

“Here it was waiting for me:” Diabetes Diagnosis Pathways and Implications for Health Policy

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ABSTRACT

Diabetes in older adults is a growing public health concern with nearly 30% of Americans 65 and older having diabetes. This includes 2.6 million older adults with undiagnosed diabetes who are at high risk of microvascular and cardiovascular complications (Centers for Disease Control and Prevention, 2022). The majority of cases are Type-2 diabetes. The past decade has witnessed an expansion in screening recommendations in an effort to reduce rates of undiagnosed older adults. Drawing on the sociology of diagnosis, we suggest further attention to the social factors that shape the diagnosis process is needed. We examine the diabetes diagnosis process from the perspective of older adults with type 2 diabetes. The data derive from diabetes illness narrative interviews with non-Hispanic White and African American older adult men and women (age ≥ 50) with type 2 diabetes (N=83). Our thematic analysis reveals four pathways to diagnosis: 1. Annual wellness exam, 2. Workplace screening, 3. Community-based opportunities, and 4. Health event or alarm. Diabetes' early symptoms are often normalized within daily life, with health insurance gaps, providers' dismissal of symptoms, and nonprescription medications reinforcing efforts to address initial symptoms within the home. Wellness visits, as well as worksite and community-based screening, critically intercede in the unfolding of symptoms. In contrast, diagnosis in connection with a health event or alarm carries an additional toll on social and emotional well-being. These findings have implications for national screening policies and local diabetes control efforts.

Keywords: health disparities, older adults, urban population, diabetes screening

“Aquí me estaba esperando eso:” Vías de diagnóstico de diabetes e implicaciones para la política de salud

RESUMEN

La diabetes en los adultos mayores es un problema de salud pública cada vez mayor, ya que casi el 30 % de los estadounidenses mayores de 65 años tienen diabetes. Esto incluye a 2,6 millones de adultos mayores con diabetes no diagnosticada que tienen un alto riesgo de complicaciones microvasculares y cardiovasculares (Centros para

el Control y la Prevención de Enfermedades, 2022). La mayoría de los casos son diabetes tipo 2. La última década ha sido testigo de una expansión en las recomendaciones de detección en un esfuerzo por reducir las tasas de adultos mayores no diagnosticados. Basándonos en la sociología del diagnóstico, sugerimos que se necesita más atención a los factores sociales que dan forma al proceso de diagnóstico. Examinamos el proceso de diagnóstico de la diabetes desde la perspectiva de los adultos mayores con diabetes tipo 2. Los datos se derivan de entrevistas narrativas de la enfermedad de la diabetes con hombres y mujeres adultos mayores blancos no hispanos y afroamericanos (edad ≥ 50) con diabetes tipo 2 (N = 83). Nuestro análisis temático revela cuatro caminos hacia el diagnóstico: 1. Examen anual de bienestar, 2. Evaluación en el lugar de trabajo, 3. Oportunidades basadas en la comunidad y 4. Evento o alarma de salud. Los primeros síntomas de la diabetes a menudo se normalizan dentro de la vida diaria, con brechas en el seguro médico, desestimación de los síntomas por parte de los proveedores y medicamentos sin receta que refuerzan los esfuerzos para abordar los síntomas iniciales dentro del hogar. Las visitas de bienestar, así como las evaluaciones en el lugar de trabajo y en la comunidad, intervienen de manera crítica en el desarrollo de los síntomas. Por el contrario, el diagnóstico en relación con un evento o alarma de salud conlleva un costo adicional en el bienestar social y emocional. Estos hallazgos tienen implicaciones para las políticas nacionales de detección y los esfuerzos locales de control de la diabetes.

Palabras clave: disparidades en salud, adultos mayores, población urbana, tamizaje de diabetes

“它在这里等着我” 糖尿病诊断途径和对卫生政策的影响

摘要

老年人患糖尿病是一个日益严重的公共卫生问题，近30%的65岁及以上美国人患有糖尿病。这包括260万未确诊糖尿病的老年人，他们极易患微血管和心血管并发症（美国疾病控制与预防中心，2022年）。大多数病例是2型糖尿病。过去十年见证了筛查建议的扩大，以期降低未确诊老年人的比例。基于诊断社会学，我们建议进一步关注影响诊断过程的社会因素。我们从患有2型糖尿病的老年人的角度分析糖尿

病的诊断过程。数据来自一系列糖尿病叙事访谈，访谈对象为患有2型糖尿病的非西班牙裔白人和非裔老年男性和女性（年龄 ≥ 50 岁）（ $N=83$ ）。我们的主题分析揭示了四种诊断途径：1. 年度健康检查，2. 工作场所筛查，3. 基于社区的机会，以及4. 健康事件或警报。糖尿病的早期症状通常在日常生活中被正常化，这归因于医疗保险缺口、医疗提供者对症状的忽视、以及一系列促进在家解决初始症状的非处方药。健康访问以及基于工作场所和社区的筛查对症状的出现起到关键的干预作用。相比之下，与健康事件或警报相关的诊断会对社交健康和情绪健康造成额外的影响。这些发现对全国筛查政策和地方糖尿病控制工作具有启示。

关键词：健康差异，老年人，城市人口，糖尿病筛查

Introduction

Reducing the morbidity and mortality burden of diabetes is a U.S. public health priority ([Diabetes - Healthy People 2030 | health.gov](#)). However, approximately 8.5 million adults in the U.S. have undiagnosed diabetes, 2.6 million of whom are age 65 and older (Centers for Disease Control and Prevention, 2022). The majority of cases represent type 2 diabetes (hereafter diabetes), the focus of this paper. The past decade has witnessed an expansion in screening recommendations in an effort to reduce these numbers (Davidson et al., 2021). Others note the need to enhance treatment support following diagnosis, particularly for those with the greatest risk of complications (Gregg & Moin, 2021). Calls also exist to address variables such as education regarding the condition's early, indistinct symptomatology (O'Connor et al., 2006). We examine the diabetes diagnosis process from the perspective of older

adults (age ≥ 50) with diabetes. Building on the sociology of diagnosis (Brown, 1990; Jutel & Nettleton, 2011), we argue discussions of diabetes screening policies need to recognize diagnosis as a social process that is deeply informed by the resources and relationships within which older adults are embedded. Efforts to reduce the number of undiagnosed must address the extensive social barriers to early diagnosis.

The Impact of Diabetes

Diabetes is the eighth leading cause of mortality in the United States (Ahmad & Anderson, 2021). The number of severe complications like end stage kidney disease have steadily risen over the past decade (Ríos Burrows et al., 2022). Considerable racial and ethnic disparities exist in rates of diabetes and diabetes complications (Centers for Disease Control and Prevention, 2022). For example, African American men and women have dou-

ble the risk of death from diabetes than non-Hispanic Whites (Office of Minority Health, 2021). African American adults additionally tend to experience diabetes at younger ages than non-Hispanic White adults (Lee et al., 2019) and lower rates of screening (Casagrande et al., 2014).

Although considerable variability exists in the progression of diabetes (Yudkin & Montori, 2014), older adults in general carry an increased risk of complications (Caspersen et al., 2012), including macrovascular disease and death (Meneilly & Tessier, 2001; Zoungas et al., 2014). Hypoglycemia is an additional threat among older adults, depending on their underlying health status (Abdelhafiz et al., 2015; Bruce et al., 2018; Strain et al., 2018).

The financial burden of diabetes is high. Medical and nonmedical costs for diagnosed diabetes totaled over \$327.2 billion in 2017; costs for undiagnosed diabetes totaled \$31.7 billion (Dall et al., 2019).

Undiagnosed Diabetes and Older Adults

Improving rates of undiagnosed diabetes is important to efforts to reduce the disease’s impact among older adults. Microvascular damage, including retinopathy, initiates early in the disease process, often prior to diagnosis (Harris et al., 1992; Kirthi et al., 2021).

Diabetes’ diagnosis is associated with clinically significant reductions in risk factors for diabetes complications,

including improvements in blood pressure, aspirin use, and weight loss within the first year of diagnosis (O’Connor et al., 2006). Diagnosis also correlates with modest increases in physical activity (Schneider et al., 2013). Early glycemic control additionally may have a “legacy effect” that reduces complications (Holman et al., 2008; Khunti et al., 2018; Laiteerapong et al., 2018). However, tight glycemic control over time is not without risk (Reaven et al., 2019), with older adults at particular risk of overtreatment (Bruce et al., 2018).

Diabetes diagnosis is hindered by the condition’s subtle early symptoms. Common initial signs, such as increased thirst, frequent urination, unexplained weight loss, and fatigue can take months to recognize (Singh et al., 1992). Older adults at times experience additional nonspecific symptoms, such as confusion, or have an absence of symptoms, e.g., thirst can be suppressed with age (Meneilly & Tessier, 2001). Diagnosis is often then “serendipitous,” i.e., dependent upon patients identifying concerning signs or receiving care for other conditions (Koopman et al., 2004). Diagnosis is more likely to occur in the context of acute care than in a preventive care visit (O’Connor et al., 2006).

Much of the policy focus regarding diabetes diagnosis has centered on diagnostic criteria, risk factors supporting screening, and the cost-benefit of screening approaches (American Diabetes Association Professional Practice Committee, 2021). Simulation research in the U.S., for example, suggests initiat-

ing regular screening between the ages of 30 to 45 can cost-effectively improve quality-adjusted life-years (Kahn et al., 2010). Other note the cost-savings to health systems through diabetes screening (Chatterjee et al., 2010). Population-based screening trials elsewhere, however, found screening of persons at high risk of diabetes does not reduce mortality (Simmons et al., 2012). Identifying a “moderate net benefit” based on systematic review of the literature, the U.S. Preventive Services Task Force suggests lowering screening initiation in primary care from age 40 to 35 for adults meeting criteria for overweight or obesity based on BMI and who have no symptoms of diabetes (Davidson et al., 2021). Missing from these analyses, however, is discussion of the way diagnosis occurs in the lives of older adults, that is, how do older adults encounter diabetes screenings that result in diagnosis; how might policy address the challenges surrounding diagnosis that are encountered in U.S. urban contexts?

Sociology of Diagnosis and the Diabetes Context

Efforts to improve diabetes diagnosis need to more fully recognize that disease diagnosis is an intensely social process, with social conditions shaping not only disease risk, but the construction and assignment of disease categories (Brown et al., 2011; Jutel & Nettleton, 2011). Diagnosis is racialized (Carter, 2021) and entails providers dissecting complex human experience “into bytes and bits of ‘evidence’” (Smith-Morris, 2015, p. 3).

In the case of diabetes, the disease has long been associated with “lifestyle,” a term that connotes the failings of the individual (Carruth & Mendenhall, 2019). Yet, public policy (Carney, 2015; Gálvez, 2018) and systemic racism (Hill-Briggs et al., 2021) critically shape the epidemic across settings. Within U.S. cities, inequities in the built environment, working conditions, and health care access, among other factors, heavily contribute to racial, ethnic, and socioeconomic variation in diabetes (Hill-Briggs et al., 2021). Where and how diabetes screening occurs (Vasquez, 2021) as well as diagnostic criteria (Bunkley, 2021; Hunt et al., 2021) additionally can reflect political and private interests.

This paper seeks to extend these discussions by examining how diabetes diagnosis unfolds for older adults in the urban U.S. context. We take a qualitative approach to identify how diagnosis is situated in everyday life, exploring older adults’ perceptions of their diagnosis. Participants’ discussions provide important insights for both public policy and clinical providers.

Data and Methods

Data Collection

Data for this analysis are drawn from The Subjective Experience of Diabetes Study, a National Institute on Aging-funded study of African American and non-Hispanic White older adults’ (age \geq 50) experiences with diabetes (N=83). Utilizing a modification of the McGill Illness Narrative Interview

(Groleau et al., 2006), ethnographically-oriented interviewers asked participants to share the story of their diabetes, including the context of the diagnosis and diabetes’ management in daily life. The prompt to initiate the interview involved an open-ended statement, “please tell me about your diabetes.” The participant was encouraged to begin as they saw fit. With a narrative approach, the participant then guides the discussion, elaborating on elements of the illness and life context that are of personal importance (Chase, 2003). Any descriptions of their disease status, e.g., blood glucose levels, represents their self-report. Participants can emphasize areas of relief or accomplishment as well as misgivings. The illness narrative thus is a window into how illness unfolds and is experienced by an individual within the broader social context (Acuff & Paulus, 2016; Phoenix et al., 2010). The ability to reflect on the meaning of a story as it is told greatly enhances the analysis and interpretation (Chase, 2003). We focus here on participants’ discussions of how they came to be diagnosed with diabetes. The study received institutional review board approval from the University of Maryland, Baltimore County. All names used here are pseudonyms. Unique personal details, including distinct illnesses, also are masked.

Interviews were conducted by three qualitatively trained, non-clinician women, matched by race when possible to facilitate rapport. Interviewers met participants in their preferred location, with most participants inviting the interviewer to their home. Meet-

ing in the participant’s home stimulated storytelling and introductions to family and friends. Interviewers completed the consent process in-person, prior to the start of the interview. Interviews were audio-recorded and averaged 100 minutes in length. Participants received a US\$50 honorarium.

Data Coding

Following each interview, interviewers wrote fieldnotes to capture details of the participant’s home, neighborhood, and interactions. Interviews were transcribed verbatim by professional transcribers. The original paired coding process through which data were coded is described elsewhere (Chard et al., 2017). Briefly, the research team reviewed a selection of transcripts (n=8) line-by-line to identify an initial set of inductive codes. Team members then reviewed additional transcripts in order to identify additional codes and test the codebook. This process continued until pattern saturation was reached (n=20) (Saldana, 2016). Rotating teams coded transcripts line by line via qualitative data management software. Throughout our coding and analysis processes discrepancies between team members were resolved through discussion by the entire team; these discussions at times involved returning to the original audio recording. Our process of rotating, dual coding and team discussion was aimed at reducing bias and strengthening validity (Bernard & Ryan, 2010). Demographic data were analyzed using a statistical software package.

Study Sample and Setting

The Subjective Experiences of Diabetes project sample was recruited from a longitudinal study of health disparities in Baltimore city (Evans et al., 2010). We employed a purposive sampling frame designed to fill race and gender inclusion criteria for male and female, African American and non-Hispanic White adults age ≥ 50 . We selected age 50 and above as our inclusion criteria in order to include persons from across stages of later life. A clinical diabetes diagnosis (e.g., blood glucose >7 mmol/L, fasting) was an additional criterion for inclusion; major cognitive impairment was an exclusion criterion. We recruited through this epidemiological project in order to identify participants who were community-living older adults with confirmed diabetes. We then engaged with participants as non-clinicians, as well as independent from the project through which they were recruited, in order to hear the details of diabetes that the participants themselves felt were important.

The study focuses on African American and non-Hispanic White adults because of the city's long history of systemic racism towards African American residents. Decades of redlining and deindustrialization in Baltimore, for example, have led to large racial and socioeconomic inequities in the distribution of amenities and disamenities (Grove et al., 2018). Wide racial and economic disparities exist in the experience of violence, heart disease and diabetes (Baltimore City Health Department, 2017); 26% of residents at the lowest income level reporting unmet medical needs

over the previous year (Spencer et al., 2011). Community health assessments also have found a high sense of social isolation among persons living below the poverty line (Baltimore City Health Department, 2017). At the same time, the city is home to strong neighborhood-based civic and religious organizations, activists, and business owners, many of whom devote significant time to the community.

Thematic Analysis

The thematic analysis discussed here involved co-authors SC, LG, and LH engaging in independent close reading of the transcript data coded for diagnosis. The diagnosis code captured participants' discussions of how they came to know they had diabetes, from first indications of sickness through the formal diagnosis and next steps. This close reading also included examining the diagnosis discussions within the broader transcript to identify what brings persons into contact with an opportunity for diagnosis and the experiences following the diagnosis. The first two authors reviewed and reconciled the coding notes on the diagnosis process through a side-by-side comparison and discussion. They then identified patterns or groupings within their coded material that represented major themes (Roulston, 2010). As a validity check, co-authors engaged in additional review of interviews and fieldnotes to identify confirming and disconfirming evidence (Bernard & Ryan, 2010). The co-authors, who represent persons who identify as African American Women (N=2), White women (N=4), and as

a White man (N=1) approached each step of the analysis with concern for positionality.

Through this thematic analysis we identified four pathways to diagnosis among participants: 1. Annual wellness exam, 2. Workplace screening, 3. Community-based opportunities, and 4. Health event or alarm. In the sections below we examine the diagnosis experience within each path. We then turn to the barriers and prompts leading to the diagnosis. These include how early symptoms are interpreted, the avail-

ability of nonprescription medications, health insurance, and the intervention of family and friends. Within each section, quotations from participants’ narratives were selected to provide cogent illustrations of the findings.

Results

Demographic data are provided in Table 1. No significant difference exists in income by race or gender. Fifty-four participants (65%) were born in the city. The remainder had lived there for over 10 years, with a mean of 51 years (SD=17).

Table 1: Demographic Characteristics^a

Characteristics	Frequency (%)	Mean (SD)
Gender		
Male	35 (42.2)	
Female	48 (57.8)	
Race		
African American	41 (49.4)	
Non-Hispanic White	42 (50.6)	
Age		
African American		61.5(5.6)
Non-Hispanic White		60.9 (6.3)
Education ^b		
<High school	26 (32)	
High school diploma/GED	36 (44)	
Some college	14 (17)	
College degree	5 (6)	
MA degree	1 (1)	
Monthly household income (U.S. dollars)		
African American		1804 (1451)
Non-Hispanic White		2563 (2179)

^aN=83

^bN=82; missing=1

Pathways to Diagnosis

Seventy-five participants (90.4%) offered descriptions of their diagnosis process over the course of their diabetes narrative. Eight participants (9.6%) did not elaborate when probed regarding how they became diagnosed; they noted simply the year they became diagnosed or precipitating events such as an injury, but not the diabetes diagnosis.

Focusing on the 75 participants who described becoming diagnosed, their discussions revealed four major pathways to a diabetes diagnosis (Table 2). For 47 participants (62.7%), diagnosis occurs in connection with a health event or the experience of alarming

symptoms, e.g., loss of consciousness while driving or sudden, extreme polyuria. Less than a quarter indicated their diagnosis occurred through annual preventive care exams or in connection with worksite testing. Ten (13.3%) reported being diagnosed through the original community-based epidemiological study from which the sample was drawn. Little gender or racial variation existed in participants' reports of their diagnosis path, except for diagnosis through the community-based study. Six of the 10 participants who were diagnosed through the community opportunity were African American women. The sections below examine each of these paths in more detail.

Table 2: Pathways to Diabetes Diagnosis (N=75)

Diagnosis Path	N (%)
Annual wellness exam	13 (17.3)
Workplace screening	5 (6.7)
Community-based opportunities (e.g., research participation)	10 (13.3)
Health event or alarm prompt health care seeking	47 (62.7)

Annual Wellness Exams: “Blessing” Diagnoses

Only thirteen participants (17.3%) were diagnosed with diabetes as part of a wellness visit with a primary care provider, i.e., during a “checkup” or “annual.” James, a 64-year-old African American man reported that his doctor had been “telling me for years that I was on the borderline. And then one day she says to me, I’m going to put you on the pills.” He further noted, “if

someone hadn’t told me that I had it, I would never have known it.” Although James speculates that he may still be “borderline,” he indicated that he takes his medication because of the trust he and his provider have established over the years. Receiving the diagnosis led him to take a diabetes education class and he has become very conscientious about his approach to meals.

In the case of Linda, a 61-year-old African American woman who de-

scribed being tested as part of her annual gynecological exam, the diagnosis “was a blessing,” because it identified what was “coming about.” She noted that her urine had become sticky, and she was using the bathroom “a lot.” That she “loved water,” however, also explained her bathroom use. She further elaborated that because she was not experiencing what she believed to be the central markers of diabetes, fainting or feeling sick, she did not perceive the need to consult a doctor. Linda reported her annual exam revealed an elevated blood glucose that was considered serious. She described many side effects from her initial prescriptions, which has led to ongoing discussions with her provider regarding her treatment plan.

Both James and Linda reveal the negotiations that surround a diabetes diagnosis. For James, it is whether he has diabetes; for Linda, it is the treatment plan. This discussion, including their ability to directly question their provider, is facilitated by their ongoing relationship. Such exchanges in turn, particularly in the case of James, further affirms the relationship.

Workplace Screening: “My Sugar Is All Right”

Workplace testing took the form of informal, voluntary testing opportunities and required employer screenings. Both similarly alerted participants to the presence of diabetes prior to a state of alarm. Graham, a 72-year-old African American man, recalled after his diagnosis that he had been experiencing mild urinary urgency, but had not

acted. His job duties require a yearly physical, at which point his diabetes was identified and he followed up with his doctor. For Graham, as well as others, work orients life; Graham identified features of work as leading to both his diabetes and its diagnosis.

Joyce, a 61-year-old African American woman, found she had elevated blood glucose when colleagues in her clinical work setting were practicing testing one afternoon. Having just eaten candy, she initially dismissed the results that were in the 300s, thinking “Oh, my sugar is all right.” Her coworkers insisted she see her doctor, “I did go and here it [diabetes] was waiting for me.”

Across her interview, Joyce reveals that she is very mindful of how she uses her time. Joyce likely would not have consulted a doctor without the urging of her coworkers following the blood glucose test. Joyce explained her approach to provider visits:

If I got a problem, then I go back. If I, if everything is OK, I’m fine, don’t bother me, I ain’t going to bother you. You take care of the people that you got to take care of that need your help, I’m OK right now ... I have not been, ever been a person that stayed in the doctor’s office all the time. Even when I was coming up, my mother didn’t go, ever went.

Consistent with her stance that there are situations that require help, Joyce did seek diabetes education following her diagnosis. Having previously worked with patients who experienced ampu-

tation due to diabetes, she explained, “I just made my mind up, I’m not going to do that, I’m not going there...” She noted that her doctor had complimented her efforts, telling her she “took control of her own diabetes from day one.” Joyce also began sharing with coworkers information she learned about diabetes.

Work screening cut through norms to keep working and minimize symptoms. Both Graham and Joyce are fortunate to have workplaces that supported their follow up and the diagnosis did not impact their livelihood. For Joyce, having a supportive workplace also meant reciprocal information exchanges among coworkers.

Community-based Opportunities: “I Wouldn’t Go to the Doctor”

Community-based opportunities for testing, which in this context was offered by the neighborhood-focused research study from which participants were recruited, identified diabetes in ten (13.3%) of participants. Participants’ experiences suggest local, accessible testing was particularly vital for very active participants, those who were not well connected to providers, and participants who have found their providers unresponsive to their self-report. African American women credited the community-based screening with identifying their diabetes more than any of the other subgroups in the sample.

Sarah, a 62-year-old African American woman, for example, had multiple symptoms that she did not associate with diabetes. She explained, “I was experiencing every symptom that

one could have with diabetes, but I was in total denial ... I had tingling fingers, my vision was blurred. I was seeing spots...” Though familiar with the symptoms of diabetes through her professional education, she did not make a connection with her own body, “I’m thinking, that can’t possibly be me.” Sarah’s hemoglobin A1c test (HbA1c) result, conducted through the community research project, was exceptionally high. She admitted that after receiving the recommendation to go to her doctor, “I still didn’t go right away.” Sarah works full time and belongs to many community organizations, which keep her very busy. When she did call and explained her test results, she received a same day appointment.

Mary, a 65-year-old African American woman, similarly noted that prior to receiving her diagnosis she occasionally had felt dizzy when sitting. At the time, she was not under the care of a provider and struggled with depression. Although she spent much of her life providing care to loved ones, it was difficult for her to give attention to herself. She said, “I was the kind of person where if I really wasn’t, wasn’t sick, sick, sick, I wouldn’t go to the doctor.” She indicated that when she had blood drawn as part of the community research project, the project informed her she should seek follow up care for diabetes. This prompted Mary to identify a regular care provider and, “from there I’ve been trying to do what I need—trying to sort of do what I need to do.” This included taking a nutrition class and other wellness seminars that her new provider recommended. She described,

“...that’s how I kind of learned about what you need to do and what not do, but at the same time I still don’t understand a lot...”

Encouragement regarding follow-up care and having documented test results from the community study were important for participants whose providers were not responsive to self-report of poor health. Jean, a 57-year-old White woman with limited resources, was frustrated with her primary care doctor “because they don’t take care of you well, I believe.” She described trying to find answers to why she was “feeling bad,” asking for further follow-up, and being dismissed. Put off by her provider, Jean brought the emergency department staff her “paperwork” from the community research study. They noted the blood glucose finding indicative of diabetes and provided Jean with her sought-after explanation for feeling ill. She subsequently switched her primary care provider, a move made feasible after she obtained insurance with more expansive coverage through the health insurance marketplace.

Health Event or Alarm: “I Passed Out One Time”

While primary care wellness visits and community-based testing represent pivotal pathways to a diabetes diagnosis, most participants (62.7%) were diagnosed after experiencing a health event or alarming symptoms, including episodes of hypo- or hyperglycemia. For these participants, a diabetes diagnosis often arrived with the additional disruption of a hospital stay and a multitude of diagnoses.

William, a 59-year-old African American man, for example, struck by the intensity of his need to urinate at night, “put a five-gallon bucket by me, by my bed just to see, just because I was curious, and I filled the bucket up within three hours.” Feeling increasingly ill over the course of the evening, William went to the emergency department. He recalled being told his blood glucose level was in the 600s and that “if I would have stayed home just one or two more hours, I would have died.” William remained in the hospital for two weeks.

Rodney, a 69-year-old African American man, similarly described a health scare that prompted his diagnosis,

I had lost a whole lotta weight. Matter of fact, I passed out one time. I didn’t know what was wrong with me ... My car, I’m thinking it was a joke ... I parked, and I started my car up and I couldn’t stop it and I’m looking straight ahead, and I saw it [another car] and I had run into this car. I couldn’t stop it [my car] at all.

Rodney then gave his car to a relative, remarking “I had just got it and [it was] brand new ... I was scared to drive because I said I don’t want to kill nobody and I don’t want to kill myself.” The toll of these health crises thus is both emotional and instrumental, involving the processing of the potential for harm and the loss of the car.

When diabetes is diagnosed as part of an assemblage of health con-

ditions, patients are often very unwell. Jane, a 62-year-old White woman described, “My body crashed when I was 51. I mean literally crashed. I was sick. Everything started going wrong. I was diagnosed with diabetes, and thyroid and arthritis and COPD and you know.” Jane had to confront multiple serious conditions within a very short time frame. For Benny, a 69-year-old White male, “pins and needles” and blurry vision resulted in a visit to the emergency department. He was admitted to the hospital and diagnosed with severe carotid artery disease. He vividly remembered the doctor’s offhand comment regarding diabetes:

“We’re going to let your primary care doctor handle your diabetes if he wants to put you on medicine or not, we don’t know what he wants to do.” I said, “Diabetes! I don’t have no diabetes.” “Yes, you do.”

Benny described his embarrassment at the time: “I had soda sitting there. Well, I didn’t know I had it [diabetes]!” As with Jane, Benny had to grapple with news of multiple conditions and feelings as if somehow, he was supposed to have known.

Barriers and Prompts to Seek Clinical Care

Throughout participants’ diagnosis narratives, but particularly within discussions of health care crises, participants reflected on the reasons for not consulting a health care provider as symptoms were emerging and the prompts that

led to a provider. Their explanations for not pursuing clinical care included how changes in their body were interpreted, the availability of numerous non-prescription medications, and health care insurance coverage. The prompts that led to a clinical encounter included obtaining insurance and the intervention of family and friends.

Interpreting symptoms: “It didn’t seem abnormal.” In describing the illness episodes that led to their diabetes diagnosis, participants suggested that early markers of diabetes were not necessarily missed or ignored. Rather, they were readily explained and resolved using cues from daily life. For example, when participants experienced persistent and excessive thirst, they justified the symptom as normal for a particular season (summertime calls for increased water). In addition, water consumption or a preference for sweet beverages are markers of identity, a habit that represents who one is, as Linda noted with her love of water.

Darrell, a 57-year-old African American man whose work took him outside frequently, attributed his water consumption and bathroom trips to the city’s hot weather:

[A]t that time it didn’t seem abnormal because it was in the summer and I was keeping myself hydrated. So, I was thinking along the lines that the more water I put in, the more water had to come out, so I kinda dismissed the fact that there could be a possibility of something being wrong medically.

Darrell noted that shortly after he became cognizant of his heavy water consumption, he "was driving and out of the clear blue, my vision became blurred." He pulled the car to the side and a friend drove him to his primary care provider who conducted a urine test:

[T]he urine stick was so high that she [the doctor] couldn't get a reading so she suggested that I shut this [the test] down and go immediately to the hospital and when I went to the hospital, they further did more extensive tests like drawing blood and things of that nature and at that time they discovered that I had diabetes.

Increased thirst and frequent urination were incorporated in the rituals of daily life for Matthew, a 63-year-old White male. Matthew described how his habit of consuming sweet beverages intensified silently:

I'd get home from work or be doing something, and I'd sit there, and I'd load the sugar up on Kool-Aid or, or anything, my coffee had like four teaspoons of sugar in the morning and I didn't realize it. And I kept drinking, drinking, drinking, I couldn't satisfy myself.

Only after visiting the emergency department due to difficulty breathing and severe weakness one evening did he learn he had diabetes. He was hospitalized for two days. Reflecting, Matthew lamented, "I didn't know no better." He elaborated, "I never thought to get test-

ed with diabetic [sic]." A Vietnam veteran who receives his health care through the Department of Veteran Affairs, he asserted that his doctors also did not consider diabetes,

[E]very time you go you get a blood test and all at the doctors, you know, it's just so simple to do. They check your blood pressure. They test your urine, you know. They take your stool samples and send 'em in but they don't check your blood, your blood sugar. That's crazy. [chuckle] ... you know they [people] got it and they totally don't realize they got it. I never would if I never thought I had it. Never would have thought that, man.

Participants across the study find ready means to account for diabetes' signals. Matthew then suggests it is the provider who needs to provide timely guidance because simply, people "don't realize they got it."

Nonprescription medications: "I ... **bought all kinds of stuff.**" The availability of over-the-counter medications also informs home treatment. For example, the common response of women participants experiencing vaginal itching was to obtain commercial products for vaginal irritation and yeast infections. As Evelyn, a 58-year-old African American woman described, "I went to a Walmart and bought all kinds of stuff, Rite Aid, still wouldn't stop itching. Still wouldn't stop itching. Did all I could. All night long, it itch, itch, itch, itch, itch." For Loretta, a 57-year-old

African-American woman, dry mouth and nausea similarly were problematic for months. Along with drinking water “constantly,” she turned to a relatively expensive dry mouth rinse at the recommendation of her primary care provider. Describing how she learned that her symptoms were diabetes after visiting the emergency department for unexplained vomiting, she exclaimed:

And I say well, God, I say you mean, I mean all this time, I mean, I’ve been feeling nauseous and my mouth being dry and everything because it went on for maybe like four months before I started throwing up ... And when I finally went to the emergency room, that’s what they told me. Because my primary care doctor could never tell me why I was feeling, you know, nauseous and my mouth was being dry, you know, until I went to the emergency room and they told me that’s what it was, I was a diabetic.

It is striking that Loretta’s primary care doctor did not identify her diabetes given her strong family history of the disease that included both parents, a grandparent, and several siblings. Loretta herself even anticipated “eventually that I would probably get it because it runs in my family.”

Early symptoms, thus, at times are visible and are readily, but inaccurately, explained by context. Participants respond in ways that are familiar and consistent with their understanding of themselves -a love of water, a re-

sponse to heat, and the promise of over-the-counter medications to discreetly resolve a vexing irritation.

“The insurance don’t kick in ‘til June.”

While health insurance coverage is an established correlate of diabetes management (Lee et al., 2019), our findings additionally highlight how health insurance coverage shapes decisions to consult a provider for preventive or acute care and the level suffering prior to diagnosis. Regarding office visits, obtaining insurance that covers routine office visits is an impetus for scheduling a wellness examination that then reveals diabetes. One female participant described her thought process after her health insurance coverage expanded: “I figured I should get to the doctor ... I went because I had the insurance and I said it’s time to go and just get checked and stuff.” The wellness visit identified her diabetes.

Gaps in health insurance in turn can extend participants’ experience of troubling symptoms. May, a 65-year-old White woman, lost her health insurance after being forced out of her retail clerk position. In the gap between the job loss and her eligibility for Medicare, she developed a severe bladder infection. She described:

I didn’t go to the doctor for it and it kept getting worse and worse and [friend] was here then and he kept, I wasn’t eating or eat very little and then he said to me, the way I looked and everything, he said, ‘you got to go to the doctors.’ And I [said] ‘no, I’m not

going. The insurance don’t kick in ‘til June.’ So soon as the insurance kicked in, and I was feeling so bad, I said to [friend], ‘come on, take me over to the hospital.’

During May’s weeklong hospitalization, she was diagnosed with diabetes and started on insulin. May directly related her reliance on insulin with her lack of insurance. She described, “I mean if I had insurance I would have went to the doctors and they probably would have found this [diabetes] out and I probably wouldn’t be on insulin today. I’d probably just be on the metformin.” May further noted that she still is paying off the money owed for the hospitalization.

Friends and family: offering alerts and intervention. For participants whose symptoms continue, friends and family play a central role in sounding alarm. Above, May’s friend urged her to consult a provider and brought her to the hospital as soon as she consented. Similarly, Evelyn, also above, vividly recalled how she “kept using the bathroom and diarrhea and feet got cold ... and I got so stumbling and weak,” at one point cutting her hand in a fall. It was Evelyn’s significant other who contacted her doctor, telling Evelyn, “You’re not eating and you’re using a lot of water, drinking a lot of water, drinking a lot of fluids but you’re not eating nothing.”

Chuck, a 66-year-old white male, said he was fortunate to have completed contract work for a physician who he was able to telephone for guidance as he was increasingly not feeling well:

I called him up. I said I don’t really feel great. I don’t know what’s going on ... I feel like I can’t get enough to drink and constantly have to go to the bathroom and I feel kinda tired. I said I hope not I said but I think I might have diabetes.

Chuck described his friend’s response:

[H]e [the doctor] says, ‘come on over, I’ll work you in, just come over ... I’ll send you down to the lab to get some lab work done, but I’m going to test your blood right here.’ My God, it was, phew, super high.

Chuck was started on “pills and with an evening injection.” Although very much alarmed at the time of his diagnosis, he credits his friend’s quick intervention with limiting the overall impact of diabetes on his life.

Discussion

Consistent with prior research, our examination of the diabetes diagnosis process found that diabetes is not commonly diagnosed through wellness visits with primary care providers (O’Connor et al., 2006; Peel et al., 2004). Rather, diabetes diagnosis more often occurs in the context of distressing symptoms, which may involve terrifying experiences of sudden blurred vision or loss of consciousness while driving, emergency visits to the doctor, or extended hospitalization.

The identification of diabetes within other health events results in

little time for detailed answers to questions and limits the development of a multi-dimensional treatment plan. Among participants in this study and elsewhere, this lack of information at diagnosis contributes to feelings of distress (Peel et al., 2004). Participants further expressed chagrin that crises and hospitalization led to the prescription of insulin. In addition to concerns regarding the use of needles (Wallace et al., 2017), insulin carries a heavy stigma (Della et al., 2016). While further research is needed to fully evaluate how the diagnosis context shapes treatment plans, participants' narratives suggest a threefold effect of diagnosis in the context of complications: the loss of autonomy in treatment decision-making, treatment plans forefront pharmaceutical intervention, and diabetes carries an additional taint of fear and distress.

The unfolding of diabetes within an episode of hyper- or hypoglycemia or with an assemblage of secondary conditions also extracts a toll on patients' social well-being. Participants like Rodney suddenly find themselves unable to drive. In the absence of safe, accessible public transportation, no longer driving means staying home and increased isolation. Rodney describes his decreased involvement with previous hobbies after transferring his car to a relative. He also is not able to provide rides to others, his means of social connection and sense of purpose. Thus, diagnoses that occur after the onset of complications can carry additional hidden costs, particularly damaging independence and quality of life.

In contrast, although few participants report being diagnosed as part of a wellness visit, participants' narratives reveal such visits provide time to process the diagnosis and examine how nutrition and physical activity can facilitate blood glucose control. Certainly not all participants diagnosed through routine screening follow the recommendations of their providers, but screening can lead to greater discussion and reflection. Within such conversations patients interpret the meaning of a diagnosis (Ledford et al., 2020). The case of Joyce, and others in the study, provides further support for the argument that in the diagnosis process patients, as well as providers, articulate their values and negotiate their relationship (Jutel & Nettleton, 2011).

Worksite screening and community encounters with testing, which in this context came in the form of a traveling, neighborhood-based research study, also represent key sites of diabetes diagnosis. Given the unresolved ethical issues surrounding workplace health promotion (Kuhn et al., 2020), particularly for older workers (Robroek et al., 2012), we are not advocating for expanding worksite screening. We suggest further research is needed to identify how employer-based diabetes screening shapes the worksite and the experience of diabetes.

The opportunity for screening near home or at work, outside of a clinical office visit, however, does importantly address gaps in care for participants across socioeconomic statuses. These findings are consistent with studies of

community interventions (e.g., Marshall et al., 2013). That African-American women disproportionately indicated their diabetes was identified through the community study further suggests community-based screening may be a valuable means to reach minority women (Berkley-Patton et al., 2020). Participants’ narratives further reveal community-based screening serves as an independent arbiter. For participants who are uncertain of the significance of their physical experience or need a justification to visit a provider, community screening substantiates the need for care.

The findings additionally speak to the interplay between insurance access and diabetes, supporting quantitative data indicating health insurance coverage improves diagnosis rates (Blicker et al., 2013). The absence of health insurance played a direct role in participants’ analysis of their symptoms and the decision to delay a provider visit. Those who fell into insurance gaps while waiting for Medicare experienced extensive suffering. In contrast, gaining access to benefit plans that promote wellness visits helps initiate care, particularly among those who must rationalize an office visit.

Participants’ diagnosis narratives reveal that daily life frequently provides an explanation for common harbingers of diabetes, such as increased thirst. “Normal” shifts across seasons and phases of life, with cultural schemas shaping symptom interpretations (Metta et al., 2015). The urge for water or a sweet beverage can reflect simply who

one is. In addition, the proliferation of non-prescription medications, such as for dry mouth or vaginal itching, reinforces the sense that conditions are appropriately managed in the home. Recognizing how diabetes’ symptoms are understood within context reveals not widespread denial, but rather rational self-interpretation and codes of self-reliance. Looking back, participants note not just how polydipsia and polyuria are incorporated into work and home life, but also times that their providers have missed these signals. As Koopman et al. (2004) argue, clinicians need to be alert to these explanatory models (Kleinman, 1980). Self-descriptions that reflect local codes as well as individual experiences and expectations may lack uniformity and not align with physician’s expectations (Smith-Morris, 2015).

The findings also add to understanding of the role of family and friends in diabetes care seeking. Much evidence exists regarding the influence of social networks on diabetes risk and disease management (Schram et al., 2021). Participants’ experiences further suggest family and friends have timely insights on behavior and are important advocates for diagnosis. These results underscore the dangers of social isolation and add further support to efforts to expand the venues for health discourse (Palmer et al., 2021).

Policy Implications

Participants’ narratives of their diagnosis experience have several policy implications. Much of the

current discussion of diabetes diagnosis focuses on the targets for screening in primary care settings. Consistent with earlier research (O'Connor et al., 2006), our findings indicate that diabetes among urban older adults is not commonly diagnosed through routine screening within primary care settings. Although this study was not designed to assess physician screening rates within primary care, participants' discussions reveal gaps in their primary care. For patients such as Loretta, who meets many of the criteria for diabetes screening, her physician neglects to evaluate for diabetes; she ultimately is diagnosed in the emergency department as her condition grows steadily worse. These findings mirror data elsewhere that city residents, particularly minority and low-income residents, have insufficient access to quality care (Turpin et al., 2021), and the high reliance on hospital-based care (Mahmoudi et al., 2020). The challenge of primary care access among urban populations, many of whom are at high risk of diabetes, needs to be more directly addressed in the development of national recommendations for diabetes screening.

These findings also offer an alternative perspective on national recommendations that "community screening outside a health care setting is generally not recommended because people with positive tests may not seek, or have access to, appropriate follow-up testing and care" (American Diabetes Association Professional Practice Committee, 2021, p. S26). The recommendation offers tentative support for

community screening with "adequate" referral. We found that having test results from a community screening led participants to follow up care. In the case of Sarah, the call to her provider likely would not have occurred in the absence of the results. Similarly, persons without a provider were motivated to find a primary care provider. We also note the value of community screenings for those, like Jean, similar to Loretta, whose physicians are unresponsive to their symptom report. In other words, it is precisely because older adults in urban neighborhoods are at high risk of suffering silently from diabetes, may have considerable work or other demands on their time, and/or do not have adequate primary care that community-based interventions are needed. We agree that referrals are important, but the value of targeted community outreach itself needs to be more firmly recognized.

This is not an argument for mass screening, which has mixed evidence in terms of effectiveness (Kahn et al., 2010; Simmons et al., 2012), and risks detracting from social programs addressing underlying social inequities (Vasquez, 2021). We also recognize the serious risks of over diagnosis as well as pharmaceuticalization (Hunt et al., 2021; Yudkin & Montori, 2014). Our aim is to highlight the diagnosis gaps for older adults in urban communities for whom diabetes is unfolding. Participants' narratives offer the intriguing proposition that specific outreach might reduce the occurrence of diagnosis through crisis and support older adults' treatment autonomy.

Finally, lack of insurance powerfully shaped how participants assessed their symptoms and the pursuit of care. The findings add qualitative support to arguments that insurance coverage enhances diabetes diagnosis and shapes treatment (Baicker et al., 2013). Participants’ experiences also underscore the risks to the estimated eight percent of adults with undiagnosed diabetes who are not yet eligible for Medicare and who did not gain health insurance under the Affordable Care Act (Myerson et al., 2019).

Limitations

While the study’s sample includes older adults who have had a wide range of work and life experiences, only 20 (24%) reported attending any years of college, with just six reporting a bachelor’s degree or beyond. This college attendance rate is not unexpected for this age cohort (Administration on Aging, 2021). However, the findings might not reflect the experiences of those with higher education. In addition, with our focus on city-dwellers, we do not capture the diagnosis process of rural older adults. At the same time, many of the experiences described are like those of more rural populations (Della et al., 2016; Lobo et al., 2018). Our data also are grounded in participants’ illness narratives. While the accuracy of memory may pose some concern, the goal in examining narrative is not quantitative detail. Rather, the focus is how persons make sense of their experience (Kleinman, 1989; Shapiro, 2011). Thus, while we are reliant

on participants’ self-report of their clinical encounters, we note narrative approaches help uncover the experiences that are most important to the person (Chase, 2003). Finally, each member of the research team participated in the research process from unique social positions, which often varied from that of the participant in terms of race, gender, and/or socioeconomic history. We acknowledge our inability to eliminate bias; we sought to reduce the impact of social position on our analysis through discussions of the lenses we used to interpret the data, continually referring back to original transcripts, and providing each other with alternative viewpoints.

Conclusion

Older adults’ narratives of their diabetes diagnosis reveal that diabetes’ early symptoms are often normalized within daily life. Providers’ dismissal of symptoms and the availability of nonprescription medications reinforce home treatment. Gaps in insurance access also delay diagnosis. Diagnosis delays that lead to a health crisis compound the toll of diabetes.

In contrast, wellness visits that include diabetes screening, as well as worksite and community-based screening, critically intercede in the unfolding of symptoms. These diagnosis paths also represent important opportunities for older adults to articulate their values with respect to treatment.

The prevalence of undiagnosed diabetes in the U.S. remains a public

health challenge. National recommendations and local diabetes control efforts need to consider how diabetes unfolds in the lives of older adults, from those who are isolated and suffering at home to those who are employed and active members of the community. A specific focus on reducing the number of older adults diagnosed through a medical crisis holds promise in shaping their relationship with diabetes and their quality of life.

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