

In Brief

Existing knowledge from the literature demonstrates that primary prevention of diabetes complications is possible. However, patient-, provider-, and health system-based barriers may prevent implementation of evidence-based practices. This article explores barriers to diabetes care that are external to the patient and that may require particular attention when attempting to translate primary prevention strategies into clinical care in the community.

External Barriers to Diabetes Care: Addressing Personal and Health Systems Issues

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Results from landmark clinical studies demonstrate that the complications of diabetes can be prevented or delayed by controlling risk factors such as hyperglycemia,^{1,2} hypertension,^{3,4} and hyperlipidemia.^{5,6} Despite knowledge gained through these studies, adherence to established evidence-based treatment guidelines aimed at controlling these risk factors and utilization of preventive care services by both providers and patients are low. This ultimately may result in patient outcomes that are less than optimal. The solution to the lack of adherence by both providers and patients is not to lay blame, but rather to investigate the factors or barriers underlying non-adherence.

Several factors are hypothesized to contribute to nonadherence, including patient-, provider-, and health care system-based issues. These factors are outlined in Figure 1.

Preventive health care is the cornerstone of primary and secondary prevention of diabetes complications.

Practice guidelines established by the American Diabetes Association⁷ and the Diabetes Quality Improvement Project⁸ are evidence-based and, if followed, are likely to improve patient outcomes. However, perceived and real barriers to preventive service utilization can result in patients not seeking care, nonadherence to treatment recommendations, and poorer health outcomes.

Most studies investigating barriers to diabetes care focus on health care system factors associated with poorer levels of care. These include the lack of health insurance and differing practice patterns between generalist and specialist physicians. Relatively few studies have attempted to understand barriers from the patient perspective. In this report, we review the literature exploring barriers to diabetes care that are external to patients. Data from the Pittsburgh Epidemiology of Diabetes Complications (EDC) Study will also be presented.

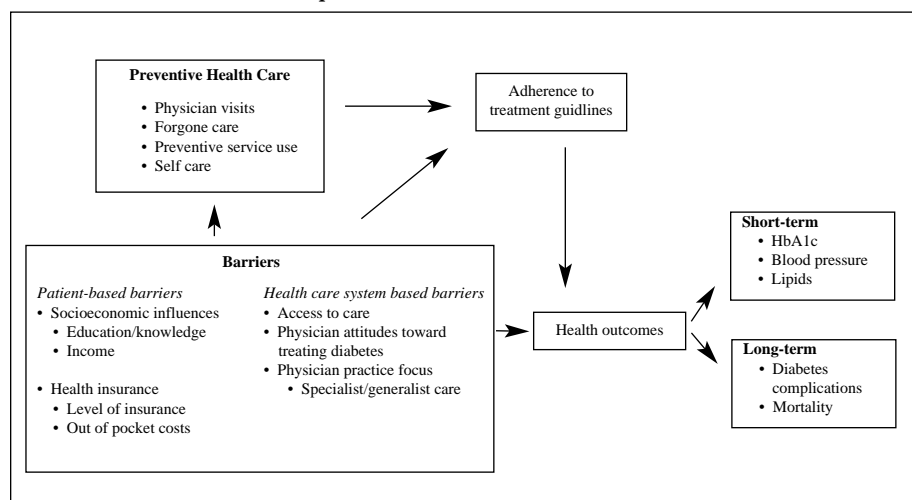


Figure 1. External barriers to care, health care utilization, and outcomes

PATIENT-BASED BARRIERS TO DIABETES CARE

Socioeconomic Status (SES)

For primary prevention of diabetes complications to be effective, patients must have access to quality medical care, the means to pay for services (either through insurance or self-pay), and the knowledge and skills to manage their diabetes on a day-to-day basis. Because access and self-care are critical contributors to outcomes in patients with diabetes, socioeconomic mediators (education and/or income) may play a significant role in these processes.

Studies have reported that diabetic patients of lower socioeconomic standing are less likely to receive specialist care⁹ or to use preventive health care services.^{9,10} Perhaps because of this, these patients have worse complication risk factor profiles,¹¹ including glycemic control.^{9,12}

Studies examining the impact of SES on the use of preventive services have established SES as an important risk factor for nonutilization of these services. A study from Kaiser Permanente in California¹³ found lower levels of education to be independently associated with nonadherence to recommendations for blood glucose self-monitoring at least daily in patients with type 2 diabetes. In patients with type 1 diabetes, living in the most impoverished areas (average annual income <\$13,959) was independently associated with monitoring blood glucose less than three times a

day. Others have found similar results showing that individuals of lower SES use preventive services such as dilated eye exams^{9,12} and diabetes education¹⁴ to a lesser degree. Lower SES has also been associated with a lower level of diabetes knowledge.^{15,16}

Evidence from the Pittsburgh Epidemiology of Diabetes Complications (EDC) Study

The EDC Study is a prospective follow-up study of childhood-onset (<17 years of age) type 1 diabetes patients that has been previously described.^{17,18} Briefly, 658 patients diagnosed between 1950 and 1980 participated in the baseline EDC Study exam between 1986 and 1988 (mean age: 28 years; mean duration of diabetes: 20 years). Results presented in this report are based on 407 participants of the 10-year follow-up clinical exam (1996–1998).

Use of preventive services and outcomes associated with SES in the EDC Study are presented in Table 1. Patients with lower levels of income reported more problems obtaining medical care, were more likely to forgo care (wanted to see a doctor but did not), were less likely to have health insurance and to see a physician in the previous year, and were less likely to report good health. They also had higher HbA_{1c} values. Those with lower levels of education were less likely to have heard of HbA_{1c} testing (a measure of diabetes knowledge, 61.4 vs. 79.0%) and were less likely to have received diabetes education or

to report good health. They also had higher HbA_{1c} values.

Targeting interventions to address these barriers, including increasing access to and awareness of diabetes education and taking steps to remove financial barriers, may improve adherence to treatment recommendations and complication risk factor profiles.¹³

Health Insurance and Out-of-Pocket Costs

Health care costs are a common topic of discussion today among patients, providers, and payers. Most often, the focus is on the high costs associated with new treatments and technologies and whether insurers should pay for them. New interventions in diabetes care, such as intensive therapy in type 1 diabetes, the use of angiotensin-converting enzyme (ACE) inhibitors, or the use of statins, are expensive relative to previous standards of treatment.

The impact of health care costs on patients is also a significant issue. Trends toward the greater use of co-payments or user fees and higher insurance premiums create situations in which some patients may be underinsured. As a result, these patients can incur large out-of-pocket costs. New treatment guidelines for diabetes are likely to exacerbate this problem. In general, patients with diabetes are being advised to increase their use of health care services and supplies, not decrease them.

Evidence of higher out-of-pocket costs in diabetes has been recently

Table 1. Associations Among Socioeconomic Status, Access to Care, and Outcomes From the Pittsburgh Epidemiology of Diabetes Complications Study (1996–98)

| | Education | | P-value | Income | | P-value |
|------------------------------------------------|-------------------------|-------------------------|---------|---------------------|----------------------|---------|
| | ≤High School n = 121 | >High School n = 275 | | ≤\$20,000 n = 77 | >\$20,000 n = 300 | |
| <i>Access to care</i> | | | | | | |
| Health insurance (% yes) | 92.5 | 94.9 | 0.35 | 84.2 | 96.7 | 0.0002 |
| Problems obtaining care (% yes) | 12.8 | 11.4 | 0.68 | 21.3 | 9.8 | 0.006 |
| Forgone care (% yes) | 14.8 | 13.6 | 0.75 | 18.9 | 12.8 | 0.17 |
| Regular source of care (% yes) | 82.4 | 78.2 | 0.35 | 77.6 | 79.3 | 0.76 |
| Physician visit in previous year (% yes) | 92.8 | 91.4 | 0.66 | 84.1 | 93.2 | 0.01 |
| Specialty care (% yes) | 36.7 | 56.8 | 0.0002 | 39.5 | 52.4 | 0.05 |
| <i>Self-management</i> | | | | | | |
| Testing ≥ 4 times a day | 69.2 | 72.8 | 0.47 | 76.7 | 70.0 | 0.26 |
| Diabetes education in previous 3 years (% yes) | 13.6 | 20.2 | 0.12 | 23.3 | 15.8 | 0.13 |
| <i>Outcomes</i> | | | | | | |
| Fair or poor health (% yes) | 35.8 | 20.4 | 0.001 | 40.8 | 20.3 | 0.0002 |
| HbA _{1c} (%) mean (SD) | 10.4 (1.8) | 9.9 (1.7) | 0.005 | 10.5 (1.6) | 9.9 (1.6) | 0.009 |

reported in a study of families dealing with childhood diabetes. Average out-of-pocket health care costs (as a percentage of household income) were significantly higher in families affected by type 1 diabetes (5.6%) than in a comparison group of families with no children with diabetes (3.1%).¹⁹ These higher costs were primarily related to the greater use of health care by the family members with diabetes. Seventeen percent of the cohort interviewed had out-of-pocket costs exceeding 10% of their household income. High out-of-pocket costs for patients with diabetes have also been noted in other populations, including reports from India²⁰ and New Zealand.²¹

High out-of-pocket health care costs are cause for concern because they may influence the health care decisions made by people with diabetes. Indications from the published literature suggest that decisions made could be detrimental to the individuals' health. For example, a report from Karter et al.¹³ noted that people with diabetes with the highest co-payment rates tested their blood glucose levels at a lower frequency than did those with no co-payments. Simmons et al.²¹ reported that up to 49% of subjects interviewed did not participate in regular blood glucose self-monitoring because of high out-of-pocket costs.

Health care-seeking behavior and costs in the EDC Study

Evidence supporting the association of costs with health care-seeking behavior was examined in the EDC population. Approximately 12% of this population reported problems obtaining medical care, with the most common reasons relating to cost (33.3%), physician availability (18%), physician office hours (15.0%), and health insurance (15%). Additionally, 14% of the EDC population reported not seeking care for a diabetes-related health problem when they would have liked to, with the most frequently reported reason being cost (27.7%).

We were interested in finding out if those reporting problems obtaining care actually decided to forgo care. Of those who reported problems obtaining care, approximately half (46.7%) did not seek care for a diabetes-related health problem, with cost being the most frequently reported reason (43.4%).

There is some indication, then, that level of education and income, as well

as health care costs incurred by patients, can be barriers to diabetes preventive care and subsequent outcomes. Because barriers related to finances and cost may force patients to forgo care or be less compliant with treatment recommendations, poor outcomes may not just be an issue of nonadherence, but rather one of patients' financial environment influencing preventive care-seeking behavior. It therefore becomes essential for payers and providers to be sensitive to the financial burden (either perceived or real) that a chronic disease places on individuals.

Physical Access to Services in Rural Versus Urban Settings

When examining issues surrounding barriers to diabetes care, patients' residency (urban vs. rural) should be considered because diabetes care requires access to continual follow-up.²² The Congressional Office of Technology Assessment (OTA) report titled "Health Care in Rural America" noted that "rural populations are unique in the extent of physical barriers they may encounter when obtaining health care."²³ Rural residents have a poorer perception of overall health, lower income, and a higher proportion of elderly and children compared to those residing in urban settings. This population experiences increased rates of chronic disease including diabetes (31.6/1,000 rural vs. 26.7/1,000 urban).²³ Other challenges facing those who reside in rural areas are access to public or reliable transportation and increased time that must be taken away from work or families to reach quality care.²³

Few data are available regarding place of residence and receipt of preventive care specific to diabetes. However, the OTA report²³ identified several important differences between rural and urban residents on access to care that are directly relevant to patients with diabetes.

Transportation

Residents of the rural community face issues of distance and adequate transportation when seeking health care. The young and affluent members of the rural community are more likely to seek care in urban areas where the desired health care services (e.g., specialist care) are more readily available. They may also seek care outside of their rural area to have more choices for care.²³

Few data are available specifically addressing transportation issues for patients with diabetes. However, because the prevalence of diabetes is higher among the elderly and those with lower income (also characteristics of rural populations), rural residents with diabetes may be less likely to seek care outside their residential area and therefore may have fewer treatment choices.²³ Patients in rural settings may live a considerable distance from diabetes clinics or physicians with expertise in the treatment of diabetes and may need to travel for longer time periods to see a specialist. Increased rates of disability among rural residents²⁴ may also relate to patients with diabetes who are particularly affected by early disability,²⁵ thus adding to difficulties accessing diabetes care at distances.

Availability of health care personnel

Rural areas have half as many physicians as do urban areas. In sparsely populated areas, it is estimated that there is one physician for every 2,000 residents,²³ and there are 106 rural counties nationwide with no physician at all.²⁴ Primary care providers are twice as likely as non-primary care providers to practice in rural areas, and of all physicians who practice in non-metropolitan areas, only one-third are specialists.²³ Small communities simply cannot support the medical subspecialties.²³ General practice physicians must obviously have expertise in a variety of conditions and may have limited time to provide the necessary intensity of care for patients with diabetes.

The supply of other health professionals is also less than adequate in rural settings. There are fewer nurses, dietitians, emergency personnel, and laboratory technicians available.²³ Danksy and Dirani²² found that elderly Medicare patients with diabetes in rural settings (particularly thinly populated settings) have access to fewer hospital beds, primary care physicians, and specialty physicians, with 13 specialists per 100,000 in large metropolitan core counties (population \geq 1 million) compared to 1 specialist per 100,000 in thinly populated counties (<2,500 urban residents). Rural residents in this study had more home health visits than those in urban counties, demonstrating a need for increased diabetes education efforts from nontraditional sources.

Receipt of preventive care

Rural residents do not receive the same number and type of chronic care services as their urban counterparts. They are also less likely to be insured (particularly privately insured), have lower rates of physician utilization, and are less likely to participate in preventive screening.²³

These findings are particularly problematic for patients with diabetes because good glycemic control and early detection of diabetes complications is dependent on access to continual preventive care and complication screening from health care providers. One study examining receipt of diabetes care in rural settings found that this group was less likely to receive annual HbA_{1c} measures, eye exams, total cholesterol measurements, and blood glucose measurements than their urban counterparts.²⁶ In another study, rural residents were less likely to participate in diabetes education.¹⁴ In contrast, Ahluwalia and colleagues did not find any differences in recommended levels of care, including health care provider visits, foot exams, blood pressure measurement, and dilated eye exams, by residency.²⁷ Although few data are available examining the role of residency as it relates to preventive care in patients with diabetes, issues of rural residency in the general community can be particularly problematic for patients with diabetes, who rely heavily on preventive services for the primary and secondary prevention of diabetes complications.

Summary

These financial, educational, and access barriers demonstrate a need for innovative efforts on the part of health systems and providers to offer increased access to diabetes services in rural settings. Outreach programs such as peer-supported education and diabetes mini-clinics that include access to diabetes specialty services may offer a mechanism for improving access to diabetes care in rural settings.

HEALTH CARE SYSTEM-BASED BARRIERS TO DIABETES CARE

Access to Quality Diabetes Care

A recent report from NHANES III²⁸ found high rates of access to care in terms of having a regular source of care, health insurance coverage, and receipt of preventive services among

people with type 2 diabetes. However, despite having access, outcomes were inadequate, with 58% of patients having an HbA_{1c} >7%, 60% of those with hypertension and dyslipidemia not controlled to accepted levels, and 42% of those surveyed assessing their health as fair or poor. Thus, barriers to diabetes care may not be entirely about access to *any* care, but rather about access to *quality* care.

One aspect of quality diabetes care is accessibility of diabetes specialists. This is important because in the United States, the trend toward managed care is placing more responsibility for the care of diabetic patients in the hands of primary care providers. It is estimated that more than 90% of physician visits of diabetic patients are to primary care providers.²⁹ Evidence has demonstrated differential service provision by specialist compared to generalist physicians, with lower use of preventive services and poorer glycemic control found in patients who receive their diabetes care from primary care providers.³⁰⁻³⁴

Specialty care and preventive service utilization and outcomes in the EDC Study

A recent report from the EDC Study⁹ demonstrated that care received from a diabetes specialist (endocrinologist, diabetologist, or attendance at a diabetes clinic) is associated with higher rates of self-monitoring of blood glucose (93.8 vs. 79.5%), and in those who monitor, more frequent monitoring (18.9 vs. 11.1 tests/week). Additionally, those receiving specialty care were more likely to have received diabetes education in the previous 3 years (23.0 vs. 13.3%), to have seen an ophthalmologist in the previous 2 years (84.2 vs. 76.1%), and to have more diabetes knowledge (had heard of the results from the Diabetes Control and Complications Trial: 52.2 vs. 35.2%; knew about HbA_{1c} testing: 83.1 vs. 67.5%). Those seeing specialists also had better glycemic control (9.7 vs. 10.3%). Interestingly, when associations with glycemic control were examined by level of education and income, those with higher incomes and lower levels of education appeared to receive the most benefit from specialist care.

Thus, results demonstrate that access to specialist care may be essential for preventive service utilization and improved glycemic control. The EDC Study also provides further evi-

dence for understanding what factors or barriers prevent certain subgroups of the population from receiving the full benefits of diabetes specialist care.

Physician Attitude Toward Treating Diabetes

Physician attitudes toward caring for diabetic patients with diabetes can be another barrier. Studies of physician attitudes have found that primary care providers consider diabetes more difficult to treat than other chronic diseases because diabetes requires more monitoring and medication adjustment to achieve treatment goals.³⁵ Physicians also felt that guidelines for reaching these goals were not clear.^{35,36} Another concern reported by physicians was that patients do not have a sense of urgency or understanding about treating their diabetes and thus are less likely to adhere to provider recommendations.^{33,37} Physicians also reported that there was not adequate administrative support for the increased time and effort required to treat diabetic patients.³⁶ Additionally, patient finances were viewed by physicians as a barrier to diabetes care³⁸ and adequate glycemic control.³⁷

Summary

Patients with diabetes may encounter several systems barriers preventing them from freely accessing specialty services. They may also encounter great difficulty in navigating the ever-complex health insurance system that would allow this access. This may be particularly problematic for those in lower SES groups.³⁹ Additionally, if health care providers face administrative, time, and information constraints, patients may be placed in a less-than-optimal position for receipt of necessary preventive care.

Increased efforts aimed at disseminating evidence-based clinical care guidelines through problem-based learning models^{40,41} and/or academic detailing⁴² (one-on-one physician education) and at increasing the availability of diabetes educators in primary care settings on a regular basis may improve the level of diabetes knowledge for both patients and providers. Informed physicians partnered with empowered patients will ultimately yield better health outcomes for patients with diabetes.⁴³ Health systems must also become aware of the complexities involved in providing quality care to patients with diabetes

and subsequently provide more support to health care professionals.

CONCLUSION

There are many challenges to understanding external barriers to diabetes care. There are common themes between the categories of barriers to care that impact preventive service utilization and outcomes in patients with diabetes. Movement from the acute care model of health care delivery to one that focuses on long-term management and preventive care⁴⁴ requires a greater understanding of barriers to diabetes care from patients' perspective so that health systems can develop programs to address and overcome these barriers. Programs developed accordingly may ultimately result in improved patient outcomes.

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