Evidence-Based Guidelines Meet the Real World

The case of diabetes care

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OBJECTIVE — Improving diabetes care in the U.S. is critical because diabetes rates are increasing dramatically, particularly among minority and low-income populations. Although evidence-based practice guidelines for diabetes have been widely disseminated, many physicians fail to implement them. The objective of this study was to explore what happens to diabetes practice guidelines in real-world clinical settings.

RESEARCH DESIGN AND METHODS — A qualitative research design was used. Open-ended semistructured interviews lasting 1–2 h were conducted with 32 key informants (physicians, certified diabetes educators, researchers, and agency personnel) selected for their knowledge of diabetes care in South Texas, an area with a high diabetes prevalence and a large proportion of minority and low-income patients.

RESULTS — Health professionals stress that contextual factors are more important barriers to optimal diabetes care than physician knowledge and attitudes. Barriers exist at multiple levels and are interrelated in a complex manner. Examples include the following: time constraints and practice economics in the private practice setting, the need to maintain referral relationships and maldistribution of professionals in the practice community; low awareness and low socioeconomic status among patients; and lack of access for low-income patients, low reimbursement, and insufficient focus on prevention in the U.S. health care system.

CONCLUSIONS — Contextual barriers must be addressed in order for diabetes practice guidelines to be implemented in real-world clinical practice. Suggested changes include an increased focus on prevention, improvements in health care delivery for chronic diseases, and increased attention to the special needs of minority and low-income populations.

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Improvement of diabetes care in the U.S. is critical because diabetes rates have been increasing dramatically over the past few decades, particularly among minority and low-income populations (1–3). Diabetes research has yielded substantive knowledge of effective management of the disease and the prevention of long-term complications. An issue of growing concern among diabetes researchers and government funding agencies, however, is how to effectively translate research knowledge into improved clinical care. To aid the process of research translation, evidence-based practice guidelines have been disseminated widely by the American Diabetes Association (ADA) (4), and outcome measures related to these guidelines have been developed, such as the ADA Provider Recognition Program and the Diabetes Quality Improvement Program of the National Center for Quality Assurance. Such efforts are intended to improve patient care through increasing physician access to the latest information and evaluating efforts to use it.

The ADA standards of care for diabetes include recommendations for drug therapies, glycemic control goals, and other actions—foot examinations at every visit, annual screening for microalbuminuria and lipids, annual eye and dental examinations, and referral to diabetes education—that target the prevention of complications (4). Yet chart reviews conducted in study after study document that physicians are not implementing these standards of care (5–13). The implication of these studies is that physicians are at fault for not keeping up to date on the latest advances in diabetes treatment. Researchers have also explored attitudes toward diabetes and its treatment as possible influences on provider practice behaviors (14–16). As Glasgow (17) notes, however, it is important to look beyond provider knowledge and attitudes to the broader practice context for other factors that may influence provider behaviors. Unless contextual factors are addressed, practice guidelines are unlikely to be followed.

The objective of this study was to explore what happens to diabetes practice guidelines—in particular, barriers to guideline implementation—in real-world clinical settings. To develop an in-depth case study and allow for unexpected findings and complex interrelationships to emerge, we used a qualitative research design to explore in an open-ended fashion.

RESEARCH DESIGN AND METHODS

Study site
The study was conducted in 1996 in a four-county area along the border be-
between Texas and Mexico called the Lower Rio Grande Valley (LRGV), also known as “the Valley,” of South Texas. The LRGV has a combined population of ~850,000 (18), largely concentrated in the environs of Brownsville, Harlingen, and McAllen. According to 1990 census data, the majority (85%) of the population is Mexican-American, 41% are migrant/seasonal farm workers, 42% live below the poverty level, and ~38% are uninsured (19). Diabetes prevalence in Valley residents of all ages has been estimated to be as high as 21% (18).

Participants
There were 32 key diabetes-related professionals who participated in the study. A criterion-based snowball, or network, sample was used (20) and was recruited in the following manner. Interviews began with diabetes center personnel and diabetes researchers who provided the names of diabetes care providers regarded to be opinion leaders—professionals with extensive knowledge of diabetes and diabetes care—in the local practice community. New names were elicited at the end of each interview until they began to repeat, resulting in 56 potential interviewees. Criteria for selection included number of mentions as an opinion leader, diversity in professional background, geographic distribution throughout the Valley, and availability and willingness to be interviewed. Interviews and sample recruitment continued until the saturation point (20) was reached in the data (i.e., when no new information was being gained). The resulting sample included a total of 19 physicians and 13 other diabetes-related professionals. Twelve of the physicians were specialists (five endocrinologists, two ophthalmologists, two nephrologists, two perinatologists, and one cardiovascular surgeon), and seven were primary care providers (five internists and two family practice physicians). An additional 13 interviews were conducted with 2 podiatrists, 3 certified diabetes educators (nurses) from hospital diabetes centers, 3 dietitians working in association with physicians, 3 leaders of diabetes service organizations, and 2 local diabetes researchers.

Data collection and analysis
Open-ended interviews lasting 1–2 h were conducted in the professionals’ offices by the first author (A.C.L.) between January and May of 1996. Interviews were semistructured. During the interview, an interview guide was followed, but the discussion was allowed to move in unexpected directions if pertinent to the central research questions (i.e., “What happens to standards of care for diabetes in real-world clinical settings?” and “Why aren’t physicians following standards of care?”). After they were asked about their professional background and involvement in diabetes care in the LRGV, professionals were asked for their views on diabetes care in the LRGV, including diabetes resources, reasons for poor diabetes outcomes, barriers to following standards of care, referral relationships, and reimbursement issues. Specialists and diabetes center personnel were also asked for their opinions on the general quality of diabetes care provided by primary care providers. (Interview guide available from the authors upon request.)

Interviews were audiotaped, and typed field notes were checked with audiotapes for accuracy. Textual data were analyzed using standard qualitative techniques (21). As such, segments of text were coded by topic; the codes were grouped into themes, and broader patterns linking the themes were discerned. The data were analyzed by the first author (A.C.L.) and reviewed by the second author (J.A.P.), a physician with experience in diabetes care and research on continuing medical education for diabetes in the LRGV. To increase validity, preliminary results were presented to the Rio Grande Valley Diabetes Task Force, an ad hoc group of professionals formed to address the diabetes problem. Task force members agreed that the analysis accurately reflected the quality of diabetes care in the LRGV (6 of 51 task force members had also participated in the interviews, primarily to start the snowball sample.)

RESULTS — The health professionals interviewed agreed that some Valley physicians lacked knowledge of up-to-date standards of care for diabetes or had negative attitudes about diabetes and diabetic patients. However, they emphasized that contextual factors were much more important barriers to optimal diabetes care in the Valley than knowledge or attitudes. The contextual factors they discussed are grouped below into four broad overlapping categories: private practice setting factors; local practice community factors; general public/patient factors; and health care system factors. Themes within the categories are listed in the order of emphasis that interviewees put on them.

Private practice setting factors
Time pressures and the bottom line. Physicians explained that low reimbursement rates from government programs, too many low-income patients unable to pay their bills, and high malpractice insurance costs make it difficult for some providers to stay in business in the Valley. They reported that some physicians, in order to pay their overhead costs and still make a profit, have increased the number of patients they see to as many as 50–100 per day. They have time only to refill prescriptions, not to make referrals or to educate patients. Many Valley physicians are able to stay in business only because the income derived from their insured and/or paying patients subsidizes the care of their low-income patients.

Lack of support staff. Interviewees noted that physicians in private practice generally do not have a sufficient number of nurses or other support staff to assist them in carrying out standards of care. Reasons included the following: physicians do not hire additional staff because they do not place a high priority on diabetes education and other support for diabetic patients, they do not appreciate the value of teamwork in diabetes care, and they cannot afford to hire additional staff members.

Local practice community factors
Collegial respect. A specialist noted that there is extreme respect for and among doctors in the Valley—a fact that prevents physicians from directly challenging each other when they detect problems in diabetes care. In addition, according to an internist, physicians do not like to be told what to do, be told that they are at fault, or admit that they lack knowledge. Specialists and diabetes center personnel described how they instead worked indirectly—i.e., through patients—to change their colleagues’ behavior, because when a primary care provider saw improved outcomes as a result of his or her specialized diabetes care, he or she might then refer patients earlier or ask for advice. Specialists and diabetes center personnel also counseled their diabetic patients to be more proactive in managing their disease, including their requesting...
screening referrals from their primary care providers, and even making their own appointments with specialists. They noted that working indirectly through patients, rather than challenging primary care providers directly, had the added benefit of preserving referral relationships in the community. The disadvantage, however, was that appropriate care for diabetic patients was sometimes delayed.

Lack of teamwork with other professionals. Another problem impeding comprehensive diabetes care, according to those interviewed, was a lack of teamwork in diabetes care. Physicians were generally not interested in sharing responsibility for diabetes care with other physicians or with allied health professionals. Some thought that they could handle all aspects of the disease and were unaware that they lacked the knowledge to provide comprehensive care. Others seemed unaware, or were negative, about how other health professionals such as podiatrists, nurse case managers, and dietitians could support them in diabetes care. In addition, practitioners noted that there were not enough specialists and allied health professionals in parts of the Valley. They thought that physicians might begin referring patients if and when they had access to these professionals.

Another suggested impediment to teamwork in diabetes care was competition for patients. Some physicians fear that specialists or diabetes centers might steal their patients or advise patients to go elsewhere for health care. Moreover, in certain areas of the Valley, established physicians were reported to be actively discouraging new physicians from setting up practice. Interviewees speculated that shutting out new physicians impeded optimal diabetes care from a team of professionals because patient access to a variety of physicians and health services, including newcomers with up-to-date knowledge of diabetes care, was restricted.

Shortage and maldistribution of physicians. Those interviewed complained that a shortage of physicians in certain parts of the Valley—whether a result of actual shortage, competition, or high physician turnover—also contributed to physicians’ inability to follow standards of care. Prevention takes time, a specialist noted, and “physicians are too busy putting out fires to worry about smoke.” Respondents pointed out that physicians are so overwhelmed with treating acute problems that they have insufficient time to follow prevention-oriented standards of care for diabetic patients. A lack of both primary care providers and specialists was reported for two of the four counties, and primary care providers complained of a lack of specialist support. On the other hand, they reported that in other parts of the Valley there were so many specialists that some had begun to provide primary care.

Respondents also noted that high physician turnover was a problem in the Valley. Reasons given included the difficulty of financial survival because of the high proportion of low-income patients, the difficulty of treating low-income/less-educated patients, high malpractice rates, lack of subspecialist support, professional isolation, and social and cultural characteristics of the Valley lifestyle. They noted that physicians who stayed were generally from local families or were interested in “frontier medicine.”

General public/patient factors

Low public awareness of diabetes. According to those interviewed, diabetes care is especially difficult in the Valley due to a low public awareness of the seriousness of diabetes. Because of this, people may not discover their diabetes until it has reached an advanced stage, and many do not follow physician recommendations for management or follow up on referrals to specialists or to diabetes education. Providers suggested that increased public awareness would make their jobs easier, and suggested that awareness campaigns begin as early as possible, such as in elementary schools.

Obesity and poor nutritional habits. Providers also complained that obesity and poor nutritional habits increased diabetes rates and made it more difficult to motivate patients to make changes in behavior. They expressed the opinion that local foods and food preparation methods are especially high in fat, and that food habits are especially difficult to change because they play such an important role in the local Mexican-American culture.

Low income and educational levels. The majority of diabetic patients in the Valley have low incomes, interviewees noted, which presents a special challenge to diabetes care. As a result, patients often cannot afford home glucose-monitoring supplies, regular doctor visits, medications, diabetes education, or specialist care. To save money, some people self-medicate with pharmaceuticals purchased without a prescription across the border in Mexico, which interferes with medications and continuity of care provided by physicians on the U.S. side of the border. Patients may also lack the means of transportation to visit health care providers. Interviewees suggested that all of these issues, in addition to high numbers of migrant workers in the Valley, influence continuity of care for diabetic patients.

Interviewees reported that less-educated patients often have difficulty understanding clinicians’ explanations about diabetes and its management, and that inaccurate beliefs (such as insulin causing rather than preventing complications or that herbs and home remedies are adequate to control diabetes) sometimes interfere with care. Providers complained that their efforts to educate Valley patients were hampered by a lack of culturally appropriate low-literacy teaching aids, particularly concerning diet.

Diabetes center nurses stressed that patients needed resources even more than education, however. They felt that patients would take care of themselves if they had the means to do so. They also felt that it would be more effective to focus educational efforts on health care professionals, because ultimately more patients would be affected.

Lack of assertiveness with physicians. Several of the physicians suggested that it is incumbent on diabetic patients to be knowledgeable about diabetes and to feel empowered to request referrals and screenings from providers, as busy Valley providers often do not take the time to make referrals. “It’s always important to educate doctors,” a specialist noted, “but patients need to demand care.” They agreed, however, that low-income, less-educated patients in the Valley, particularly if they are older or female, have an especially difficult time asking questions of their doctors due to an extreme respect for physicians and authority.

Threat of malpractice. Practitioners reported a high rate of malpractice lawsuits in the Valley, and that the threat of lawsuits drives a wedge between patients and providers, inhibiting the ability to work as a team in managing diabetes. The malpractice threat also limits diabetes treatment alternatives for low-income patients. Physicians feel that they cannot suggest
low-cost diabetes treatment alternatives to patients because they might be sued for substandard care, even though their patients cannot afford optimal care. Providers suggested that short appointment times (whether due to a physician shortage or due to compensating for low reimbursement rates by increasing patient loads) undoubtedly contributed to low patient satisfaction and high malpractice rates in the Valley.

Health care system factors
Access to health care for low-income patients. Professionals interviewed complained that a lack of access to health services for low-income patients impeded physicians’ ability to follow standards of care for diabetes. They noted that there are few free or low-cost places to which to refer patients for diabetes education or for specialist care in the Valley. Most diabetes centers charge for classes, and few low-income patients can afford them. Some specialists will not accept the low Medicaid/Medicare reimbursement rates. The closest state hospital that is willing to perform surgery for indigent patients with diabetes complications is located in Galveston, more than 350 miles away, and patients cannot afford the cost and inconvenience of the lengthy trip. Physicians try to refer indigent patients to federally qualified clinics, but these are insufficient to handle the large number of such diabetic patients in the Valley. “Physicians tend to withdraw when there are no patient resources,” a physician commented, and patients end up with inadequate care.

Providers pointed out that a large proportion of the poor diabetic outcomes in South Texas results from a general lack of access to health care for low-income people in the U.S. Many people never make it in to see doctors for preventive or maintenance health care for diabetes because they cannot afford it. They enter the health care system only at the complication stage, when hospitalization has become necessary and the costs are absorbed by the hospital. In the border area, there are also many undocumented immigrants who are not covered by government programs, yet contribute to the poor outcome statistics. As one physician noted, “The patients who make it in to see doctors get good care. It’s the ones who never make it in that we need to worry about.”

Reimbursement levels for Medicaid and Medicare. The physicians interviewed complained that reimbursement levels for diabetic care from state and federal programs, including Medicaid, Medicare, and the State Eye Program, are unrealistically low. To compensate, they explained, many of their colleagues have increased the number of patients seen per day, reducing the amount of time they spend with diabetic patients and their ability to follow standards of care. An ophthalmologist, despite his concern for the diabetes problem and interest in diabetes care, confirmed that he too was contemplating no longer accepting patients from the State Eye Program because of the low payments, noting that this reaction was not uncommon.

The government is “pushing too hard” on physicians to try to contain health care costs, stated another physician; instead, it should be focusing on hospitals and pharmaceutical companies. However, he speculated, the government continues to focus on physicians because hospitals and pharmaceutical companies are well organized and have strong lobbies.

Emphasis on treatment versus prevention. The providers interviewed felt strongly that the emphasis on treatment rather than prevention in the U.S. health care system was an important barrier to physicians’ following standards of care for diabetes. A lack of emphasis on prevention severely limits resources allocated to prevent complications, whether patients are covered by Medicare, Medicaid, private insurance, or the State Commission for the Blind. Limited resources to prevent complications make physicians’ work more difficult because patients cannot afford to follow their recommendations for preventive care. Further, inadequate compensation is a disincentive for physicians to provide comprehensive care. Those interviewed gave many examples of how government programs and insurance covered treatment, but not prevention, of diabetes complications. For example, at the time of the study, dialysis, amputation, blindness, high-risk pregnancy and delivery for diabetic women, and inpatient diabetes education were covered, but preventive care such as outpatient diabetes education, home glucose-monitoring supplies, preconceptual counseling for diabetic women, postpartum follow-up of gestational diabetes, and eye care to prevent blindness were not covered. Sometimes, only a portion of necessary diabetic supplies was covered (e.g., insulin but not syringes). They also noted that pre-retirement-aged adults in particular lose out because they are too old for Medicaid and too young for Medicare, yet this life stage is the most important time to prevent diabetes complications.

Physicians commented on the limits of their own medical training, which also emphasized treatment over prevention. Several mentioned that they did not learn about the prevention of diabetes complications until they were in practice in the Valley and were faced with large numbers of diabetic patients. A diabetes center nurse pointed out that the emphasis on treatment over prevention is reinforced by pharmaceutical companies, which heavily advertise medications to treat disease. In effect, she noted, these companies provide most of the education that primary care providers receive on diabetes care after completing their training.

Impact of managed care. At the time of the study, managed care organizations were moving into the Valley. The physicians interviewed expressed the fear that managed care was going to worsen the current state of diabetes care, because under managed care there would be even less time for patients and less emphasis on prevention in order to cut costs.

CONCLUSIONS — As illustrated by the case of diabetes care in South Texas, knowledge deficits and negative attitudes of physicians may interfere with diabetes care, but there are also numerous contextual barriers that impede physicians’ ability to implement standards of care for diabetes. These contextual barriers are interrelated in a complex manner. Physician characteristics, such as negative attitudes toward diabetes care, are intertwined with patient characteristics, such as lack of resources, which are intertwined with the problem of low government reimbursement, which is intertwined with the problem of increased patient loads and lack of time for diabetes care. In addition, lack of awareness of diabetes among members of the general public and lack of knowledge of up-to-date standards of care by physicians are two conditions that serve only to worsen each other. Physician, practice setting, practice community, patient community, and health care
system barriers interact to create an interlocking multilayered self-reinforcing system that impedes the delivery of optimal diabetes care.

This case study provides clues as to what may be limiting the effectiveness of diabetes care by private practice physicians and others in the U.S. It furthers our understanding of why, despite research advances in diabetes treatment and the prevention of complications, diabetes care continues to be inadequate and complication rates continue to rise. While it could be argued that the high prevalence of and emphasis on diabetes in the LRGV of South Texas means that the findings of this study are too specialized to be applicable to other U.S. settings, this extreme case renders contextual barriers visible and makes it possible to outline them in relief. Recognizing and understanding contextual barriers in one setting may help to recognize and understand similar barriers in other settings, and may provide hypotheses for further research. Additional research will help to ascertain whether the findings of this study are applicable to other geographic locations and practice settings in the U.S. Finally, the case of diabetes care in the LRGV of South Texas may serve as a wake-up call for the U.S. health care system. It paints a sobering picture of the future, when the nation’s demographic and epidemiological profile will look more like the current profile of the LRGV, with increasing numbers of underserved minorities and an increasing proportion of chronic diseases as the population ages (22), including diabetes (2).

Our findings suggest that, although it is important to disseminate practice guidelines and provide continuing medical education on diabetes to physicians, a narrow focus on physician knowledge is insufficient for research translation to occur. Contextual barriers to optimal diabetes care must also be addressed for research to be translated into real-world clinical practice and used for the benefit of patients (17).

The health care professionals interviewed for this study echo diabetes experts’ recommendations for changes in the U.S. health care system that are necessary to improve diabetes care and the care of chronic disease in general. First is increased attention to diabetes prevention. Such prevention includes universal access to health care, including comprehensive preventive services at all stages of life and adequate reimbursement for them (23); preventive efforts that target people of younger ages, in particular toward the prevention of obesity, a major risk factor for diabetes (2,24,25); and increased awareness of the seriousness of diabetes and the importance of early detection and prevention by patients, the general public, and physicians (23,24). The National Diabetes Education Program and the Centers for Disease Control and Prevention–affiliated state diabetes control programs are good examples of ongoing efforts to raise diabetes awareness at the community level.

Other changes involve improvements in the nation’s health care delivery system. These include improved training in diabetes management for primary care providers during residencies and continuing medical education programs (23); a team approach to diabetes care among primary care providers, specialists, allied health practitioners, and patients (17,23,26,27); the development and implementation of practice guidelines and standards of care for diabetes (23,26); and longer appointment times to deal with the complexities of diabetes care and adequate reimbursement for them (17, 27). Above all, improved care for diabetes requires expanding the nation’s model of health care to accommodate chronic diseases more effectively (17,23–27).

The diabetes professionals interviewed for this study also remind us of the imperative to focus on the special needs of minority and low-income populations—who suffer disproportionately from diabetes—and on the health care professionals who serve them, when planning changes in the delivery of diabetes care. Increased health care resources are needed for low-income patients so that they can purchase diabetes medications and supplies and receive diabetes education and specialist care. Also needed are educational materials and techniques suitable for less-educated and non-English-speaking patients. Inequalities in health resources and infrastructure need to be addressed to improve patient access to quality diabetes care and the ability of health professionals to provide it. Finally, the threat of lawsuits and high malpractice insurance rates, in addition to other economic concerns of physicians in private practice, need to be addressed because they affect (or are perceived to affect) physicians’ ability to implement standards of care.

Clearly, a multifaceted strategy for change is needed to support practitioner efforts to provide effective diabetes care. These efforts must address contextual as well as practitioner factors in diabetes care and address the special needs of minority and low-income populations. A multifaceted approach will address changing health care needs in the future and will ultimately reduce the high cost—both economically and in terms of human suffering—of diabetes complications in the U.S.

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