

Getting the Patients' Perspective: A Survey of Diabetes Services on Guam

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Abstract

The prevention and control of diabetes is a major public health priority for the US Territory of Guam. As part of a strategic planning process, a survey of diabetes patients was conducted to determine patients' perceptions of the availability and adequacy of preventive and clinical services to control diabetes. A total of 125 survey questionnaires were distributed to diabetes patients attending either one of the Guam Department of Public Health and Social Services Community Health Centers or a private Internal Medicine/Endocrinology clinical practice of the only endocrinologist on the island. All 125 questionnaires were returned. Respondents were highly aware of the duration of their diabetes, and almost 75% have had the opportunity to discuss the chronic nature of the illness and the importance of key lifestyle changes to help prevent or retard the progression of the disease. However, almost 40% of patients were not aware of the type of diabetes they had, and one in five have not received diabetes self-management education from their health care providers. Key interventions, such as nutritional counseling, brief tobacco cessation interventions, regular eye and foot examinations and immunization services were not being provided to 30 to 60% of patients, despite clinical practice guidelines that recommend these interventions for all diabetics. While over half of respondents were generally satisfied with the quality of preventive and routine medical care that they receive from their service providers, they identified the need for better quality diabetes self-management education, preventive services, enhanced access to specialists and specialized care, especially for diabetes-related complications, and better financial support to assist them in meeting the costs of chronic care and medications. The feedback from these respondents should provide guidance regarding service gaps and needs as the Department of Public Health and Social Services and its community partners collaboratively develop a strategic plan to better address diabetes prevention and control on Guam. The information should also serve to direct quality improvement efforts to enhance existing diabetes services on the island.

Introduction

Diabetes exacts a significant burden on Guam's people. Over the past decades, diabetes has risen in prevalence and currently is the fourth leading cause of mortality and morbidity on the island.¹ Diabetes also directly contributes to two of the top three causes of death on Guam—namely, heart disease and stroke. The health burden from this chronic and disabling condition is compounded by the economic costs of diabetes treatment and care and the impaired quality of life that results from uncontrolled diabetes. Thus, the prevention and control of diabetes is a major public health priority for Guam.

The Guam Department of Public Health and Social Services (DPHSS) is the designated lead agency responsible for addressing the problem of diabetes. In recent years, the DPHSS Diabetes Prevention and Control Program initiated partnerships with other stakeholders in the community to create a community Diabetes Control Coalition that would oversee and guide the creation of a Comprehensive Diabetes Control Plan for the island.

The coalition recognized the importance of mapping out existing diabetes prevention and control resources within the island to identify needs and service gaps, and to assess if existing services are meeting accepted standards of practice. The importance of obtaining feedback from the end-users of the services—diabetes patients—was deemed essential to provide a more comprehensive picture regarding the availability and utilization of public health and clinical services to prevent or control diabetes.

This report contains the results of a survey to determine diabetes patients' perceptions of the availability and adequacy of preventive and clinical services to control diabetes. While primarily intended as a planning tool for Guam's Diabetes Prevention and Control Program, the survey provides useful feedback to assist diabetes service providers, community advocates and diabetes patients and their families in improving the quality of diabetes services on Guam.

Methods

DPHSS contracted Health Partners, L.L.C., a private sector company providing technical assistance and consulting services in public health, to develop a survey instrument and conduct the diabetes prevention and control patient survey. Following a review of existing survey instruments, a draft survey was developed in close collaboration with the DPHSS Diabetes Control and Prevention program staff. The survey instrument and methodology underwent a process of peer review by the Guam Diabetes Control Coalition, to ensure technical accuracy and compliance with ethical standards.

The survey was conducted in 2 clinical settings: the DPHSS Community Health Centers (representing patients utilizing public sector health services) and a private Internal Medicine/Endocrinology clinic (representing patients utilizing private sector facilities). The private clinic was chosen specifically because its main clinician is Guam's only endocrinologist, with the largest concentration of diabetes patients among other private sector clinical providers on the island.

Survey forms were distributed by fax, e-mail or in person to each of the survey sites. Follow-up phone calls and visits were conducted to maximize the response rate. All survey participants were informed at the outset of the nature and purpose of the survey, and informed consent was obtained from each participant.

An electronic database was developed using Microsoft Excel to record entries in submitted survey forms. Descriptive statistics were applied to the data collected. Chi square analysis was utilized to determine if differences in diabetes service utilization and patient satisfaction existed between patients utilizing the private clinic and patients using the community health centers.

Results

Response Rate:

A total of 125 survey forms were distributed to patients with a diagnosis of diabetes attending the DPHSS Community Health

Centers (n=65) or the private clinic (n=60) during the 2 weeks allotted for the survey. All 125 survey forms were completed and returned for analysis.

Patient Demographics

Of the 125 diabetes patients completing the survey, 63 (50%) were women and 57 (46%) were men; 5 (4%) respondents did not provide data on sex. 124 respondents provided data on age (Figure 1). Respondents' ages ranged from 13 years to 84 years, with a mean of 53.45. The median age was 54 years, and the mode was 59 years. There were no statistically significant differences in age and sex composition between the public and private sector patients.

Overall, fifty percent (50%) of survey respondents were Chamorros, while Filipinos comprised one-fourth and Micronesians made up nearly one-fifth of survey respondents. Based on the relative proportion of each ethnic group in the general population, Chamorros and Micronesians were over-represented while other Asians and other ethnicities were under-represented among patients with diabetes at the survey sites. The public sector patients were more likely to be Chamorro or other Micronesian, while the private sector patients were more likely to be Filipino, other Asian or Caucasian ($p < 0.000044$).

Type and duration of Diabetes

More than half (53%) of the diabetes patients surveyed knew that they had Type 2 (non insulin-dependent) diabetes. Five percent (5%) were aware that they had Type 1 (insulin-dependent) diabetes. Close to two-fifths (38%) of respondents reported not knowing what type of diabetes they had.

Over 62% of the survey respondents were diagnosed more than 5 years ago. Thirty percent (30%) were diagnosed within the past 5 years, while only 5.6% were diagnosed within the past year. Only 2 persons did not respond to this question, indicating a high level of awareness of the duration of diabetes since diagnosis.

Self-care Practices

Over half (51%) of patients checked their blood sugar at home regularly, while 4% did so occasionally, and 1% did so rarely. Forty-three percent (43%) did not check their blood sugar at home at all. Patients attending the private clinic were more likely to check their blood sugar levels at home than patients attending the community center clinics ($p < 0.000045$). Close to 80% reported taking oral medication to control their diabetes, while 13% did not currently use oral medication. Forty percent (40%) of respondents reported injecting insulin to control their blood sugar levels.

Information and General Patient Education on Diabetes Self-management

The majority (93%) of patients obtained information about diabetes from their physicians. Patients also cited the Department of Public Health and Social Services (33%), family members (28%), the internet (20%), media (19%) and the Guam Diabetes Association (14%) as sources of information. Almost 75% of patients have had someone who adequately explained to them that diabetes is a chronic disease that requires lifestyle adjustments, and also identified what lifestyle changes are needed to control blood sugar. There were no statistically significant differences between private clinic patients

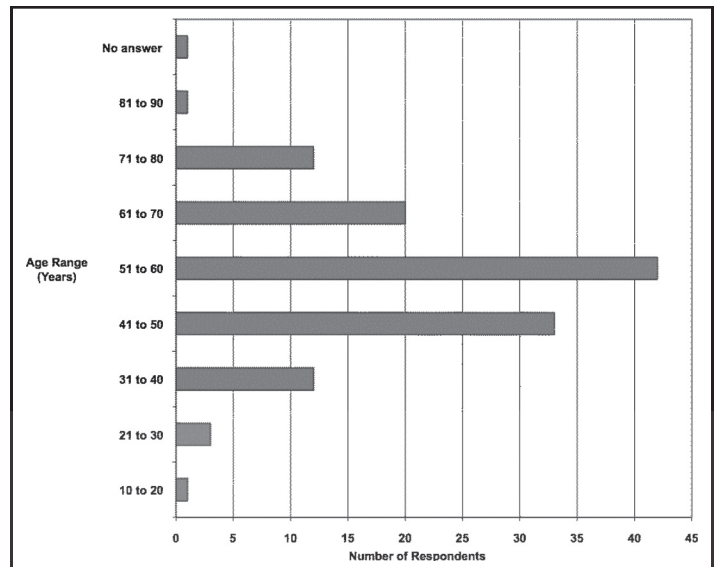


Figure 1.— Age Distribution of Respondents

and community center patients with regard to receiving adequate information on diabetes and diabetes self-management. Over half of respondents (51.6%) had this discussion with their physician, and 10% reported having received this information from DPHSS. However, nearly one in five (18%) stated that they have not had this critical discussion on diabetes self-management.

Diabetes Self-management

More than half (53.6%) of the respondents stated that they had received counseling regarding nutrition and appropriate dietary choices for diabetics, but 40% reported never having received this type of counseling. Of those who received nutrition counseling, 22.4% identified their doctor as the source of counseling, 16.4% reported receiving counseling from DPHSS, 14.9% received counseling from the Seventh Day Adventist (SDA) clinic and 10.4% stated they were counseled by other health professionals. Patients attending the private clinic were more likely to have received nutrition and dietary counseling than community center patients ($p < 0.036$).

Of the 125 diabetes patients, 46.4% have never smoked or used other tobacco products, while 28.8% are former smokers/tobacco users. About one in five (22.4%) are current smokers/tobacco users. Community center patients were more likely to be current or former tobacco users than private clinic patients ($p < 0.011$). Because tobacco use in any form seriously compounds the complications of diabetes, it is standard clinical practice to strongly advise and assist all diabetics who smoke or use tobacco to quit tobacco use. Among the patients surveyed on Guam who are former or current tobacco users, 55.9% reported receiving advice to stop using tobacco, while 37.6% reported not having received this advice. Community center patients were equally likely to receive advice to quit tobacco use as private clinic patients. Of those who received advice to quit tobacco use, 65.4% obtained this from their physician/diabetes service provider, 19.2% from family and friends, and 1.9% from the Veterans Affairs (VA) Hospital.

Preventive Care

Current standards for preventive care of diabetics recommend vaccination against pneumococcal pneumonia and annual flu vaccinations. Only 37.6% of the survey respondents had received the pneumococcal vaccine, while 67.2% reported obtaining annual influenza immunization. Of those who had not received the recommended vaccinations, only one-fifth (20.0%) were offered the pneumococcal vaccine and 14% were offered the flu vaccine by their doctor. Patients attending the private clinic were more likely to have received the flu vaccine annually ($p < 0.001$) than patients at the community health centers.

Diabetics need to have regular eye and foot examinations to screen for early diabetic eye and/or foot disease. Among the survey respondents, 70.4% reported having had their eyes checked for diabetic eye disease. Sixty-eight percent (68%) stated that their feet are regularly checked for wounds and infections. These percentages are consistent with reported figures based on the Behavioral Risk Factor Surveillance System results.² Private clinic patients were more likely to have had their eyes checked for signs of diabetic eye disease than community center patients ($p < 0.0013$). No differences were noted between the two subsets of respondents with regard to foot examination.

Other Types of Care

12.8% of survey respondents indicated the need for personal counseling to help them deal with the chronic nature of their disease. Only nine (7.2%) patients reported needing to go off-island to receive care for their diabetes or a diabetes-related complication. Of the 4 patients who provided additional information regarding their off-island care, 2 (50%) were for diagnostic and treatment procedures that are not currently available on Guam.

Perceptions of Diabetes Services on Guam

Participants were asked about their satisfaction regarding a variety of preventive, routine and specialized clinical services for diabetics on Guam. Overall, a little over half (56%) of survey respondents reported being content with the quality and types of diabetes services on Guam. Table 1 summarizes the percentage of patients who reported that they were satisfied with specific types of services for diabetics on Guam. Community health center patients were more likely to be satisfied with nutritional counseling services ($p < 0.0139$), tobacco cessation advice ($p < 0.0149$) and other support services for diabetics (0.00658) than private clinic patients.

Respondents were also asked which services they felt were lacking or inadequately provided on Guam. Respondents who were not satisfied with existing diabetes services identified the following as unavailable or inadequate on Guam (Table 2). The top 5 services that respondents felt needed to be prioritized for the island's diabetic patients were:

- Education on prevention and healthy lifestyles (diabetes self-management education)
- Specialist services, specifically for endocrinologists and cardiologists, and specialized clinical services, particularly for diabetes-related cardiac problems
- Financial assistance, especially for the uninsured/underinsured

Table 1.— Percentage of Diabetes Patients Who Think that the Following Diabetes-related Services are Available and Adequately Provided on Guam

Type of service available on Guam	% of patients satisfied with this service on Guam % (95% CI)
Education about diabetes	62.4% (+/- 8.49%)
Nutrition and dietary counseling for diabetics	61.6% (+/- 8.53%)
Exercise facilities	57.6% (+/- 8.66%)
Advice and assistance to quit smoking/tobacco use	56.8% (+/- 8.68%)
Immunization for diabetics	63.2% (+/- 8.45%)
Routine medical care for diabetics	67.2% (+/- 8.23%)
Specialized care for diabetics (specialist services and care for diabetes-related complications)	54.4% (+/- 8.73%)
Dialysis services	54.4% (+/- 8.73%)
Medical care for diabetes-related heart disease	41.6% (+/- 8.64%)
Medical care for diabetes-related stroke	47.2% (+/- 8.75%)
Medical care for diabetes-related eye disease	55.2% (+/- 8.72%)
Advocacy for policies and programs to prevent and treat diabetes	47.2% (+/- 8.75%)
Support services for diabetics	46.4% (+/- 8.74%)

Table 2.— Diabetes services identified by survey respondents as lacking or inadequate on Guam

Type of service	% of patients identifying this service as lacking on Guam % (95% CI)
Public awareness and education about diabetes	15.0% (+/- 11.07%)
Lifestyle management including nutrition and dietary counseling for diabetics	15.0% (+/- 11.07%)
Greater access to specialists and specialty care	10.0% (+/- 9.3%)
Assistance to improve self-care skills	7.5% (+/- 8.16%)
Financial assistance/better insurance coverage for diabetics	7.5% (+/- 8.16%)
Emergency care for diabetic emergencies	5.0% (+/- 6.75%)
Home care for elderly diabetics	2.5% (+/- 4.84%)
Care giver education	2.5% (+/- 4.84%)
Services for physically disabled diabetic patients	2.5% (+/- 4.84%)
Properly equipped wellness center in every mayor's office	2.5% (+/- 4.84%)
Increased government support to diabetes programs	2.5% (+/- 4.84%)
Insulin pump therapy	2.5% (+/- 4.84%)

- Preventive services, including tobacco cessation assistance
- Lifestyle management services, including nutrition and dietary counseling

Discussion

This was a voluntary survey using a convenience sample of respondents attending either an Internal Medicine/Endocrinology private practice clinic or the Community Health Centers of the DPHSS. The diabetes patients who participated in this survey comprised a mix of those who seek services in the public sector and those who use private sector health services. Recently released data indicate that about 43% of Guam's uninsured and underinsured seek care from primarily from the community health centers, and about 18% of the uninsured are diagnosed diabetics.³ The rest of the patients attending the community health centers are predominantly covered under the federal Medicaid program or the locally administered Medically Indigent Program (MIP). In contrast, patients seeking care from private clinics tend to have private insurance. Thus, the respondents of this survey present a spectrum of health care coverage, with private clinic patients representing individuals with private insurance and community health center patients representing those with social insurance or are uninsured.

The sample's sex distribution was consistent with the composition of Guam's general population. The relatively older median/mean age of the pool of respondents reflected the chronic nature of Type 2 diabetes, with increasing prevalence among older individuals, as well as the nature of the clinics, catering to mostly adult patients, from which the convenience sample was drawn. The higher proportion of Chamorro and other Micronesian respondents paralleled the increased prevalence of diabetes among these ethnic sub-groups.⁴ Chamorro and other Micronesians are more likely to have social insurance or be uninsured in the general population,⁵ which would explain the higher proportion of these ethnic sub-groups attending the community health centers.

The survey respondents were not drawn from a random sample of the general population, and the results from this survey cannot be generalized to the entire population of diabetics on Guam. However, the survey population was representative of that segment of Guam's diabetic population that actively seeks care for their disease. Thus, for the purposes of this survey (to assess the availability and adequacy of services for diabetics on Guam from the patients' perspective), this was a well-informed group of individuals with valuable feedback for the DPHSS Diabetes Prevention and Control Program and its community partners and stakeholders.

Because diabetes a chronic disease that necessitates substantial changes in lifestyle and personal behavior, it is essential that all patients receive sufficient education regarding effective interventions and healthy lifestyle practices to control diabetes and prevent its complications. The survey demonstrated that majority of patients have received education about the chronic nature of diabetes and the lifestyle adjustments needed to control blood sugar, with no difference noted between private and public sector patients. Patients' physicians and DPHSS were the most frequently identified sources for this information. However, nearly one in five respondents stated that they have not had this critical discussion, highlighting the need for greater efforts to expand diabetes self-management education and outreach to cover all diabetic patients.

In January 2009, the American Diabetes Association published a set of updated clinical practice recommendations for the prevention and control of diabetes, derived from an extensive review of the evidence and from expert opinion. These recommendations affirmed

that certain clinical interventions should be universally implemented for all diabetes patients.⁵ The feedback from the patients covered under this survey indicated essential diabetes-related services on Guam are failing to reach the desired 100% coverage, as recommended by the American Diabetes Association. Diabetes health service providers are ensuring regular eye and foot examinations and annual flu vaccinations for about 70% of the diabetic patients surveyed, but tobacco cessation advice, nutrition and dietary counseling and pneumococcal vaccination are being offered by these providers to less than half of diabetic patients (Figure 2). Private clinic patients were more likely to receive nutritional counseling, annual flu vaccinations and diabetic eye examinations than patients attending community health centers. In part, this may be ascribed to the greater flexibility afforded by private insurance, which covers the additional costs of these services and allows covered individuals to select from among numerous private sector providers, many of whom do not accept social insurance. While the community centers have a nutritionist on staff, the demand for services often exceeds the centers' current capacity to meet the service needs, and at present the centers do not have optometrists or ophthalmologists. This is a critical service gap and strategic efforts are needed to ensure that essential preventive and clinical services are made available to all patients with diabetes, regardless of insurance coverage.

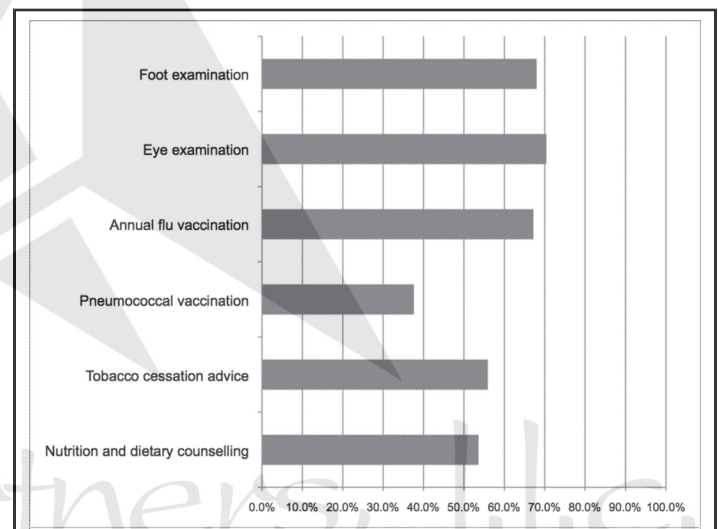


Figure 2.— Adherence to the American Diabetes Association's Clinical Practice Recommendations on Guam, Based on Patient Self-report

Patients on Guam are more likely to be satisfied with preventive, lifestyle management and routine clinical services and less likely to be content with specialized care for diabetes complications and support services such as mental health counseling. However, patients are also most likely to identify education, prevention and lifestyle management as service gaps on the island. This could be explained by noting that while diabetes self-management education and preventive services are readily available, the quality and coverage of these services need to be enhanced, particularly when access to these services is limited by insurance coverage. On the other hand, access to specialized care and ancillary/support services are suboptimal because of the paucity of service providers for these kinds of services. These findings have implications for service improvement,

health care financing and human health resource planning, given the growing burden of diabetes on the island.

Financial assistance for diabetes care and medications was also identified as a priority for Guam. The need for financial support impacts upon access to specialists and specialty care, as a number of survey respondents indicated that their lack of private insurance hindered them from availing of the services of relevant specialists on Guam who work in the private sector. Data from this survey also indicates that insurance status may affect diabetics' access to essential preventive services. This highlights the importance of ensuring more equitable access to preventive and specialty care through innovative financing for diabetes services.

The successful prevention and control of diabetes in a high-prevalence area such as Guam requires public health program planning that quickly and effectively responds to community needs. Most quality assurance processes in public health rely on data from the point of care, through chart audits and surveys of service providers. However, chronic diseases such as diabetes that rely heavily on lifestyle changes for prevention and control are dependent on patient comprehension and engagement for success. For these diseases, patient feedback is crucial for quality improvement. This patient survey provides information on service gaps and needs that will guide the development of Guam's Comprehensive Diabetes Control Plan. At the same time, it delineates areas for quality improvement to inform diabetes control program planners, service providers and community advocates in both public and private sectors how best to strengthen and enhance existing preventive and clinical services to stem the rising burden of diabetes on Guam.

Disclosures

This patient survey regarding patients' experiences and feedback on diabetes services on Guam was developed by Health Partners, L.L.C. for the Guam Department of Public Health and Social Services (DPHSS) Diabetes Prevention and Control Program, through a contractual agreement. Dr. Annette M. David of Health Partners, L.L.C. conceptualized and developed the survey methodology used to collect information, and served as the Technical Writer/Author for this publication. Dr. Joel Marc C. Rubio provided technical assistance for the manuscript. Ms. Jeanine Pacson was the Research Assistant for this project, and was responsible for data collection and data entry.

Ms. Rose V. Zabala, MSW and Mr. Patrick S. Luces (DPHSS) provided oversight and guidance for the project. Mr. J. Peter Roberto, Director, DPHSS, was the overall project leader. Members

of the Guam Diabetes Control Coalition, under the leadership of Dr. Keith Horinouchi, Dr. Patrick Santos and Ms. Doris Crisostomo, provided assistance in identifying survey participants and reviewing the survey instrument and methodology for technical accuracy and compliance with ethical standards. Ms. Linda Unpingco-Denorcey, Ms. Mary Mantanane and Ms. Lora Castro facilitated the conduct of the survey at the DPHSS Community Health Centers, while Dr. Joel Marc C. Rubio, Ms. Heidi Cameron, Ms. Nora Jackson and Ms. Jacqueline Dayrit facilitated the conduct of the survey at the Health Partners, L.L.C. clinic.

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