Unmet Primary Care Needs in Diabetic Patients with Multimorbidity in a Medically Underserved Area

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Abstract

Background: Diabetic patients with multimorbidity in medically underserved minority communities are less engaged in primary care and experience high emergency department (ED) utilization. This study assesses unmet primary care needs among diabetic patients in a medically underserved area (MUA).

Community Context: A suburb of Memphis—Whitehaven, Tennessee (Shelby County, ZIP codes 38109 and 38116)—majority African American (96.6%) with 30.5% below the poverty level.

Methods: Community case study using multiple data sources including diabetes registry, individual interviews, focus groups, and a survey of 30 ED patients with diabetes and multimorbidity.

Results: Diabetes registry data indicated that 95.5% of 5723 diabetic patients had multimorbidity. Over 91.5% were uncontrolled at some point in 2014 to 2015. Only 83% of patients with diabetes and multimorbidity reported having a primary care provider (PCP) and those without a PCP were more likely to report delays in needed care. Patients expressed strong interest in health coaching (88%) and receiving text messages from the doctor’s office (73%). Individual patient interviews (n = 9) and focus groups (n = 11) revealed common primary care and self-care experiences and needs including diabetes education, improved patient–provider communication, health-care access and coverage, and strengthened primary care and community.

Conclusion: This study demonstrates that almost 1 in 5 ED complex diabetic patients in an MUA do not have a PCP, and that difficulty accessing primary care often results in patients forgoing needed care. Qualitative findings support these conclusions. These results suggest that primary care capacity and infrastructure to support diabetes self-care need strengthening in MUAs.

Keywords
diabetes, primary care, medically underserved area, multimorbidity

Introduction

Patients with diabetes and multimorbidity in medically underserved minority communities are often less engaged in primary care, are high utilizers of emergency departments (EDs) and hospitals, and are at the highest risk of diabetes complications and adverse clinical outcomes.1 Research demonstrates that having a usual source of care is strongly associated with better diabetes care quality.2,3 However, previous studies suggest that between 2.5% and 10.4% of people with diabetes lack a usual source of care.2,3 Even for diabetic patients who have a usual care source, 30% reported delaying care due to inadequate primary care.2–4 Consequently, the estimated 43 million Americans who reside in medically underserved areas (MUAs) frequently utilize other sources of care including the ED.5 These

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vulnerable citizens also experience lower health literacy, which has been correlated with poorer control of chronic illness and increased hospitalization rates.6-8

This community case study describes unmet primary care needs among diabetic patients with multimorbidity in 1 MUA by cross-validating diverse sources (diabetes registry, survey, patient interviews, and focus groups). This project was designed to provide pilot data for a Patient-Centered Outcomes Research Institute (PCORI) initiative entitled, “Improving Self-Care Decisions of Medically Underserved African-Americans with Uncontrolled Diabetes: Effectiveness of Patient-Driven Text Messaging versus Health Coaching.” Specifically, we sought to assess the prevalence of multimorbidity among diabetics, the experience of people living with diabetes and multimorbidity in an MUA, levels of engagement in primary care, and patient perspectives on ways to best support self-care, prevention, and health promotion for people with diabetes and multimorbidity.9-11 Understanding levels of primary care engagement and its role in health system infrastructure could contribute to improved health-care delivery and health outcomes, particularly for vulnerable patients in MUAs.

Community Context

Whitehaven, Tennessee (Shelby County, zip codes 38109 and 38116), population 46,594, is a majority African American (96.6%) medically underserved suburb of Memphis. Nearly, 31.5% of residents live below the poverty level, and 40.7% of households are single parent.12 In the 38109 zip code, average body mass index is 28.1 for adults, 14.3% have diabetes, and 49.6% have hypertension.13 Ten years ago, the people of Whitehaven formed a Congregational Health Network and Diabetes, Wellness, and Prevention Coalition (DWPC) to help people living with diabetes. The DWPC is a patient, provider, and research partnership aimed to address and reverse the diabetes epidemic within the Whitehaven community, primarily through proactive disease management and increased use of outpatient treatment. However, today coalition members are concerned that their efforts are failing. Obesity and diabetes are among the highest in the United States, and Whitehaven is designated as an MUA and primary care health professional shortage area.14 As one of the pastors leading the charge recently noted: “Now there are more dialysis centers in Whitehaven than primary care clinics.”

Methods

This community case study used multiple methods and sources of data including diabetes registry data, interviews, focus groups, and a cross-sectional survey of patients with diabetes and multimorbidity to assess unmet primary care needs.

Diabetes Registry Data

The DWPC Registry (Institutional Review Board [IRB] # 14-03088-XP) is a community-based diabetes registry, which includes clinical, laboratory, diagnostic, and health-care utilization data for the major safety net hospital and affiliated primary and specialty care providers. We used this registry to assess demographic characteristics, prevalence of chronic conditions, and rates of multimorbidity and uncontrolled diabetes (defined here as a diagnosis of uncontrolled diabetes, an A1c value ≥7, or a missing A1c result over the entire measurement period) for the target population.

Survey

The aim of the survey was to assess primary care engagement, reasons for delaying needed care, and to evaluate patient assessments of continuity of care and chronic illness care. We also sought to gauge patient interest in self-care interventions that may help improve primary care engagement. The eligible study population included adults, aged 40 to 75, with diagnosed diabetes and multimorbidity seeking care for diabetes and nondiabetes-related complications, in the major safety net ED serving Whitehaven, Tennessee. Multimorbidity was defined as physician or nurse diagnosis in the hospital electronic health record of 2 or more of the 20 chronic conditions (including diabetes) listed in the Centers for Medicare and Medicaid Services Chronic Condition Data Warehouse.15 Patients were excluded for critical illness, decreased level of consciousness or cognitive ability, or lack of English language proficiency (IRB# 14-03285-XP UM).

The research team developed a 5-page questionnaire that included questions from validated surveys. The paper-based survey took approximately 10 to 15 minutes to complete. Primary care engagement was measured by 2013 National Health Interview Survey questions regarding usual source of care and delaying needed care,16 the Patient Assessment of Chronic Illness Care Questionnaire (PACIC) for quality of care,17-19 and a modified version of the Nijmegen Continuity of Care Questionnaire for continuity of care.20,21 Additional variables collected included age, sex, race/ethnicity, education, health literacy using a validated 1-item assessment,7 technology use (cell/smartphone and text messaging frequency), and interest in health coaching. Study eligibility was determined through chart review using a convenience sample of sequential patients seen at the participating hospital ED from January to February 2015.

Statistical Analysis

To assess the associations between patient characteristics, and primary care engagement, independent sample t tests and χ2 tests of independence were utilized. Independent sample t tests were conducted to measure relationships between primary care engagement and survey scale mean scores. Fisher’s exact tests were used to measure relationships between primary care engagement and categorical variables, such as gender, race, education level, chronic conditions, insurance status, and so on. Statistical significance was established to be a P value
≤.05. Reliability of survey scales was measured using Cronbach α. All statistical analyses were carried out in IBM SPSS version 21.0.

**Individual Patient Interviews**

The aim of the interview was to learn about the experience of living with diabetes and multimorbidity in patients who had been hospitalized due to uncontrolled diabetes and referred to a safety net clinic. Patients with uncontrolled type 2 diabetes attending a safety net primary care clinic were asked to participate in a 30 to 45 minute interview on their experience of living with diabetes (IRB# 13-02603-XM). There was a response rate of 100%, as 8 female patients and 1 male patient were approached and all agreed to be interviewed. Three patients were not approached because they left before the interviewer had an opening. Interviews were conducted in a private examination room. Those who completed the interview were given a US$10 gift card. The interview guide included questions on how diabetes affects the patient’s life, experience of managing diabetes, living well with diabetes, and support for managing diabetes. Recordings of the interviews were transcribed, and interpretative thematic analysis performed by 2 qualitative researchers.

**Focus Groups**

A focus group of low-income African American participants from a congregation within the Whitehaven, TN area was conducted to assess barriers and supports for diabetes self-care using a semistructured focus group guide (IRB# 13-02603-XM). Participants were recruited through in-person announcements at congregation events. Those with type 2 diabetes were asked to attend and all acknowledged having type 2 diabetes. No effort was made to probe for other comorbidities, having a primary care provider (PCP), or the level of control of their diabetes. The session was audiotaped and 1 researcher took notes. Thematic analysis was conducted manually from transcribed data by 2 qualitative researchers.

**Results**

**Diabetes Registry Data**

Diabetes registry data for 2014 to 2015 identified 5723 unique adults, aged ≥18, with diabetes seen in the DWPC participating hospital or clinics in Whitehaven, TN. A total of 92.4% were African American and 95.5% of all patients with diabetes experienced multimorbidity (>1 chronic condition in addition to diabetes) with hypertension (83.3%), obesity (45.3%), and hyperlipidemia (39.4%) being the most common chronic conditions. For 91.5% of all patients, their diabetes was classified as uncontrolled at some point in the 2-year period. For 75.5% of patients, their diabetes was classified as uncontrolled in 2015. For patients with data available for ≥2 outpatient primary care visits, 60.6% were uncontrolled in 2015, 43.7% had an A1c ≥7.0, and 9.9% were missing an A1c value for the year.

**Survey**

Of 272 patients screened, 55 were eligible, and 30 agreed to participate in the survey, for a 55% participation rate. Surveyed ED diabetic patients were found to have a mean of 3.3 chronic conditions (including diabetes) and 30% screened positive for low health literacy. The majority (86.7%) had insurance, with 80.8% of those reporting some form of public insurance (23.1% Medicaid, 30.8% Medicare, and 26.9% dual eligible). Only 23.1% reported having some form of private insurance (Table 1).

Only 83% of patients with diabetes and multimorbidity reported having a PCP and 44.8% of patients overall reported delaying needed care for 1 or more reasons (Table 2). Patients most commonly reported delaying needed care because of inability to get an appointment (29.6%), lack of transportation (26.9%), and inconvenient office hours (22.2%). Those without a PCP were generally more likely to report delays in needed care. Despite general trends suggesting potential protective effects of primary care, the presence of a PCP was only significantly protective for delays in needed care due to lack of transportation ($X^2[1, n = 26] = 12.831, P = .002$). Of the 83.3% of patients with a PCP, 52% had visited their PCP 3 to 4 times within the last year. Almost all patients (96%) with a PCP reported having a usual source of care when sick; only 56% sought care when sick from the doctor’s office, while the remaining patients went to clinics or health centers, the ED, or a hospital outpatient department.

Patient assessment of quality of chronic illness care and continuity of care were generally higher for patients with PCPs (data not shown). Patients with a PCP reported higher PACIC scores (mean PACIC score = 3.32) compared to those without (mean = 2.95). Overall, 35.7% reported being given treatment choices to consider, 71.4% were asked about their medications and its side effects “always” or “most of the time”, and 67.9% were always asked about how their condition affected their lives at least some of the time. However, 35.7% reported that they were never asked for ideas when a treatment plan was made, 33.3% were never given a written list of things to do to improve health, and 57.1% were never encouraged to go to a specific group or class to help cope with chronic condition. Overall, patients reported strong continuity of care, with 51.7% of patients strongly agreeing that their provider knew their medical history very well, and nearly half (48.3%) strongly agreeing that their provider knew what was important to their care. But patients with a PCP reported higher continuity of care as evidenced by a significantly lower Nijmegen Continuity of Care score (M = 2.07, where M = Mean), than those without a PCP (M = 2.33).

Current use of cell phones was very high at 92.9%, with 76.9% using smart phones (data not shown). Fifty percent of patients with mobile phones (both smart and cell phones)
reported sending or receiving text messages 1 or more times a day and 20.8% 1 or more times a week. Although 20.8% reported never sending or receiving text messages, there was strong interest in receiving text messages from the doctor’s office (73%) overall. Similarly, 88% of patients were “very” or “somewhat” interested in meeting with a health coach to help reach health goals (data not shown).

**Individual Patient Interviews**

Nine people (8 females, 100% African American/non-Hispanics, mean age: 53 [range: 22-78 years]) completed the interview. On average, they had been living with type 2 diabetes for 14 years. These patients had a history of uncontrolled diabetes, complications (amputations, loss of sight), and difficulty with mobility and caring for themselves. Patient concerns about diabetes centered on diet, exercise, “keeping blood sugar down,” checking blood sugar, and medication side effects. Diet, exercise, and taking medication as the means to living well with diabetes within the context of personal/spiritual constructs and financial constraints emerged as predominant themes. Provider education about diet, exercise, taking medication, and monitoring blood sugar were deemed beneficial, but many indicated they did not get enough information. As shown in Table 3, prominent themes related to primary care and self-care needs included diabetes health education during visits, patient–provider communication, and health care for other problems besides diabetes.

**Focus Groups**

Participants included 9 females and 2 males, all African Americans with type 2 diabetes for several years, with some multimorbidity and no primary care. Age ranged from 40s to 70s, several were on Medicare where others did not have health insurance, and rated their health as good. Their mobility was normal (no canes, walkers, or assistance). Focus group findings revealed common barriers to diabetes self-care such as insufficient finances, motivation, knowledge, and resources for healthy eating and being more active. Family, culture, and religion were strong positive influences on health behaviors, whereas poor health-care access and patient–provider interactions adversely impacted self-care ability. As shown in Table 3, prominent themes related to primary care and self-care needs included health-care access and coverage, patient–provider communication, and primary care and community supports and resources to achieve primary care diabetes goals. Access to health care was limited by insurance constraints and out-of-pocket costs for most participants. Participants voiced concerns about availability of competent and caring providers, providers who spent adequate time with patients, and getting the information they need during provider visits. Specific statements represent those voiced by at least 1 participant, with group members nodding or expressing verbal agreement.

**Discussion**

This community case study demonstrates substantial unmet primary care needs in diabetic patients with multimorbidity.

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**Table 1. Characteristics of Emergency Department Patients with Diabetes and Multimorbidity Identified by Cross-Sectional Survey.**

| Characteristic                          | Patient Has a Primary Care Provider |       |       |       |       |
|----------------------------------------|-------------------------------------|-------|-------|-------|-------|
|                                        | Yes (n = 25)                        | No (n = 5) |
|                                        | Count | %   | Count | %   | \(P\)   |
| Gender                                 |       |     |       |     |       |
| Female                                 | 16    | 64.0| 4     | 80.0| .640   |
| Male                                   | 9     | 36.0| 1     | 20.0| –      |
| Race/ethnicity                         |       |     |       |     |       |
| Non-Hispanic white                     | 3     | 12.0| 0     | 0.0 | 1.00   |
| Non-Hispanic black                     | 22    | 88.0| 5     | 100 | –      |
| Education                              |       |     |       |     |       |
| Grades 1 to 8                          | 3     | 12.5| 1     | 20.0| .043   |
| Grades 9 to 11                         | 2     | 8.3 | 3     | 60.0| –      |
| Grades 12 or GED                       | 6     | 25.0| 1     | 20.0| –      |
| College 1 to 3 years                   | 11    | 45.8| 0     | 0.0 | –      |
| College 4 or more years                | 2     | 8.3 | 0     | 0.0 | –      |
| Chronic conditions                     |       |     |       |     |       |
| Anemia                                 | 3     | 12.0| 0     | 0.0 | 1.00   |
| Arthritis                              | 4     | 16.0| 2     | 40.0| .254   |
| Asthma                                 | 3     | 12.0| 1     | 20.0| .538   |
| Benign prostatic hyperplasia           | 0     | 0.0 | 0     | 0.0 | –      |
| Cancer                                 | 3     | 12.0| 1     | 20.0| .538   |
| Chronic kidney disease                 | 5     | 20.0| 0     | 0.0 | .556   |
| Chronic obstructive pulmonary disease  | 1     | 4.0 | 0     | 0.0 | 1.00   |
| Congestive heart failure               | 3     | 12.0| 1     | 20.0| .538   |
| Coronary artery disease                | 1     | 4.0 | 0     | 0.0 | 1.00   |
| Dementia                               | 0     | 0.0 | 0     | 0.0 | –      |
| Depression                             | 2     | 8.0 | 0     | 0.0 | –      |
| Diabetes                               | 25    | 100 | 5     | 100 | –      |
| Hip/pelvic fracture                    | 0     | 0.0 | 0     | 0.0 | –      |
| Hyperlipidemia                         | 11    | 44.0| 2     | 40.0| .100   |
| Hypertension                           | 18    | 72.0| 5     | 100 | .304   |
| Ischemic heart disease                 | 0     | 0.0 | 0     | 0.0 | –      |
| Osteoporosis                           | 0     | 0.0 | 0     | 0.0 | –      |
| Stroke/transient ischemic attack       | 5     | 20.0| 1     | 20.0| 1.00   |
| Multimorbidity                         |       |     |       |     |       |
| 2 chronic conditions                   | 11    | 44.0| 2     | 40.0| 1.00   |
| 3 chronic conditions                   | 6     | 24.0| 1     | 20.0| –      |
| >4 chronic conditions                  | 8     | 32.0| 2     | 40.0| –      |
| Insurance status                       |       |     |       |     |       |
| Insured                                | 23    | 92.0| 3     | 60.0| .119   |
| Uninsured                              | 2     | 8.0 | 2     | 40.0| –      |
| Insurance type\(^b\)                   |       |     |       |     |       |
| Medicaid                               | 5     | 21.7| 1     | 33.3| 1.00   |
| Medicare                               | 8     | 34.8| 0     | 0.0 | .304   |
| Dual eligible                          | 5     | 21.7| 2     | 66.7| .565   |
| Private insurance                      | 6     | 26.0| 0     | 0.0 | .553   |

Abbreviation: GED, general education development test.

\(^a\)Total N was 30 patients. Actual percentages reported for those responding to each question not considering missing values.

\(^b\)Patients may have reported more than 1 insurance type.
in an MUA. Our study further demonstrates extremely high rates of uncontrolled diabetes in a predominately African American MUA with inadequate primary care capacity—75.5% were uncontrolled, and 91.5% were uncontrolled at some point in the 2-year study period. These poor diabetes control rates surpass those seen in most previous studies and suggest that in certain hotspot communities where ED care is the norm and primary care difficult to find, patients are particularly at high risk for diabetes complications. Consistent with previous studies of medically underserved patients, we found that almost 1 (17%) in 5 patients with diabetes and multimorbidity seen in the ED reported not seeing a PCP within the last year. Of note, 80% of these patients without a PCP were more likely to report delays in needed care, particularly because of transportation difficulties. Furthermore, the study demonstrates that diabetic patients with PCPs in MUA experience slightly better chronic disease care and also have greater access to PCPs. These findings suggest that self-care interventions for this specific patient population can help meet the health-care needs of diabetic patients in MUAs.
Table 3. Primary Care and Self-Care Experiences and Needs Identified through Individual Patient Interviews and Focus Groups.

| Themes                              | Examples/Quotes                                                                 |
|-------------------------------------|-------------------------------------------------------------------------------|
| Individual Patient Interviews       | “They say it (medication for cholesterol) can damage your liver and you have all these wonders if it is the medication and you don’t know.” |
| Health education to understand and manage diabetes | “On my last visit (my doctor) explained things slowly and listened and explained and she took her time.” |
| Patient–provider communication      | “Also more information about the symptoms, you know thirsty or feel like this or that if your sugar is too high or too low. I didn’t know it was diabetes.” |
| Health care for other problems besides diabetes | “Not only physical thing. Two years ago I was depressed. You need to have mental well-being.” |
| Focus Groups                        | “Well, I had a doctor that I had been with over 20 some years...and he was a good doctor; but he stopped taking my insurance.” |
| Health care access and coverage     | “I got a prescription for those lancets, went to Walgreens to get it, US$60 so forget it. I can’t afford that.” |
| Patient–provider communication      | “I lost weight and I still got sugar, they say. So what? He [doctor] told me if I lose weight, I wouldn’t be no more diabetic...and then when I dropped [the weight]...I’m gonna let one of my nurses show you how to use the needle.” |
| Supports and resources              | “Every information I got, I had to go to him [doctor] and ask, and I feel like he should be telling me these things, how I’m advancing in my diabetes.” |
|                                     | “I have a very good doctor. She takes a lot of time with me. She takes that time out to try to explain to me what I should and shouldn’t be doing...” |
|                                     | “I wonder if we had like [name of another congregation], got an exercise class at the church...And they help us with our diet, and help us exercise.” |

Previous studies have shown that reports of disjointed, low-continuity, and untrusting relationships between patients and their providers may explain why patients frequently choose to use ED services rather than primary care.26,27 As the gatekeepers of patient care, PCPs may have difficulty catering to the complex needs of diabetic patients and their complications, resulting in substandard levels of care for people with diabetes.19,28 These findings suggest that while having a regular PCP is important, it is by no means sufficient to ensure good care. Thus, our findings are consistent with previous studies showing great need for strengthening primary care infrastructure and capacity in medically underserved communities.29,30

Individual interviews and focus groups suggest that diabetic patients in MUAs need enhanced access to insurance, primary care and faith-based community resources, diabetes health education, mental health care, improved patient–provider communication and relationships, and support for overcoming healthcare barriers and achieving diabetes goals. These findings are consistent with previous studies that indicate that patient–provider communication in MUAs must improve to build relationships on the basis of authentic and shared social, cultural, and clinical knowledge.31

Evidence from earlier qualitative studies indicates that poor patient–provider communication leads to uncertainty about diagnosis32 and negatively affects self-care.32-34 Sheridan and colleagues found that seemingly outward acceptance of health care was often associated with underlying dissatisfaction with low-engagement care in MUAs.31 Our qualitative findings similarly indicate that primary care access is often hampered by individual and systemic barriers beyond the provider’s direct control (e.g., insufficient finances, affordability of copays for office visits and prescriptions, and culturally influenced lifestyle choices). Furthermore, this study showed that patients were not being referred to health programs or classes that could provide support with managing and coping with their chronic conditions, despite availability in the community. Our findings regarding unmet patient needs for better provider communication, access to information about the disease, and social network support on how to change their lifestyle were consistent with previous qualitative studies.31,34,35 Our findings contribute to the literature in identifying the need to expand local resources that can facilitate achieving primary care needs outside the health-care system.

This study demonstrated patient interest in strengthened primary care interventions for diabetes. Our survey findings that 88% of patients were interested in health coaching are consistent with previous studies suggesting that complex diabetes patients may particularly benefit from the development of programs that specialize in diabetes support through health coaching that embodies social support.36,37 Furthermore, we found, as many patients were “adequately literate” and utilized cell phones rather than smart phones, primary care-based text messaging may be a particularly apt strategy to improve diabetes self-management and mitigate the disparities in health outcomes.8 Our survey findings indicate that motivational text messages from primary care and health coaching are

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interventions that may help the needs of medically underserved patients.\textsuperscript{34,38,39}

There were some limitations to this study. This study focused on small and primarily homogenous study samples, and data were collected from only 1 ED, a congregational network, a safety net primary care practice, and a diabetes registry concentrated in 2 zip codes within a metropolitan area. The qualitative data from individual interviews may not have reached saturation, and further research on different primary care settings is needed. These limitations should be addressed with further research that explores community-wide primary care engagement in MUAs, specifically evaluating the impact of variations in primary care services on quality and accessibility of chronic illness care from the patient perspective. Comparative effectiveness research is needed to assess the impact of various approaches for strengthening primary care capacity on improving patient experience and clinical outcomes for patients with complex multimorbidity.

As primary care plays an essential role in diabetes prevention, treatment, and management, it is important that health-care organizations are accessible and actively engaged in providing patients with the proper diabetes care, particularly for those patients located in MUAs. Increased efforts in coordination of care from clinicians, public health, and social programs are essential in order to improve quality of life for people with multiple chronic conditions. This community case study suggests that diabetic patients in MUAs have deficits in quality and quantity of primary care, and that low-cost interventions such as primary care-based text messaging and health coaching have potential to help address these unmet needs.

Authors' Note

All statements in this report, including its findings and conclusions, are solely those of the authors and do necessarily represent the views of the Patient-Centered Outcomes Research Institute, its Board of Governors or Methodology Committee, or any other institutions mentioned.

Declaration of Conflicting Interests

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