicable, employer-chosen plans dictate the options, many Americans are distributed across a mix of public, private, and both types of health insurance; others lack health insurance completely.[21] Even within payer types, there is heterogeneity. For example, commercially insured people can have managed care, high-deductible, or preferred provider benefit plans. Lack of transparency and variation in plan benefits can hinder the access that people with diabetes have to services and treatments.[22] In addition, there is little, if any, coordination and continuity of benefits as people move between payer types.

At the individual level, chronic conditions such as diabetes require person-centered prevention, care, and vigilance,[23,24] and they are particularly sensitive to disruptions in insurance coverage.[10] Transitions that occur as a result of changes in employment status or age, as well as movement between individually purchased plans, are associated with coverage changes, and there is potential for discontinuity in the networks, services, and medications to which people with diabetes can gain access. In addition, annual formulary changes imposed by payers subject people with diabetes to changes in coverage or copays to maintain their medication regimens.[25] Disruptions in continuity of care resulting from loss or change of health insurance or related benefits and coverage can be especially challenging for historically disadvantaged populations, especially as these groups are at higher risk of losing insurance and are slower to reenroll.[23]

At the population level, fragmentation and lack of shared population health goals across stakeholders mean that there is no ownership for large segments of the population at risk for or affected by diabetes. Payers carry the liability for the health service costs of their beneficiaries and can track utilization. Enrollee churn reduces payers' incentives to take on long-term responsibility or investments in higher-quality preventive services for which returns are only realized in the long term. This is especially the case as Medicare eventually takes over the largest cost burdens when people get too old or too sick to stay employed.

Similarly, the movement of people between health systems undermines incentives for long-term, high-value care. Health systems and clinicians who deliver preventive care and treatment for people with chronic conditions might consider it their responsibility to achieve good health outcomes for those they serve. However, many payers still reimburse clinicians and delivery systems using fee-for-service payment. Fee-for-service incentivizes volume and high-cost service delivery, so there is low incentive to optimize high-value services (such as nutritional counseling) to keep people with diabetes out of the hospital where, instead, they can receive high-cost, highly reimbursed services such as dialysis, amputations, and surgical procedures. The purchasers of coverage—employers or individuals themselves—should be incentivized by the good health of beneficiaries to minimize expenditures and lost productivity associated with chronic conditions such as diabetes. That said, employers and people go where premiums are affordable, within the bounds of what insurers or insurance exchanges offer. Asymmetry of information and lack of price transparency hinders employers and people from recognizing that they are purchasing and receiving poor-quality, low-value care, respectively.[26] Additionally, people with diabetes may have limited health literacy, numerous competing priorities, and present bias—the tendency to prefer shorter-term rewards over a (possibly) larger longer-term benefit.[26,27] As such, market-based systems that assume that consumers have full information, are forward looking, and can exercise rational decisions to manage their health are not well suited to address population health and equity for people at risk for or with diabetes.

Service Delivery

Americans with diabetes experience fragmentation in receiving health care and preventive services across settings of care, geographically, and over the life course. Across settings of care, there are physical siloes between services offered by generalists and specialists (such as primary care and nephrology) and between specialties (such as podiatry and vascular surgery) that make it challenging for people with diabetes and comorbidities to navigate. Geographic access to health services is also influenced by market characteristics: Hospitals and clinics are incentivized to operate in locations with more dense, well-insured populations. The amount, type, and level of competition between health care delivery systems in each market also influence the quality of services available. Data suggest that in dense urban environments, delivery systems compete on price and quality, while this is less often the case in rural areas, which have fewer options and greater distances between primary care physicians and specialists.[28] New entrants in the market, such as the expansion of retail clinics, may also influence quality. These clinics provide faster access but have a more limited scope of practice that tends to be focused more on acute conditions and less on continuous, chronic conditions.

Transitions between health care delivery systems, whether due to age, changes in employment, geographic moves, or disability, also carry a high risk of discontinuity of a person's health information. Medical records in the US tend to be "owned" by the delivery systems providing services. Lack of health information sharing, even in the same geographical vicinity, further results in discontinuity of care, waste, and disjointed surveillance across systems and states.

Improving Health Policy, Payment, And Services For Diabetes

Addressing fragmentation in health policy, payers and reimbursement design, and service delivery in the US has the potential to improve the reach and effectiveness of evidence-based health care and preventive services for people with diabetes and, in the process, may also reduce disparities. It is also likely that many of these changes will have broader impacts on other chronic conditions. Here we describe the evidence regarding past, ongoing, and new reforms that address the fragmentation of policies, payer and reimbursement design, and service delivery laid out above, as they relate to diabetes.

Legislating Coverage For Evidence-Based Services

Some fragmentation of policies is harder to address because of constitutionally conferred decision rights to federal and state authorities. However, short of universal health insurance coverage, one means of reform that may be considered is to legislate full coverage of specific preventive and treatment services with a strong evidence base regarding effectiveness and value to all beneficiaries, no matter their insurance type. This approach centers policy on patients, population health, quality, and equity instead of on profits. There is a foundational evidence base grounded in clinical trial data to support best practices in diabetes prevention and management.[29] Requiring coverage by payers expands the reach of evidence-based preventive and therapeutic options to bend the population curve of diabetes burdens. A minimum covered "package of benefits" might also help purchasers of coverage understand what services are critical as they compare coverage options. As an example of this in practice, the Affordable Care Act institutionalized 100 percent coverage for all US Preventive Services Task Force Grade A– and B–recommended services without patient cost sharing. This approach might be viewed as top-down and restrictive, limiting options for clinicians to tailor preventive and therapeutic approaches for specific phenotypes of diabetes; that said, continued monitoring, analytics, and optimization of the minimum benefit package could result in iterative modifications to the package over time.

Aligning Incentives With High-Value Services

Aligning the incentives of payers and service delivery systems can also address the negative impacts of fragmented payment systems in the US. A critical aspect of this approach is shifting from volume-based (that is, fee-for-service payment) to value-based (that is, paying for quality) reimbursement and understanding the need for flexibility in meeting the needs of people at risk for or with diabetes.[30] Efforts to address the misalignment of incentives such as pay-for-performance and other measures are generally imperfect Band-Aids on their own and may exacerbate disparities. For example, pay-for-performance mechanisms penalize primary care physicians who look after people with diabetes who have complex medical and social needs[31,32] but reward surgeons who perform amputations that result from poor diabetes management.[33] This strategy has the potential to exacerbate disparities if primary care physicians are driven away from caring for complex patients.

Alternative payment models (APMs) offer a more comprehensive attempt to reform and realign both patients' and health care delivery organizations' incentives away from volume and toward preventive and care services that are cost-effective, are of high quality, and achieve improved health outcomes.[30,34] The Centers for Medicare and Medicaid Services (CMS) is influential in driving the proliferation of APMs.[35,36] CMS has gradually and continually been lowering reimbursement for fee-for-service payment and has announced its intention to achieve near-universal use of value-based payment models by 2030.[37]

APMs can be broadly categorized as capitation (receiving a set amount per beneficiary per month) or episode or bundled payment models. Theoretically, under capitation, health care delivery systems would benefit from savings if beneficiaries reduced the use of avoidable health care; clinicians would benefit in terms of reducing administrative burdens; patients at risk for or with diabetes and other chronic conditions would benefit from receiving high-value services (for example, prevention, disease management, and self-care); and overall, health care costs and waste might be reduced.[38,39] Capitation can also offer delivery systems the flexibility to use resources to address a patient's social needs (such as food insecurity), which are especially important in improving disparities in health outcomes for people with diabetes.[30] Bundled or episode payments center on covering the full range of services and providers needed for a particular procedure or a condition for a specified period of time. While bundled and episode payments offer aspirations for better value care, defining the range of services covered and period of coverage expand the administrative burdens associated with this model of payment.

Earlier attempts with APMs, such as health maintenance organizations and pay-for-performance programs, were mostly unsuccessful. Modern APMs, such as accountable care organizations, have demonstrated positive outcomes such as reduced inpatient and emergency department visits; increased preventive care and chronic disease management; and, unlike with health maintenance organizations of the past, no evidence of worsening patient experiences or clinical outcomes of care.[40] With respect to diabetes care, integrated care systems and accountable care organizations have been associated with improved blood sugar control and greater use of preventive services,[38,41,42] as well as low or no differences in the quality of care received by racial and ethnic groups,[43] suggesting a possible influence on reducing health disparities. It is important to note, however, that accountable care organizations do experience high up-front costs stemming from the technological and infrastructural investments needed to implement the model.[44] Still, among countries in the Organization for Economic Cooperation and Development, greater alignment of payer and health care delivery incentives has been the norm for decades. Compared with the US, patients' experiences in countries with greater payer and delivery alignment are characterized by more stable coverage and access to services and medications.[45]

While the outlook for financing diabetes care with APMs seems certain, some areas require improvement and further study. There are considerable differences in outcomes observed as a result of variability in contracts and quality measures, especially when comparing commercial or Medicaid contracts with Medicare programs.[40] Finally, there is some concern that capitation and bundled payment can disproportionately harm safety-net clinics and hospitals that care for the highest-risk patients with diabetes. Adequate risk adjustment and enhanced payment must be incorporated into payment to primary care physicians to support the resources needed to care for socially and clinically complex patient populations.[32,46] For example, since safety-net hospitals serve patient populations who are at greater risk of diabetic amputations, not getting adequately reimbursed for eventual surgical interventions would impose high financial costs on these hospitals, which already have constrained operating budgets.[47]

Promoting Continuity And Quality Through Information Management

Boundaries at the payer, health system, or state level result in disjointed pockets of health information for people at risk for or with diabetes. To be sure, some of these challenges are related to data protections and privacy. Ultimately, patients, not payers and delivery systems, should "own" their data, which, if they were interoperable (that is, if information were accessible and could be automatically triaged and reconciled by different electronic medical record platforms without human action), could be accessed over the life course and across care settings, employers, health systems, and geographies. Interoperable, lifelong data systems exist nationally in Finland, Estonia, the Netherlands, the United Kingdom, and, increasingly, Norway and Denmark. In a 2019 international survey by the Commonwealth Fund of primary care physicians across eleven high-income countries, compared with peer countries, US primary care practices were characterized by poor two-way communication between primary care physicians, specialists, and hospitals and did not routinely exchange patient health data with external entities that could offer important services for patients.[48]

There are many anticipated benefits from reforms that promote shared or transportable health information, such as those supporting national efforts to build registries of patients with chronic diseases[49] and regional efforts to connect patients with primary care medical homes, but as yet no national-level data examining impacts on health. Health information sharing is a critical tool for measuring, monitoring, and rewarding improvements in outcomes, as well as reducing heterogeneity across settings and population segments.[50–53] This is true for medical record–based registries at single clinics or large health systems, states, and even nationally. However, to achieve this in the pluralistic market-based US health care landscape, overarching government policy and regulation, along with funding support, are likely to be the only credible paths toward establishing sustainable business models that incorporate health information sharing.[54] Standards such as e-prescribing, electronic referral loops, and registries and surveillance features are all helpful in harmonizing the efforts of generalists, specialists, and other health care and preventive services delivery systems for people at risk for or with diabetes. Optimizing the value of data systems must balance the benefits with the potential added burden on users such as information overload experienced by clinicians, interference in the patient-clinician encounter, and a historical preference for financial and reporting functions taking priority.

Conclusion

Fragmentation in health policies, payers and reimbursement design, and delivery of diabetes prevention and treatment services is emblematic of the decentralized US health care landscape. Reducing persistent individual- and population-level diabetes burdens and inequities will require a more coordinated approach that affords greater concentration on high-value services, alignment of incentives, and continuity of information and services. To be sure, even with the epitome of health-sector reforms, since diabetes burdens are multifactorial, the US still might not be able to get ahead of these devastating diabetes trends; complementary non-medical interventions and policies also are needed to truly optimize metabolic health and equity for all Americans.

A comprehensive framework of medical and nonmedical legislative initiatives was recently proposed by the National Clinical Care Commission to support diabetes prevention and control in settings where Americans live, work, and engage with each other.[55] In parallel, the reforms discussed here focus on equitable access, intentionality through aligned incentives, and accountability and consistency that may assist in reaching all Americans, including the most vulnerable segments of the population. The reforms proposed here focus on the supply of evidence-based interventions, and there may be residual gaps if demand remains insufficient. Based on our working definition of *fragmentation*, we have described new and ongoing opportunities for reform such as legislating coverage of evidence-based interventions; adopting APMs that promote high-quality and high-value diabetes services; and advancing information sharing across states, payers, and delivery systems. Together, there is evidence that these advances support a data-driven, coordinated population health–focused agenda to lower diabetes burdens and inequities.

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Notes

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EXHIBIT 1:

Median county age-adjusted percent of US adults ages 20 and older with diagnosed diabetes by state, 2004 and 2019

State	2004	2019	State	2004	2019
Alabama	6.9%	11.0%	Montana	6.1%	7.4%
Alaska	—[a]	—[a]	Nebraska	6.0	7.9
Arizona	6.2	9.2	Nevada	6.2	8.0
Arkansas	6.5	9.0	New Hampshire	6.0	7.8
California	6.3	7.8	New Jersey	—[a]	—[a]
Colorado	6.0	7.3	New Mexico	6.1	8.2
Connecticut	5.8	7.5	New York	6.2	8.9
Delaware	7.7	9.9	North Carolina	7.0	8.6
District of Columbia	7.9	9.0	North Dakota	6.1	7.8
Florida	6.7	9.8	Ohio	6.2	9.7
Georgia	6.8	9.1	Oklahoma	6.6	9.1
Hawaii	6.3	8.9	Oregon	6.2	8.0
Idaho	6.2	8.0	Pennsylvania	6.3	8.2
Illinois	6.2	7.6	Rhode Island	5.9	6.9
Indiana	6.3	8.9	South Carolina	7.4	11.3
Iowa	6.1	8.1	South Dakota	6.2	7.8
Kansas	6.2	8.3	Tennessee	6.3	9.0
Kentucky	6.4	9.2	Texas	6.2	7.4
Louisiana	7.1	9.7	Utah	6.0	8.1
Maine	6.3	8.1	Vermont	5.8	7.3
Maryland	6.6	9.6	Virginia	—[a]	—[a]
Massachusetts	6.2	7.4	Washington	6.6	8.2
Michigan	6.3	8.2	West Virginia	6.6	10.2
Minnesota	6.1	7.8	Wisconsin	6.0	7.4
Mississippi	7.5	10.6	Wyoming	6.0	7.3
Missouri	6.3	8.2	National median county	6.3	8.4

SOURCE Authors' analysis of diabetes data and statistics from the Centers for Disease Control and Prevention's US Diabetes Surveillance System.
NOTE Estimates based on 2,960 counties in both years.

[a] Data not available.