

Articles

Overcoming Social and Cultural Barriers To Care for Patients With Diabetes

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We attempted to develop a culturally sensitive alternative approach to diabetes management in a multiethnic, socially disadvantaged community (Waianae, Hawaii). The aims of this 3.5-year demonstration project were to establish regular community-based medical contact with diabetic patients who had a history of nonadherence to treatment regimens and to determine whether this strategy would lead to better health care (particularly improved self-management) in these patients. This community-based, culturally sensitive outreach system of medical follow up dramatically improved the amount and quality of medical care provided to this high-risk subpopulation of patients with diabetes.

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Managed care has focused attention on populations at high risk for adverse outcomes or excessive costs. Patients with diabetes consume two to two-and-a-half times more health care dollars than the average person. This population accounts for approximately 15% of the total cost of health care (\$90 billion dollars annually) in the United States.¹ In addition, a subpopulation of patients with diabetes fails to seek regular care or adhere to recommended care plans, thus increasing their risk of suffering acute and chronic complications. As is to be expected, patients who fail to seek regular follow-up care often have poor metabolic control and lack the skills necessary to manage their disease.²

Results of the Diabetes Control and Complications Trial show that improved metabolic control substantially reduces the rate of microvascular complications in patients with type 1 diabetes.³ The recent medical literature also strongly supports the benefits of improved metabolic control for patients with type 2 diabetes.⁴⁻⁷ It is imperative to develop methods for improving metabolic control. Most therapeutic interventions have been developed in academic or diabetic centers and do not include patients who do not seek medical care or who fail to follow medical recommendations. Recognition of the greater burden of diabetes in minority populations⁸ has focused attention on the failure of the health care system to address the unique needs of certain groups.⁹ Table 1 lists barriers that play a role in the high rates of noncompliance among minorities.

Primary care physicians are directly involved in the care of 90 to 95% of patients with diabetes,¹⁰ but they lack many of the resources and skills required to implement programs of diabetes education and self-management. In this article, we describe the results of a 3.5-year demonstration project using community health care workers as primary providers for a subpopulation of minority patients with diabetes who repeatedly failed to comply with regular medical regimens.

Methods

Setting

The Waianae Coast Comprehensive Health Center (WCCHC) is a community-owned and -operated health center with 400 employees who provide medical and support services in a community of more than 40,000 people. The WCCHC is a primary care multispecialty group practice that features a free-standing emergency room, nutrition/preventive care, and home health, behavioral health, and transportation services. Approximately one-half of the Waianae population uses the WCCHC as their principle source of primary health care. The ethnic composition of the community is predominantly Native Hawaiian or part Hawaiian (48%), with 24% Caucasians, 11% Asian-Pacific Islanders, 9% Filipinos, and 8% others. This facility provided the setting for the Diabetes Prevention Project.

ABBREVIATIONS USED IN TEXT

WCCHC = Waianae Coast Comprehensive Health Center

Project Design

The Diabetes Intervention Project was undertaken to provide a culturally sensitive, community-based alternative to the mainstream health care system in the management of diabetes. The primary objective of the project was to establish regular medical contact with patients who suffered from diabetes and who repeatedly failed to improve under the office-based medical care system. The secondary objective was to measure the impact of establishing regular contact with health care workers on metabolic control in these patients. An advisory coalition composed of health care agencies and community groups was actively involved in the project development and implementation. The project coordinated several ongoing diabetes-related activities at the WCCHC. This report focuses on the design, implementation, and impact on a local subpopulation of diabetic patients of a health care system centered on community health care workers.

The community health care workers were medical assistants or paraprofessionals with some medical background and limited formal training. The formal training consisted of a 12-week college-level curriculum in medical assessment, intervention, and case management; a

4-week clinical preceptorship working in with physicians, nurse practitioners, nutritionists, and a certified diabetic educator; and a 4-week community-based training course that involved shadowing a public health nurse. Ongoing continuing education was provided by the certified diabetes educator on a monthly basis.

The existing diabetes team at WCCHC, composed of the physician, nutritionist, certified diabetes educator, health educator, and community health worker, collaborated with public health nursing. The diabetes team functioned as a resource for the community health care workers and patients. The community health care worker's tasks were to establish regular patient contact at home or in the community setting and to develop care management plans in collaboration with the patient and the diabetes team.

Patient selection was based on a repeated pattern of missed appointments with professional health care workers with resultant poor metabolic control or a diagnosis of diabetes in pregnant women or children potentially requiring insulin. Referrals were accepted from all primary care physicians and public health nurses. Patients who met the entrance criteria were informed by their primary care physician of this alternative approach to diabetes care. Patients who consented to participate were referred to the project and assigned to a community health care worker.

The community health care worker became the principle coordinator of health services for the patient. Each

Table 1.—Obstacles to Effective Diabetes Management

Transportation	In rural communities, there is limited public transportation, and many families have no regular daytime car available by which to reach medical care facilities. There is also a significant reliance on others. It is not uncommon to have people charge for providing a ride to the doctor.
Culture	In a multiethnic community, many people have beliefs about health that influence their behavior both in health and in sickness. Western medicine has an involved and complicated system requiring multiple bureaucratic procedures to receive care. Providers may not be culturally sensitive and may attempt to impose attitudes or behavioral changes not welcomed by the patient. In providing care for some non-Western subpopulations, a more personal, trusting relationship is vital.
Family	Health is a family responsibility in some cultures. Health care (for example, insulin injections and medically relevant decisions) is provided by one or more family members who are rarely available in the office setting. The patient's need to provide care to other family members can often influence the attention given to their own health needs.
Economics	The cost of medical care for patients with chronic illnesses extends far beyond the cost of direct services. Such patients may require special food, exercise, transportation, and other comprehensive services to effectively manage their diabetes. Usually, these costs are not included in health insurance plans, leaving insufficient resources to achieve effective diabetes management and control.
Limited Access	Chronic disease management requires access to effective medical education as well as medical treatment. In the primary care setting, a team approach is rarely used, many communities having neither a chronic disease expert or nutritionist available.
Denial	Even with a full understanding of diabetes, some patients may choose to ignore the disease and live with mild symptoms. Avoidance of long-term complications may not be a sufficiently rewarding prospect with which to encourage these patients to make major life changes.
Social Issues	Families often have other major priorities that detract from or disrupt long-term chronic disease management. These crises can be either acute or chronic, but need some resolution before disease management can become a priority for the patient and his or her family.
Multiple Medical Problems . .	Often medical therapies and priorities are confusing for patients with multiple medical problems. Diabetes management is also difficult in patients with chronic mental illness or intellectual impairment.

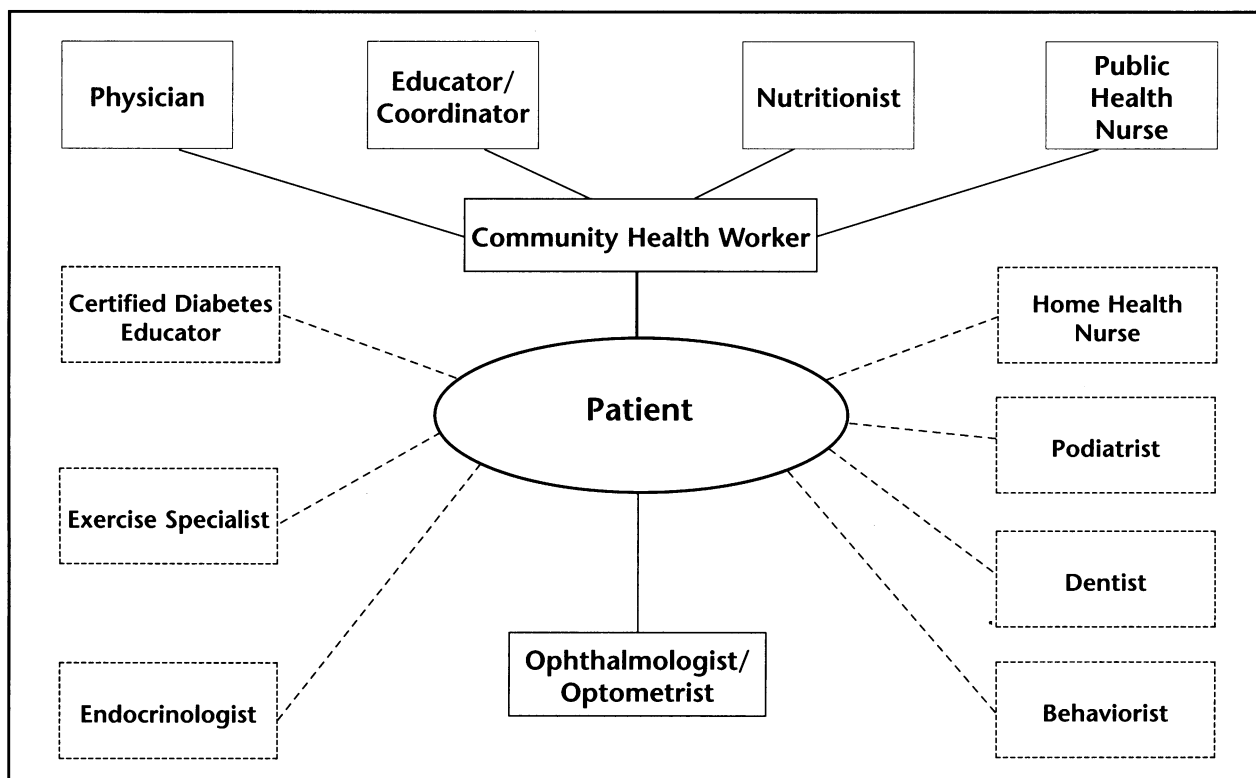


Figure 1.—Team organization of the Ohana Health Outreach Program. —, mandatory team members; - - -, optional team members.

patient was fully informed of the scope of the project and had direct access to all members of the diabetes team, but was under no obligation to have medical contact with anyone besides the assigned worker. Patients also had the option of continuing to receive community-based follow-up care. There was no effort to return the patient to office-based care or set a time limit on these community-based services.

Weekly case conferences were held that included all members of the diabetes team except the physician director. Patients were included in these meetings if they wished. All cases were reviewed on a regular basis, and other team members were updated on each patient's status. Patients were scheduled for visits based on their condition and treatment plan. New and unstable patients were also discussed and treatment plans were developed for them by the team. These patients were seen at least once a week, whereas more long-term or stable patients were seen at least once a month.

Attending physicians were contacted for changes in patient status or medical regimen. The physician director was available at any time via beeper and cellular telephone for acute situations in which the attending physician was not immediately available. The community health care workers' progress notes were entered into the patients' charts and routed to the primary physicians for review.

As the primary contacts for the health care system serving this select patient population, the community

health care workers, in conjunction with the diabetes team, were expected to provide a wide spectrum of services (Figure 1). Because most patients were not initially prepared to assume full responsibility for self-management, insulin and other medications were adjusted with the active participation of the patient and physician. This activity was viewed as "co-self-management" in that the community health care worker interacted with both patient and physician to adjust medication in a timely manner, similar to the way motivated patients adjust insulin and other medications in consultation with their physicians through home monitoring. Nutrition and diabetes education were also frequently provided by the community health care workers with the advice of the appropriate team members.

Substantial time was spent in case management to solve either individual or family problems that presented barriers to care. In complicated cases, public health nurses made joint visits with community health care workers if their presence was acceptable to the patients. It was expected that the community health care worker would attempt early in the process to establish a positive relationship with the patient and address potential obstacles to care. Often there were many visits before diabetes management became the focus of attention.

The WCCHC computer system was enhanced to capture data on blood glucose levels, blood pressure, and weight in all patients with diabetes. Data analysis averaged the first two blood glucose and blood pressure read-

Table 2.—Patient Improvement in Blood Glucose Control After Participation in the Ohana Health Outreach Program (n = 52)

	Blood Glucose Control		
	Good	Fair	Poor
Initial	13 (25%)	19 (37%)	20 (38%)
Final	18 (35%)	24 (46%)	10 (19%)

Table 3.—Conditions of Pregnant Women Who Took Part in the Ohana Health Outreach Program

Condition	Percentage of Patients (n)
Pregestational diabetes mellitus (presumed)	66 (12/18)
Required Insulin	94 (17/18)
Preterm Hospitalization	18 (3/16)
Cesarean Section	56 (9/16)
Premature Delivery	12 (2/12)
Macrosomia (weight >4,500 g)	6 (1/16)

ings and compared these with the previous two averaged readings. The patients' most recently recorded weight was compared with their initial weight. Because this was a demonstration project and because of limited funds, the project did not focus on data collection and analysis; thus the results are reported without statistical evaluation.

Results

Demographics

Ninety-four patients took part in the project and were tracked from January 1991 until March 1995. Data on 52 nonpregnant adults were accumulated by community health care workers and physicians, both before and during the intervention. The average patient was followed for 2.9 years (range 0.4–4.2 years). One patient was followed for less than 1 year, whereas a majority of the patients were followed for more than 2 years. On average, the patients had a total of 63 encounters with health care workers (range 13–170 encounters) or 2.2 encounters per month. Nineteen patients were discharged before the scheduled termination of the project for the following reasons: six patients died, six moved out of the area, two changed health plans, one was started on dialysis, three refused further services, and one was discharged out of concern for the community health care worker's safety. Of the remaining 75 patients, 56 were female and 19 were male, with the following age ranges: newborn to 20 years, seven patients; 21 to 30 years, 20 patients; 31 to 40 years, nine patients; 41 to 60 years, 26 patients; and older than 60 years, 13 patients. The ethnic composition of the patient population was as follows: 61% Native Hawaiian/part Hawaiian, 11% Samoan, 11% Caucasian, 9% Filipino, 4% Japanese, and 4% Hispanic.

Services were also provided to 18 pregnant patients, two of whom became pregnant during the study and are included twice in the total count.

Nonpregnant Adults

The 52 nonpregnant adults in the project lost an average of 5.4 pounds each. The changes in weight varied substantially, with seven (13%) losing 25 pounds or more and 19 (37%) experiencing a 10- to 24-pound loss. On the other hand, 11 participants (21%) gained 10 pounds or more.

The average decrease in blood glucose among the project participants was 49.8 mg/dl. Applying criteria developed by the Indian Health Service, the initial and final random blood glucose levels were analyzed and

categorized as follows, based on the level of blood sugar control: good (blood glucose <165), fair (>165 and <250), or poor (>250) (Table 2). Twenty-one participants (40%) improved blood glucose control (average change in blood glucose -117 mg/dl), 21 (40%) remained the same (average change in blood glucose -6 mg/dl), and 10 (20%) saw a decline in control by the end of the demonstration project (average change in blood glucose +99 mg/dl).

Seventeen of these patients initially had hypertension (blood pressure >140/90). The average systolic drop in blood pressure was 20.5 mmHg (range -5.0 to -57 mmHg) by the end of the project. Diastolic blood pressure drop averaged 6.1 mmHg (range +19 to -20.5 mmHg).

Diabetes and Pregnancy

The project co-managed 18 pregnant women with diabetes during the study period: two were 16 years old, eight were between 21 and 25, six were between 26 and 30, and two were older than 30. Twelve women presented with pregestational diabetes or a first trimester blood glucose elevation consistent with pregestational diabetes requiring insulin therapy at the time of presentation (Table 3). All but one of the cases required insulin therapy during the pregnancy. None of the women achieved pregestational diabetes control; in addition, two continued to smoke throughout gestation despite intense counseling, and at least one continued to use methamphetamines during pregnancy. Three women required preterm hospitalizations, and one patient with twins had a prolonged hospital stay as well as two short stays for treatment of premature contractions.

Nine women delivered by C-sections, seven delivered vaginally, and two moved out of the area prior to delivery. Of the two infants delivered prior to 36 weeks' gestation, one weighed less than 2500 g and the other more than 4500 g. There were no delivery-related complications. HbA_{1c} specimens were not routinely obtained during the study period, which limited our ability to assess the level of metabolic control.

Patient Satisfaction Survey

In 1994, an independent evaluator conducted a patient satisfaction survey. Forty-three patients met the criteria of

Table 4.—Ethnic Affiliation of Patients in the Ohana Health Outreach Program

Ethnic Affiliation	Proportion of Waianae Community (%)	Proportion Participating in Project (%)
Hawaiian/Part Hawaiian.	48	61
Caucasian.	24	11
Asian/Pacific Islander.	11	15
Filipino.	9	9
Other.	8	4

either being in the project for more than 1 year or receiving 20 or more visits from community health care workers. Of these patients, 24 were interviewed, one refused to be interviewed, five failed three times to show up for the interview, and 13 were lost to follow up. The patient satisfaction survey featured a series of questions assessing the patient's attitude toward the quality of health care delivery by the community health care worker using a subjective rating scale. Eighty-three percent of the patients were "always" satisfied with the care provided by the community health care workers. A response of "sometimes" was reported 9% of the time, whereas only 1% rated the care as "never" satisfying (7% responded "don't know"). In general, 54% were reportedly "always" satisfied with the project in general, 14% were "sometimes" satisfied, and 7% replied that they were "never" satisfied with the project (8% replied "don't know").

Discussion

A significant percentage of patients with chronic disease fail to consistently seek medical care or comply with recommended treatment regimens. Because of a variety of obstacles, the current office-based health care system is not capable of effectively addressing the needs of many patients with chronic diseases.¹¹ To improve care for a subpopulation of patients with diabetes, alternative approaches to management need to be developed and evaluated. The Diabetes Intervention Project provides a viable means of improving health care for a select group of patients who fail to control their diabetes using the mainstream health care system.

The patients referred to the project formed a diverse group. Many participants were young, relatively healthy, and asymptomatic and elected not to make treatment of their disease a high priority. Another group was older and chronically disabled, with longstanding resistance to care, despite suffering from diabetic complications and multiple diseases. Several patients had major chronic psychiatric disorders or suffered from mental impairment. All children and adolescents with diabetes at the WCCHC were referred to the project.

The first objective of the project was to establish regular medical contact with previously nonadherent diabetic patients. The project was remarkably successful at

improving regular contact between the patient and one or more team members. Patients had contact an average of 2.2 times per month in addition to regularly scheduled contact from the community health care workers. By offering the convenience of home- and community-based medical follow-up and placing the responsibility for a minimum of monthly contact with the community health care workers, the project succeeded in providing nonadherent patients with regular medical care. Only three of the 19 patients who were discharged from the project requested that the service be discontinued; the others were discharged because of death or other external factors. The majority of the participants belonged to ethnic minorities (Table 4). The project provided service to an increased percentage of Hawaiians and Samoans and a decreased service to Caucasians compared with the total population of the Waianae community.

The second objective of the project was to test whether this approach would result in improved diabetes management as measured by blood glucose, weight, and hypertension control. The physiologic results show clear improvement in all parameters for the total population. Despite the challenging clientele, 19 (37%) of the 52 nonpregnant patients lost 10 pounds or more. This success was partially accounted for by the integration of the project with the Waianae Diet Program, a culturally-sensitive, 3-week program stressing traditional foods and values.^{12,13} Even when patients did not participate in the Waianae Diet Program, the strong support of the nutritionist was clearly evident in the outcomes.

The total adult population, excluding pregnant women, showed an average drop in blood glucose of nearly 50 mg/dl. This success was not shared by all the participants; 40% of these adults attained the highest decrease in average blood glucose. These 52 patients were a diverse group with respect to age, concurrent diseases, ethnicity, and social situation; this diversity prevented us from ascertaining the characteristics of the group that enjoyed the greatest improvement in diabetes control as measured by reductions in blood glucose levels. Informal review of the group of patients who required the most frequent interventions and who often showed the least successful outcomes indicated that these patients often had major illness in addition to diabetes; furthermore, their conditions were often complicated by major psychiatric or social problems. In pregnant patients who went on to deliver children, there also appeared to be a postpartum period lasting up to 6 months during which they were unable to focus on adequate management of their diabetes.

The pregnant diabetic patients presented a formidable challenge. The unusually young average age of these patients is in part a reflection of the increasing prevalence of type 2 diabetes in younger members of certain minority populations. The intensive insulin therapy required to achieve acceptable blood glucose control in these patients demands resources beyond the capacity of most rural practitioners. The availability of community and home-based teaching and management markedly

improved the patients' compliance and blood glucose control over our previous office-based team approach.

The community health care worker was the cultural expert who linked the nonadherent patient with the health care professionals on the project team. Bonding between the patient and the community health care worker was critical in establishing positive relationships with the health care system and ultimately promoting self-management. This bonding was facilitated by selecting community health care workers who were culturally sensitive and lived in the community; it was further encouraged in that the community health care workers spent up to 2 hours on the initial visit, worked according to a flexible schedule, and promoted a family-centered approach by frequently assisting other family members besides the diabetic patient. In several cultures in the Waianae area, a family member takes primary responsibility for another member with chronic disease. The community health care workers were excellent at understanding and working with these key family members to improve patients' diabetes management. The patient satisfaction survey confirms the effectiveness of this bonding, as do the subsequent changes in patient behavior leading to metabolic improvement.

In general, the project complemented the mainstream health care system. Early detection of problems, coordination of care, and timely physician visits promoted effective medical intervention. Most patients preferred to have regular follow-up with the community health care workers with infrequent medical contact as long as they were continuing with effective self-management. There was an increase in the total number of professional visits made by this patient population during the study period, reflecting the fact that most of these patients had limited prior contact with health care professionals. The visits were no longer prompted by acute crisis, but were orchestrated with the community health care worker to reach disease management goals. Although resource consumption was not monitored, there were numerous occasions on which the community health care worker and the diabetes team were able to intervene during the early stage of an acute illness, avoiding hospitalization and more costly care.

The role of community health care workers in our project was unique compared with most other programs using outreach workers in that our community health care workers provided direct service. The project's community health care workers performed and were involved in supervising and encouraging complex medical and educational tasks. The project was patient-centered, targeting and promoting patient empowerment and improved self-management. The community health care worker assumed responsibility as the case manager by gathering information, contacting the appropriate professional member of the team, deciding on a course of action in conjunction with the patient and professional, and providing support and education for patient-centered implementation of the care plan. The community health care worker provided interventions targeting a

variety of infectious and chronic conditions for the patients and their families. The case load varied in intensity and complexity, although virtually all patients encountered major obstacles to effective self-management. The benefits of the approach demonstrated by our project are best appreciated by individual examples. What follows are two brief case reports of patients whose care was significantly enhanced through the efforts of the community health care workers:

1. FT, a 39-year-old, morbidly obese (322 lbs) Samoan man with mild mental retardation and limited English skills, was initially hospitalized with acute gout, severe obstructive sleep apnea, secondary right-ventricle heart failure, severe hypertension (220/140), and newly diagnosed diabetes. After he was referred to the project, the community health care worker established regular contact with him and obtained his compliance with a complex medication regimen (including nasal C-PAP through a weekly pill box) by means of constant positive reinforcement. Close work with the family allowed a family-based daily exercise routine and subsequent marked improvement in the patient's multiple medical problems.
2. SK, a 16-year-old Hawaiian girl with IDDM diagnosed at age 5, was referred to the project after reestablishing medical care at WCCHC in her 12th week of pregnancy. She was single, from a broken home, well known to public health nursing, and already enrolled in a special class for pregnant students. Her last recorded HbA_{1c} was 20.7, reflecting chronic nonadherence to diet and blood glucose monitoring. With the involvement of a community health care worker, she was placed on an insulin regimen of four injections per day following an adjustable schedule. The patient monitored her blood sugar four to six times per day and substantially improved in dietary compliance. At 38 weeks' gestation, she had gained 30 pounds, presented with a HbA_{1c} level of 7.2, and delivered a normal-weight infant.

Limitations of the Project

An obvious drawback to using community health care workers as the primary providers of care is their relative lack of professional training and expertise. These workers were acutely aware of their limited medical knowledge. Assuming this level of responsibility challenged them and, at times, became problematic. There were occasions when patients were given incomplete or inaccurate information, particularly early in the workers' training. Sometimes they did not respond immediately to abnormal blood pressure or blood glucose readings, deferring intervention until after case conference or direct contact with the physicians. This pattern of care delayed appropriate intervention initially, but improved with time and training. Over time, the community health care workers become more comfortable as members of the team and became more familiar with the specific criteria that called for making a change in their patients'

care plans. The diabetes team progressively developed policies and procedures, refining the project and structuring guidance for the community health care workers and other team members, although at no time were medications changed without direct contact with the physician.

A second, more specific weakness that came to light during the course of the project was the community health care workers' lack of preparation in training and counseling related to death and dying. For weeks or months at a time, these workers were often the only health care professionals to have contact with patients having complex medical problems. Because of the design of the project, the community health care workers became very close to their patients and felt a deep sense of responsibility regarding their well-being. When a patient died, the workers experienced intense feelings of failure and guilt even though the death was clearly from progressive complications usually related to large-vessel cardiovascular disease. The professional team provided support and training for the community health care workers in managing the emotional burdens of caring for severely and terminally ill patients.

The project was designed to test whether a community-based program of care would improve patient compliance with regimens for managing diabetes. Although information was gathered, the project intentionally did not stress data collection or metabolic control, focusing instead on sustained patient contact. As a preliminary study of this approach, the data that were collected clearly support the value of this alternative to the office-based care model. Further research is needed to better quantify the metabolic impact and determine whether this approach is effective in other communities.

As with most chronic diseases, diabetes requires major behavioral changes to bring about improved metabolic control. Equal to the need for quality medical management is the need for a health care delivery system that promotes sustained, culturally sensitive care. We believe that the partnership between the professional diabetes team and the community health care workers in

delivering community-based care provides an effective model that merits further research and development. In the evolving managed care environment, quality care needs to be available to the largest possible proportion of the population, sometimes through unique approaches to address the numerous obstacles to effective care.

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