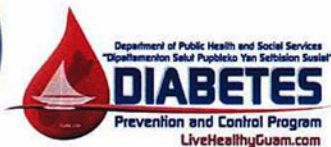


DIABETES PATIENT SURVEY

Getting the patients' perspective

This report summarizes findings from a survey of diabetes patients regarding the availability and adequacy of a spectrum of diabetes services on Guam.

health partners, l.l.c.
— promoting health, providing care —



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GETTING THE PATIENTS' PERSPECTIVE

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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.

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 Control Program initiated partnerships with other stakeholders in the community to build the island's capacity to prevent and control this major cause of premature death and poor health. To date, accomplishments include the formation of a community Diabetes Control Coalition and initial steps towards the development of a Comprehensive Diabetes Control Plan for the island.

Diabetes is the fourth leading cause of death on Guam.

As part of the initial needs assessment, the coalition recognized the importance of identifying and mapping out existing diabetes prevention

and control resources within the island. A separate report details the findings of a systematic effort to collect and collate information on available services and expertise relevant to diabetes prevention and control on Guam. However, the importance of obtaining feedback from the end-users of the services – diabetes patients – was deemed essential to provide a more comprehensive picture of the situation regarding the availability, accessibility and affordability of public health and clinical services to prevent or control diabetes. This report contains the results of that survey. It is anticipated that both this summary of patient feedback and the services inventory will serve as valuable resources for diabetes prevention/control program planners, diabetes service providers, community advocates and for diabetes patients and their families.

♦ The contents of this report reflect the best efforts of Health Partners, L.L.C. to assimilate and organize information provided by diabetes patients and their families who responded to the patient survey.

METHODOLOGY

After discussions with the DPHSS Comprehensive Diabetes Control program staff, Health Partners, L.L.C. developed a survey instrument to capture the data required for the diabetes prevention and control patient survey. The survey instrument was peer-reviewed by members of the Guam Diabetes Control Coalition. A copy of the final survey instrument is included in the Appendix.

Because it was important to obtain a representative cross-section of diabetes patients within a narrow time period, the survey was conducted in 2 clinical settings: the DPHSS Community Health Centers (representing patients utilizing public sector health services) and the Health Partners, L.L.C. clinic (representing patients utilizing private sector facilities). The Health Partners, L.L.C. clinic was chosen specifically because its main clinician, Dr. Joel Marc C. Rubio, is Guam's only endocrinologist, and likely has the largest concentration of diabetes patients among other private sector clinical providers on the island. All information provided by the survey respondents was assumed to be valid. A separate attempt to validate the data was not conducted.

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. Responses were all voluntary.

An electronic database was developed using Microsoft Excel to record entries in submitted survey forms. Descriptive statistics were applied to the data collected.

RESULTS

Response rate

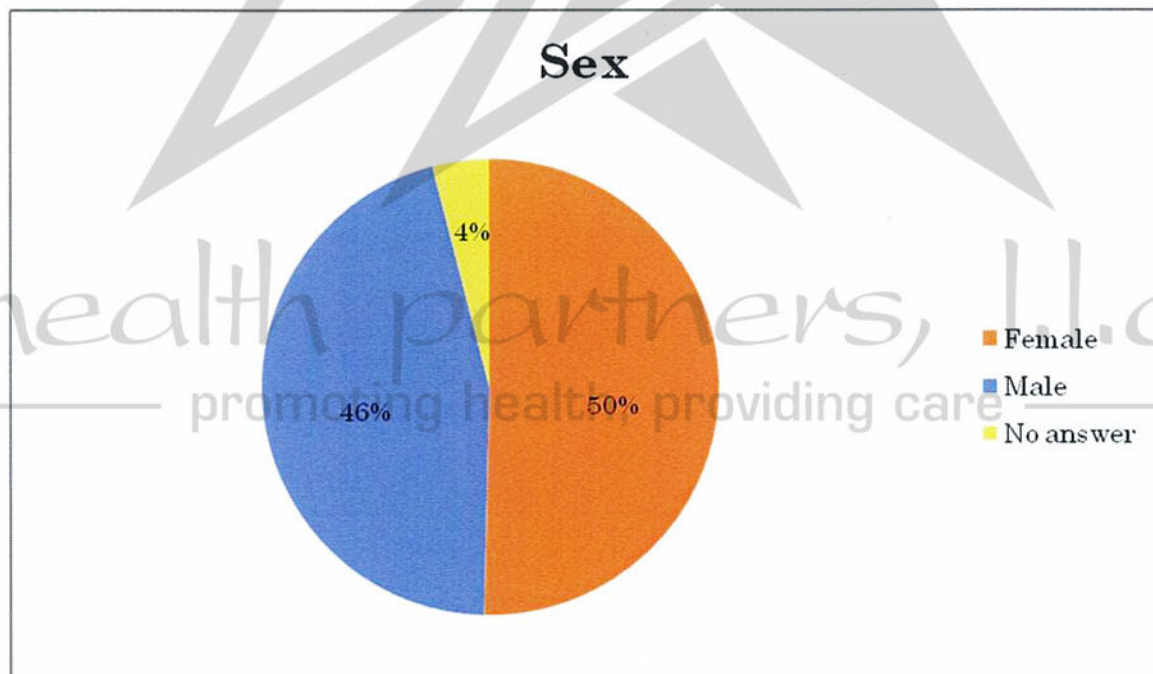
A total of 125 survey forms were distributed to patients with a diagnosis of diabetes attending the DPHSS Community Health Centers or the Health Partners, L.L.C. clinic. All survey participants were informed at the outset of the nature and purpose of the survey, and that participation was voluntary.

125 survey forms were completed and returned for analysis, for a response rate of 100%.

Patient demographics

Of the 125 diabetes patients completing the survey, 120 provided data on sex. Of these, 63 were female and 57 were male (Figure 1).

Figure 1. Sex distribution of respondents



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. Surprisingly, 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.

Almost 40% of patients reported they did not know what type of diabetes they had.

Self-care practices

Over half (51%) of patients check their blood sugar at home regularly, while 4% do so occasionally, and 1% does so rarely. Forty-three percent (43%) do not check their blood sugar at home at all.

Close to 80% report that they take oral medication to control their diabetes, while 13% do not currently use oral medication. Forty percent (40%) of respondents report injecting insulin to control their blood sugar levels.

Information and general patient education

Majority of patients reported that when they have questions about their disease, they obtain information from their physicians. The Department of Public Health and Social Services, family members, the internet, media and the Guam Diabetes Association were also frequently cited as sources of information (Table 1). 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. More than half (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.

Table 1. Sources of diabetes information as identified by diabetes patients

Information Source	% of Patients reporting this as an information source they utilize
Physician or clinic	92.8%
DPHSS	32.8%
Family members	28.0%
Internet	20.0%
Mass media	19.2%
Guam Diabetes Association	13.6%
Other diabetes patients	5.6%
Other source	1.6%

Lifestyle 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.

Of the 125 diabetes patients, 46.4% have never smoked or used other tobacco products, while 28.8% are former smokers/tobacco users. Over two-fifths (22.4%) are current smokers/tobacco users. 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, 55.9% reported receiving advice to stop using tobacco, while 37.6% reported not having received this advice. Of those who received advice to quit tobacco use, 65.4% obtained this from their physician, 19.2% from family and friends, and 1.9% from the Veterans Affairs (VA) Hospital.

Over half of the diabetics surveyed are current or former smokers/tobacco users, but 37.6% have never received advice to stop smoking/using tobacco despite the established adverse impact of tobacco use in any form on diabetes outcomes.

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 have received the pneumococcal vaccine, while 67.2% report obtaining annual influenza immunization. Of note, of those who have not received the recommended vaccinations, only one-fifth (20.0%) were offered the pneumococcal vaccine by their doctor.

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% report having had their eyes checked for diabetic eye disease. Sixty-eight percent (68%) state that their feet are regularly checked for wounds and infections.

Diabetes complications

The following table (Table 2) summarizes the percentage of the diabetes patients participating in this survey who report having various diabetes complications:

Table 2. Percentage of diabetes patients reporting diabetes-related complications

Diabetes-related complication	% of patients with this complication
Heart disease	16.8%
Stroke	4.8%
Kidney failure	4.8%
Diabetes-related nerve damage	6.4%
Diabetes-related visual loss	6.4%
Diabetes-related amputation	1.6%
Other	5.6%

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.

Only nine (7.2%) out of the 125 patients reported needing to go off-island to receive care for their diabetes or a diabetes-related complication.

Perceptions on 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 3 summarizes the percentage of patients who reported that the following specific services were adequately provided on Guam:

Table 3. 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
Education about diabetes	62.4%
Nutrition and dietary counseling for diabetics	61.6%
Exercise facilities	57.6%
Advice and assistance to quit smoking/tobacco use	56.8%
Immunization for diabetics	63.2%
Routine medical care for diabetics	67.2%
Specialized care for diabetics (specialist services and care for diabetes-related complications)	54.4%
Dialysis services	54.4%
Medical care for diabetes-related heart disease	41.6%
Medical care for diabetes-related stroke	47.2%
Medical care for diabetes-related eye disease	55.2%
Advocacy for policies and programs to prevent and treat diabetes	47.2%
Support services for diabetics	46.4%

Respondents were asked which services they felt were lacking or inadequately provided on Guam. Table 4 lists the types of services and the percentage of respondents who identified these services as lacking on Guam. Table 5 lists the top 5 services that respondents felt needed to be prioritized for the island's diabetic patients.

Table 4. Diabetes services identified by survey respondents as lacking on Guam

Type of service	% of patients identifying this service as lacking on Guam
Public awareness and education about diabetes	4.8%
Lifestyle management including nutrition and dietary counseling for diabetics	4.8%
Greater access to specialists and specialty care	3.2%
Assistance to improve self-care skills	2.4%
Financial assistance/better insurance coverage for diabetics	2.4%
Emergency care for diabetic emergencies	1.6%
Home care for elderly diabetics	0.8%
Care giver education	0.8%
Services for physically disabled diabetic patients	0.8%
Properly equipped wellness center in every mayor's office	0.8%
Increased government support to diabetes programs	0.8%
Insulin pump therapy	0.8%

Table 5. Top 5 diabetes services identified by survey respondents as priorities for Guam

Education on prevention and healthy lifestyles

Specialist services, specifically for endocrinologists and cardiologists, and specialized clinical services, particularly for diabetes-related cardiac problems

Financial assistance, especially for the uninsured/underinsured

Preventive services, including tobacco cessation assistance

Lifestyle management services, including nutrition and dietary counseling

DISCUSSION AND CONCLUSIONS

This was a voluntary survey using a convenience sample of respondents attending either an Internal Medicine/Endocrinology private practice clinic or either of the Community Health Centers of the DPHSS.

The diabetes patients who participated in this survey comprise a mix of those who seek services in the public sector and those who use private sector health services. The sex and ethnic distribution are relatively consistent with the composition of Guam's general population. The relatively older median/mean age of the pool of respondents reflects 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.

*A significant percentage (38%) of respondents reported not knowing what type of diabetes they had. **This indicates a critical gap in patient-doctor communication and/or patient awareness regarding diagnosis.***

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 is 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 would be a well-informed group of individuals whose feedback likely would be valuable for the DPHSS Diabetes Control Program and its partners and stakeholders.

As expected, majority (53%) of the diabetes patients reported having Type 2 (non insulin dependent) diabetes. A minority (5%) reported being diagnosed with Type 1 (insulin-dependent) diabetes. What was of concern was the finding that a significant percentage (38%) of respondents reported not knowing what type of diabetes they had. This indicates a critical gap in patient-doctor communication and/or patient awareness regarding diagnosis. Patients were more likely to be

aware of the duration of their illness (since diagnosis) than of the nature of the diabetes they were diagnosed with.

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. It is encouraging that majority (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. Patients' physicians and DPHSS were the most frequently identified sources for this information. However, nearly one in five (18%) stated that they have not had this critical discussion, highlighting the need to extend this type of information sharing to encompass all patients with the disease.

In January 2009, the American Diabetes Association published a set of clinical practice recommendations for the prevention and control of diabetes.² These recommendations were derived from an extensive review of the evidence and from expert opinion. Based on these recommendations, certain interventions should be universally implemented for all diabetes patients. The feedback from the patients covered under this survey indicates the degree of Guam's compliance with this standard of acceptable clinical practice (Figure 4). Efforts are needed to extend the current coverage by these preventive and routine clinical services to 100% of patients with diabetes.

It is encouraging that majority (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.

Patients' physicians and DPHSS were the most frequently identified sources for this information.

However, nearly one in five (18%) stated that they have not had this critical discussion, highlighting the need to extend this type of information sharing to encompass all patients with the disease.

Figure 4. Adherence to ADA Clinical Practice Recommendations on Guam

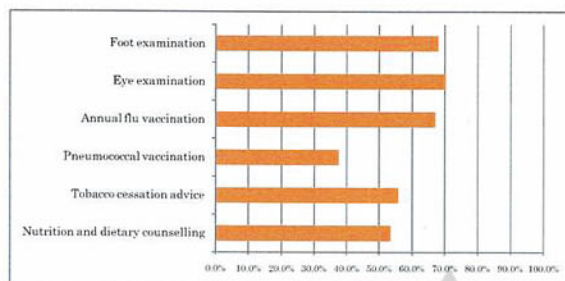


Figure 4 graphically depicts the extent by which some essential diabetes-related services on Guam are failing to reach the desired 100% coverage, as recommended by the American Diabetes Association. Diabetes health service providers are ensuring regular eye and foot examinations and annual flu vaccinations for about 70% of the diabetic patients surveyed, but tobacco cessation advice, nutrition and dietary counseling and pneumococcal vaccination are being offered to barely half of diabetic patients.

Based on Table 3, 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. Perhaps this could be explained by noting that while education and preventive services are readily available, the quality and coverage of these services need to be enhanced.

Other service gaps that were identified as priorities for Guam include improved access to specialists and specialized care, specifically for diabetes complications, and financial assistance for diabetes care and medications. The

need for financial support also 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.

Overall, the survey results present a mixed picture. Respondents are highly aware of the duration of their diabetes, and most 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. Patients actively seek out diabetes information and are knowledgeable about the various sources where educational materials and information are available on Guam. Physicians and the DPHSS are frequently cited as the key sources of information---this is indicative of the effectiveness of the DPHSS Diabetes Control Program's outreach efforts. Respondents are also generally satisfied with the quality of preventive and routine medical care that they receive from their service providers. However, almost 40% of patients are not aware of the type of diabetes they have, and key interventions, such as nutritional counseling, brief tobacco cessation interventions and immunization services are not being provided to all diabetic patients, as recommended by the current clinical standards of care. Patients have also identified the need for 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 as the DPHSS and its partners develop a strategic plan to better address the issue of diabetes on Guam.

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APPENDIX: DIABETES PATIENT SURVEY INSTRUMENT

DIABETES PATIENT SURVEY

Demographic Information

Age: _____

Sex: Male Female

Ethnicity:

- Chamorro
- Other Micronesian (please specify): _____
- Filipino
- Other Asian (please specify): _____
- Caucasian
- Other (please specify): _____

How long ago were you diagnosed with diabetes or told by a health professional that you had diabetes?

- Within the past year
- 1-5 years ago
- More than 5 years ago

What type of diabetes do you have?

- Type 1 diabetes
- Type 2 diabetes
- Don't know

Do you check your blood sugar level at home?

Yes No

Are you taking oral medications (pills, tablets, etc) for your diabetes?

Yes No

Are you injecting insulin for your diabetes?

Yes No

Who is **primarily** responsible for supervising your diabetes medical care?

- My primary care health professional
 - Pediatrician
 - Family medicine doctor
 - Internal medicine doctor
 - Other (please specify): _____
- Diabetes specialist
- Other (please specify): _____

If you need to know something about diabetes, where do you go to get the information you need? (Choose your **top 3** information sources)

- My doctor
- Other health professional (please specify): _____
- Media (e.g. TV commercials, newspaper articles)
- Internet
- Guam Diabetes Association

- Department of Public Health and Social Services
- Family members
- Other diabetes patients
- Other source (please specify): _____

Diabetes is a chronic disease that requires lifestyle adjustments. Has anyone adequately explained to you what diabetes is and what lifestyle changes are needed to control your blood sugar?

Yes No

If yes, who? _____

Have you ever received counseling regarding nutrition and dietary choices for diabetics?

Yes No

If yes, who provided the counselling?

Are you a smoker or tobacco user?

- Current smoker/tobacco user
- Ex-smoker/tobacco user
- Non-smoker/tobacco user

If you are a current or ex-smoker or tobacco user, has anyone ever advised you of the harmfulness of smoking/tobacco use for diabetics and the importance of quitting tobacco use?

Yes No

If yes, who? _____

Have you received the pneumococcal vaccine (to prevent pneumonia)?

Yes No

If no, has it been offered to you by your doctor?

Yes No

Do you receive the flu vaccine every year?

Yes No

If no, is it offered to you by your doctor each year?

Yes No

Have your eyes been checked for diabetic eye disease?

Yes No

If yes, where do you go to get your eyes checked?

Are your feet regularly checked for wounds and infection?

Yes No

If yes, who checks your feet?

If you need foot care, who provides the care?

Do you have any of the following diabetes complications? (check all that apply) If yes, who oversees the medical care for each complication:

Condition	Do you have this complication?	Who provides care for this complication?
Heart disease	<input type="checkbox"/> Yes	
Stroke	<input type="checkbox"/> Yes	
Kidney failure	<input type="checkbox"/> Yes	
Nerve damage	<input type="checkbox"/> Yes	
Loss of vision	<input type="checkbox"/> Yes	
Amputation	<input type="checkbox"/> Yes	
Other: (pls. specify)	<input type="checkbox"/> Yes	

Have you ever needed personal counseling to help deal with your diabetes? Yes No

If yes, where did you obtain this counseling?

Do you think that the following services for diabetics are adequately provided for and available on Guam?

- Education about diabetes Yes No
- Preventive services for diabetics
 - Nutrition and dietary counseling Yes No
 - Exercise facilities Yes No
 - Advise and assistance to quits smoking/using tobacco Yes No
 - Immunization services Yes No
- Routine medical care for diabetes Yes No
- Specialized care for diabetes Yes No
- Special services for diabetes-related complications
 - Dialysis Yes No
 - Medical care for diabetes-related heart disease Yes No
 - Medical care for diabetes-related stroke Yes No
 - Medical care for diabetes-related eye disease Yes No
(example: laser eye surgery)
- Advocacy for policies and programs to prevent and treat diabetes Yes No
- Support services for diabetes patients Yes No

Have you ever needed to go off-island to receive care for your diabetes or a diabetes-related complication? Yes No

If yes, what was/were the service/s you needed?

Are you content with the quality and types of diabetes services available on Guam? Yes
 No

What services for diabetes are lacking on Guam?

Of these services, what in your opinion is the most important service that should be prioritized by health service providers on Guam?



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¹ Department of Public Health and Social Services. Vital Statistics, 2005 (Preliminary data). Mangilao, Guam, 2008.

² American Diabetes Association. Executive summary: Standards of medical care in diabetes—2009. *Diabetes Care* January 2009 32:S6-S12; doi:10.2337/dco9-S006

