The Influence of Healthcare Systems Factors on Racial Disparities in Diabetes Care Barriers Faced by African American Patients

Barriers Faced by African American Patients in Access to Care and Patient-Provider Relationships

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Part I. Systems Analysis

Diabetes is a quickly growing epidemic in the U.S., and presents both complex healthcare and public health challenges. The racial disparities in diabetes are well documented, with African Americans in the U.S. facing a disproportionately high burden of the disease compared to Whites. Diabetes control metrics are becoming increasingly utilized as part of healthcare system quality and performance measures across the country. Here, a healthcare system lens is used to identify two main elements most immediately affecting the detection and management of diabetes within the African American population: accessibility of care and the patient-provider relationship. Interventions in these two areas, including sustainably funded community health worker programs and culturallyrelevant chronic disease management programs, would work to disrupt rules of the system, break reinforcing loops, improve information flows, and begin to change clinical paradigms. These shifts would improve both early detection and collaborative management of diabetes, leading to a reduction in diabetes racial disparities and improvement in healthcare system quality measures in the long-term.

The Problem

Diabetes (here referred to primarily as type two diabetes mellitus) is a growing epidemic in the United States: one in three adults are living with prediabetes, and one in ten have diagnosed diabetes. In 2017 alone, the estimated cost of diagnosed diabetes in the United States was \$327 billion. In addition to the tremendous direct resource burden the diabetes epidemic places on the U.S. healthcare system, it is simultaneously a massive public health problem, with well-documented racial disparities. According to the

CDC, non-Hispanic Blacks (8.2 cases per 1000 persons) have a higher incidence of diabetes compared to their non-Hispanic White counterparts (5.0 cases per 1000 persons).¹ These disparities exist in long-term outcomes as well: compared to Whites, African Americans have a higher risk of peripheral artery disease and amputation, diabetic retinopathy,²,³ and diabetes-related mortality. In 2017, African Americans had 2.1 times the risk of death due to diabetes compared to Whites.⁴

The hemoglobin A1C test (HbA1C), which is a measure of a person's average blood sugar levels over the past three months, is commonly used to diagnose diabetes and determine how well a patient's diabetes is controlled.5 The HbA1C test, blood pressure measurements, and lipid profiles together form the primary standards of diabetes care put forth by the American Diabetes Association.⁶ The 2015 National Healthcare Quality and Disparities Report found that, between 2003-2012, African Americans had consistently poorer A1C and blood pressure control compared to Whites.⁷ Disparities in these control metrics are tightly associated with disparities in diabetes incidence and outcomes, and can be explained in part by patients' differing experiences with several healthcare system elements that determine the effectiveness of detection and management of diabetes.

Diabetes care has long been a focus of quality and performance measures across U.S. healthcare systems, and is one of the first conditions in which clinical guidelines for disease-specific control metrics have been used to evaluate the quality of care and preventive services. A systems approach to understanding the complexities in the delivery of diabetes care is needed to identify leverage points where these control metrics can be improved,

particularly within the African American population. These efforts are critical for effectively fighting the growing diabetes epidemic in the U.S., for informing healthcare system quality improvement initiatives, and for reducing racial disparities in diabetes care.

The System

The causes of the disparities in diabetes incidence and outcomes are multifactorial, and involve individual-level factors (such as knowledge and health behaviors), community-level factors (such as access to healthy foods and social supports), and healthcare system factors, which will be the focus of this analysis. It is important to note that, although not explicitly addressed here, individual and community-level factors, along with socioeconomic conditions and structural racism, are understood as having strong influences on the ability of the African American population to interact with the healthcare system and to achieve their optimal health.

The most immediate healthcare systems factors influencing the detection of diabetes and control of the disease in the African American population are access to care and patient-provider relationships. The general purpose of this "system" is to educate and treat patients, and to improve their quality of life by helping them to prevent the onset or progression of diabetes. However, within such systems, it is also possible that the purposes of the subunits of the system may add up to an overall behavior or outcome that is not truly wanted.9 In this case, the elements of the system have a less overt purpose of perpetuating deep-rooted social and economic injustices, and creating disproportionately poor diabetes-related health outcomes for African Americans compared to Whites. In this system, five different stocks are considered: individuals with normal A1C, those with diagnosed prediabetes, those with diagnosed diabetes, those living with controlled diabetes, and those suffering complications of diabetes leading to death. The following healthcare system factors greatly influence how an individual moves from one stock to the next, and are important leverage points upon which public health interventions and policies should be focused (Figure 1).

Access to Preventive Clinical Care and Diabetes Detection: Healthcare Rules and Norms

The detection of diabetic conditions and the quality of diabetes control within the African American

population is highly dependent on their access to preventive care services and providers. Several long standing "rules" or norms of the U.S. healthcare system impose massive barriers which perpetuate poor health outcomes for this population, in a reinforcing loop: inadequate health insurance coverage, low Medicaid reimbursements for healthcare providers, and the prohibitive costs of diabetes medications and supplies.

A long history of social and economic injustice and racism has placed a disproportionate share of the African American population in poverty: according to 2018 U.S. Census Data, 20.8% of African Americans lived in poverty, compared to 10.1% of Whites.¹⁰ In 2018, 34% of nonelderly African Americans were enrolled in Medicaid in the U.S.. compared to just 15% of Whites. 11 Diabetic patients on Medicaid have reported poorer A1C control and quality of life compared to those on Medicare and private insurance. The 2013 US Roper Diabetes Patient Study found that 61.5% of Medicaid patients had a most recent A1C score greater than or equal to 7% (a diabetes control "goal" for adults), compared to 38.4% of Medicare patients and 48.9% of those on private insurance. 12 Additionally, 42.5% of diabetic patients on Medicaid reported being unable to work due to a diabetes-associated disability, compared to 23.7% of those on Medicare and 3.5% of those on private insurance.12

Compounding this problem is the element of low Medicaid reimbursement rates. There is a well-documented association between low Medicaid reimbursement rates and fewer providers accepting new Medicaid patients. In 2016, Medicaid paid 72% of what Medicare paid, on average. A highly variable patchwork of Medicaid provider access has been the result, with 69% of physicians accepting new Medicaid patients nationwide. Of note, states that adopted Medicaid Expansion under the Affordable Care Act have seen significant improvements in self-reported access to health care, diabetes management, and health status compared to states that have not expanded Medicaid.

These healthcare system "norms" in which lower-income, minority populations are disproportionately enrolled in Medicaid, and in which relatively few physicians accept such patients due to low reimbursement rates, have emerged from mental models of quality healthcare as a privilege for those who can afford it, rather than a right for all. This creates a positive feedback loop that perpetuates poor health outcomes in these

marginalized populations. Intervening at this level would disrupt the rules and incentives of the system, which Meadows describes as one of the "deeper" leverage points likely to have higher transformative impact,¹⁶ as well as work to break the reinforcing loops that keep African Americans on Medicaid from achieving early detection and proper control of diabetes. Sustainably funded, well-integrated community health worker programs could improve quality of diabetes care for patients on Medicaid and incentivize proper disease management rather than reactionary care for these traditionally underserved populations.

Prediabetes Management and Diabetes Control: Patient-Provider Relationships

Supportive and trusting patient-provider relationships play a critical role in ensuring the effective clinical and patient self-management of diabetes, as well as in patient compliance with treatment plans and adherence to medication regimens. A lack of clinician support and communication, poor shared medical decisionmaking, and a cultural distrust of the medical establishment work to reinforce weak relationships between African American patients and healthcare providers. These interpersonal factors, among others, lead to racial disparities in diabetes control and related outcomes in the long-term. Research suggests that strengthening these patient-provider relationships would lead to improved diabetes management and reduced disparities in diabetes care.17

A 2020 integrative review of articles delineating barriers faced by inner-city African Americans in diabetes care found the most frequently-cited healthcare system barrier to be management and decision support from nurse case managers, pharmacists, and physicians. This type of support helps patients to better understand high blood sugar readings and decisions to titrate their medication, and is important for patient education and problem solving. The level of communication between patients and physicians was also a commonly cited barrier, particularly with regard to tests ordered (such as A1C), discussions of patient history and social factors, and the patient's ability to engage with treatment plans. 18

An important component of open communication between patients and providers is shared decision-making, in which patients are active participants in healthcare discussions and assist in making decisions alongside their providers. ¹⁷ Importantly,

patients with diabetes who participate in shared decision-making tend to have enhanced diabetes self-management and are more likely to adhere to care plans. ¹⁹ Compared to White patients, African American patients are less likely to engage in shared decision-making with their physicians: they tend to rate their physicians as less participatory, they experience shorter outpatient visits and less positive clinical interactions, and they are more likely to report having experienced racial discrimination within healthcare compared to White patients. ¹⁷

An underlying cultural distrust of physicians and the medical establishment can also contribute to the challenges of poor communication and shared decision-making between patients and providers. The combination of historical medical mistreatment of African Americans, along with the traditional role of the church in one's health and spirituality, can present cultural conflicts in patient interactions with the healthcare system. ²⁰ The Tuskegee Syphilis Study, for example, is remembered by many in the African American community, and has had long-lasting negative implications for their participation in clinical trials and compliance with physician-directed treatment plans. ²⁰

The challenges in developing effective patientprovider relationships evolve partly from a timeconstrained healthcare system that is incentivized to provide reactive, acute care rather than chronic disease management and prevention. Additionally, underlying racial patient-provider power dynamics, often rooted in historical racism and perpetuated through implicit biases, create less tangible interpersonal barriers to proper management of diabetes in the African American population. Intervening at the patient-provider level within this system would improve the information flows between actors and begin changing the paradigm around the passive role of the minority patient in their diabetes care. 16 Culturally-relevant chronic disease management programs built on a peer support model could help to form trusting connections between patients, providers, and communities while improving diabetes outcomes within the African American population. In the long term, improving these relationships would lead to increased patient compliance with treatment plans and more effective collaboration in diabetes management.

Stakeholders

The primary "winners" in this system are commercial health insurers, which avoid large amounts of risk by not covering a significant portion of this African American population, and pharmaceutical companies, who make incredible profits by continually increasing the cost of medications upon which diabetic patients depend. The "losers" of the system include primary healthcare providers, who face tremendous challenges in achieving optimal patient outcomes for this population, and who face low reimbursement rates for the care they provide. Health care systems also face the mounting costs of chronic disease management and gaps in quality of care outcomes. African American patients themselves, however, are the true "losers:" the system upon which they depend for healthcare and health education serves instead to reinforce a long history of social and economic injustice and to exacerbate health disparities.

Conclusion

When looking at racial disparities in diabetes care through a healthcare systems lens, two influencing elements become clear: the "rules" around access to care (including insurance coverage and Medicaid reimbursements) and patient-provider relationship dynamics.

Interventions which target these leverage points, including Medicaid coverage for community health workers and culturally-relevant chronic disease management programs, could work to shift the flows within the system by reducing the onset and progression of diabetes in the African American patient population. By disrupting the rules, breaking reinforcing loops, improving information flows, and changing clinical paradigms, such interventions would work to improve healthcare quality measures around diabetes care, reduce racial disparities in diabetes incidence and outcomes, and slow the growing epidemic of diabetes in the U.S.

Part II. Recommendations

Proposed System Interventions for Increasing Access to Quality Diabetes Care and Improving Patient-Provider Relationships for African American Patients

Current Efforts

Given the increasing use of diabetes-specific control metrics as measures for quality of care within healthcare systems in recent years, it is not surprising that there has been a corresponding increase in healthcare sector-led design and implementation of interventions intended to improve these metrics and to reduce disparities.²¹ Some of the most successful diabetes interventions target patient, provider, organization, and community factors together,²² and emphasize equity by ensuring programs are available, accessible, and acceptable to the communities they serve.²³

Community health workers (CHWs) and chronic disease self-management programs (CDMPs) are two evidence-based, cost-effective approaches that show promise as successful system interventions. CHW programs work to improve glycemic control, physical activity, and nutrition, and reduce overall healthcare use among diabetic patients.²⁴ In addition, multifaceted chronic disease selfmanagement programs have been shown to reduce HbA1C, improve diabetes knowledge and medication adherence, and enhance communication between patients and providers.²⁵ Two recommendations are proposed for tailoring these programs appropriately to African American patient populations and for making them more sustainable and viable within the U.S. healthcare system.

Community Health Worker Model: Sustainable Funding & Health System Integration

To most dramatically disrupt feedback loops and transform paradigms within the healthcare system surrounding diabetes care for African Americans on Medicaid, addressing the social determinants of brithealth must become a "normal" component of medical care for which services can be reimbursed. To do this, a more sustainable and culturally relevant method for funding CHW programs is required in many states. Medicaid reimbursement for CHWs is a more sustainable funding option than the more traditional methods which rely on time-limited organizational operating budgets and grants.²⁶ The method through which states seek this reimbursement, however, significantly impacts the integration of CHWs into the health system (Table 1).26 The funding option that would provide reimbursement for the broadest scope of services and allow CHWs to be most meaningfully

integrated into care teams is through managed care contracts. ²⁶ With nearly 70 percent of U.S. Medicaid beneficiaries enrolled in managed care plans, ²⁷ plus the ability of managed care organizations (MCOs) to cover a wider array of services than traditional Medicaid, this option is likely to be most attractive for states to adopt. ²⁶ A critical component would be the involvement of CHWs themselves in the decision-making: by establishing standards for involving CHWs in the process of obtaining Medicaid reimbursement, states can ensure that funding and health system integration reflect the cultural expertise and unique needs of existing CHW programs. ²⁶

Several limitations with this proposal exist. Unless states outline clear contract requirements for the employment of CHWs in MCOs, the impact of this type of funding model is likely to be weak, and a high degree of state variability is likely to persist. As of 2020, only 19 states require employment of CHWs as part of their MCO contracts.²⁸ This proposal also relies on the availability of MCOs in a manner that might generate equity issues. In fact, 12 states do not currently have MCOs and would need to utilize different, more restrictive methods of Medicaid reimbursement for CHWs.²⁸

Chronic Disease Self-Management Programs: Cultural Relevance & Peer Support

A second impactful system intervention aimed at improving information flows and disrupting healthcare system rules around who is "worthy" of quality care requires redesigning traditionally White-centric chronic disease self-management programs (CDMPs) to be more culturally relevant and accessible to African Americans with diabetes. Research indicates that traditional CDMPs best serve the needs of middle class, White women, and do not address the needs of more socially complex patients facing socioeconomic and cultural barriers to effective self-management.²³ Specifically, African Americans are more likely than Whites to prefer CDMPs which allow them to bring a family member or friend, are led by someone of the same race, provide child care services, and are delivered at a local church.²⁹ Importantly, emphasizing the peer support elements of CDMPs might be particularly beneficial: peer support interventions have been shown to improve diabetes self-management among traditionally underserved patient populations,30 and are important for empowering patients and increasing their sense of control over their care.³¹ The design of effective diabetes CDMPs

for African American patients must involve beneficiary input, be appropriately tailored to the self-identified needs of the community, and include culturally-relevant peer mentors with experiential knowledge of diabetes care.

A potential limitation to this proposal is the fact that, as of 2016, only 25 states required diabetes self-management education (DSME, a specific type of chronic disease management) coverage for all or nearly all Medicaid beneficiaries, while 41 states required DSME to be covered under private insurance.32 Without consistent funding and support of CDMPs available across all states, implementing these tailored programs may place undue financial and resource burdens on - or may not even be possible - in certain communities. There is also a tendency for CDMPs to be outsourced to corporate vendors or commercial health maintenance organizations, which can result in programs becoming marketing tools for pharmaceutical companies and success being measured in profits rather than in patient outcomes.³³ The dynamics of peer support elements must also be carefully evaluated, as they hold the potential to establish uneven power relationships between mentees and mentors in the program.³¹

Evaluation

Several indicators can be used to measure the effectiveness of these proposals. A process evaluation for CHW programs might include measuring changes in the number of African American Medicaid patients served by CHWs in MCOs nationwide, or the number of states adopting MCO Medicaid reimbursement plans over a certain number of years. A process evaluation for CDMPs might include the number of programs implementing a peer support model, or changes in the number of African American patients served by these programs. In the longer term, intervention outcomes should be measured via changes in diabetes management metrics (such as HbA1C and blood pressure), health behaviors and attitudes (such as level of communication with providers and degree of social support), and overall amount of healthcare utilization among patients enrolled in these programs. Cultural relevance might also be measured in terms of the locales of program delivery and the racial and ethnic backgrounds represented in the enrolled patient populations.

Figure 1. Healthcare System Factors Influencing Diabetes Diagnosis and Severity in the African American Population

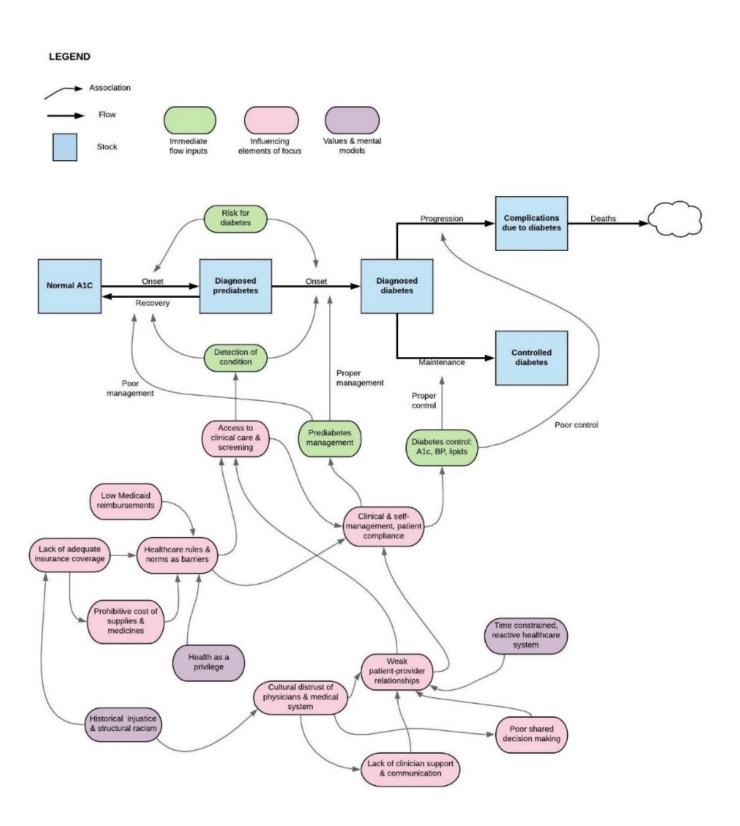


Table 1. Methods of Medicaid Reimbursement for Community Health Workers*7

METHOD	Implementation Process	Scope of Services	Degree of Health System Integration
State Plan Amendments (SPAs) for Reimbursing Preventive Services	States must submit a SPA to CMS describing education, training, and credentialing requirements for CHWs. The SPA must define which preventive services would be provided and how they would be reimbursed.	Limited: CHW services can be reimbursed only if they are recommended by a licensed medical provider. Services must involve direct patient care and address the physical or mental health of the patient.	Small: Licensed medical providers act as "gatekeepers" to authorize services, limiting the degree of freedom and integration of CHWs into care teams.
Section 1115 Waivers	States must submit a waiver to be approved by CMS. Waivers are short-term (3-5 years) but renewable.	Modest: Often used to test new models of delivering care, and for reimbursements of CHW services for specific Medicaid populations.	Modest-Large: CHW care team integration varies by plan type and population of focus for each separate program. States have a significant amount of flexibility in how programs are designed.
State Plan Amendments (SPAs) for Broader Medicaid Reimbursement	Requires passing of legislation that authorizes funding for CHW reimbursement, and submission of a SPA defining who is eligible to be reimbursed and for what services.	Modest: A broader range of CHW services can be covered if states expand their list of services. There is no federal standard for CHW training or limits on services under this model. A lack of standardization has created difficulties with reimbursing for care coordination services.	Small-Modest: CHWs must work under the supervision of a physician or other licensed medical professional. Issues with role clarity and health system integration have been documented.
Reimbursement through Managed Care Contracts	States can leverage existing contracts with managed care organizations to require employing a minimum ratio of CHWs to beneficiaries, minimum lists of services offered, etc.	Broad: MCOs have more flexibility to cover a wider array of services than can be covered under traditional Medicaid, and states have more power to decide the scope and types of services that are required.	Largest: More likely to establish CHWs as full and equal members of the care team within health systems. CHWs can be effective in community based organizations if providers are educated and aware of their services.

^{*}Current financing systems, education policies, and legislative action around CHWs vary widely by state, so choosing an effective Medicaid reimbursement method depends heavily on an accurate assessment of the current state landscape.³⁴

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