Disease management: the interface between Hawai'ian health and the Western health care system

JOSEPH HUMPHRY, MD, FACP*
TYRONE LEE KEALIIAIMOKU REINHARDT**

Abstract

The Western health care system is changing from a model that focuses on acute care to one that includes components critical to the promotion of effective care of patients with chronic disease. These patients often fail to seek care or make appropriate lifestyle changes until the disease process is far advanced. Effective chronic disease management occurs less often among Native Hawai'ians and other ethnic minorities due, in part, to their distrust of the dominant culture and the absence of culturally appropriate treatments in the western health care system. Working with the International Diabetes Center of Minneapolis Minnesota, Papa Ola Lokahi has implemented the Staged Diabetes Management Program with provider groups in Hawai'i. This article describes the program implementation as well as the successes and barriers encountered in the process of changing. This initiative promotes improved use of the services provided by the Native Hawai'ian Health Care Systems. Staged Diabetes Management establishes an environment of participation for traditional healers and other providers of cultural health services in the management of diabetes and other chronic diseases in Hawai'i.

Introduction

Foreign domination and subsequent annexation of Hawai'i by the United States has resulted in the importation of the western health care system. Many view "modern medicine" as a miracle of science and technology. For the majority of Hawai'ians, western influence has meant exposure to previously unknown infectious diseases and, in recent times, the adoption of a diet and life style that lead to chronic disease, certain cancers and premature death. Lack of access to care figures prominently into the dismal health status of many Hawai'ians. If the financial, social and cultural barriers were effectively addressed, Hawai'ians and other ethnic minorities could achieve parity in medical care equal to the Caucasian population.

Effective chronic disease management occurs less often among Native Hawai'ians and other ethnic minorities due, in part, to their distrust of the dominant culture and the absence of culturally appropriate treatments in the Western health care

The inherent assumption of western medicine is that it provides a superior method of medical care. Whereas we need to step back and ask, "What do we get from 'modern medicine?' How does this relate to the health of Hawai'ians? How can Hawai'ians best benefit from the western health care system?"

A paradigm shift has occurred with the rapid advances in controlling acute infectious diseases over the last 50 years. Despite this shift from a model of acute curable symptomatic disease to chronic disease and chronic illness, and despite 80% of the resources being directed toward people with chronic diseases, there has not been comparable quality care for these individuals.[1]

The needs of patients, many of whom have few or no early symptoms, are dramatically different from those of the past with acute illness. More effective methods of screening, identification, and diagnosis are necessary given the lack of symptoms for chronic diseases. In addition, these patients need training in effective behavioral life style changes, psychological support to cope with illness over a long duration, access to a complement of providers, medication, foods and supplies, and an information system that tracks, measures and adjusts therapy over the course of the illness. The western health care system does not provide the elements needed to effectively manage people with chronic diseases. For example, the average patient with Type 2 diabetes has the disease for 7 to 10 years prior to diagnosis and one third of the people with diabetes in the United States have not been diagnosed.

*Waianae Coast Comprehensive Health Center, 86-260 Farrington Hwy, Waianae, HI 96813. **Papa Ola Lokah, 222 Merchant Street 206, Honolulu, HI 96813.

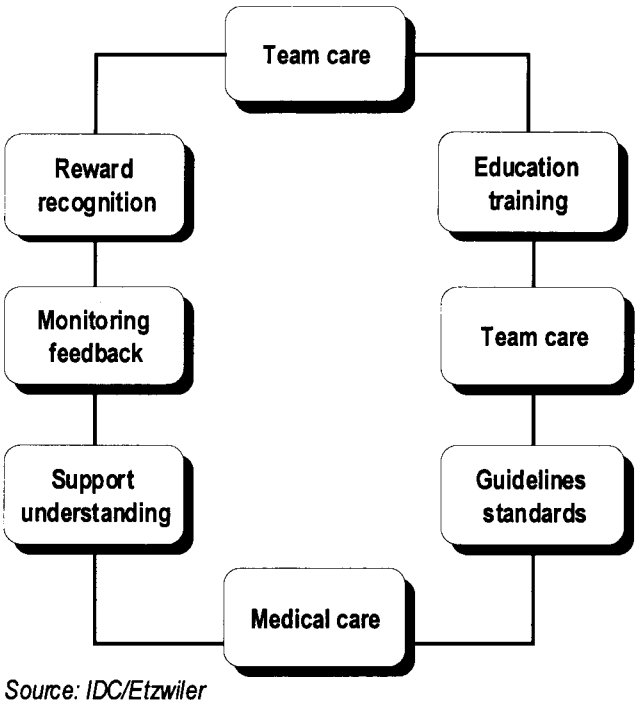
Further, a critical evaluation of the available literature documents the results of a costly and ineffective delivery system. In the decade from 1980 to 1990, there was no apparent improvement in diabetes care in the primary care setting in spite of recognition that control was important in diabetes management.[2] The availability of home monitoring, glycohemoglobin, and improved diabetes education had little effect on the actual control of blood glucose. Up to one third of all patients with diabetes in a given year failed to have even a single physician encounter.[3] Only one third of patients received the recommended annual eye evaluation, and an estimated one half of all patients could have avoided amputations with regular foot inspections and education about the care of the "numb" foot.

The ineffective management of diabetes leads to a balloon payment cost towards the end of life. Diabetes leads to end stage renal disease, strokes, heart attacks, blindness and amputations. The U.S. health care system is now struggling over the cost of care for people with episodic acute complications due to the lack of effective chronic disease management. The more that is spent on preventive health care for individuals with chronic diseases, the greater the long-term benefits in terms of both quality of life for the patients and cost of overall care. Those at the end of their disease process consume the lion's share of the dollars in hospital costs and highly technical procedures. Those early in the course of their disease when intervention is most effective are essentially left in the hands of primary care physicians who lack the resource to provide effective care.

These issues raise the question, "Should Hawai'ians with chronic disease see 'western practitioners?' ". The answer is an unequivocal, "Yes," for patients with selected complications. A patient with angina and three-vessel heart disease or a progressive foot infection has clear gains in quality of life and survival by receiving care in the "western health care system." However, for chronic disease, does receiving care correlate with receiving benefit? A remarkable study reported by Orchard et al. found that young patients with Type 1 diabetes did not differ in diabetes control whether they saw a physician or not over a one-year period.[4] Therefore, we would challenge the efforts to increase access to physician care for minorities without also addressing the ineffective long-term outcomes of care. One needs to ask what the western health care system has to offer Hawai'ians over no care or the care of a traditional practitioner? Will episodic or even regular physician visits alter the long-term course of diabetes if there is not the support to bring about the essential behavioral changes required for good blood glucose control?

Papa Ola Lokahi, a coalition of organizations addressing the health needs of Hawai'ians, in conjunction with the International Diabetes Center initiated a project in December 1994 directed at changing the way diabetes was managed in Hawai'i. Efforts were made to integrate the Native Hawai'ian Health Care Systems such that structural changes in the focus and organization of the western health care system could be accomplished. The following is a report on our experience to date and the efforts to enlarge and sustain the current effort.

Figure 1. Chronic Disease Model



Source: IDC/Etzwiler

A chronic disease model

Figure 1 shows the elements needed for effective chronic disease management as developed by Etzwiler and the International Diabetes Center.[1]

The primary recognition that the patient determines outcomes in the management of chronic disease is central to refocusing the health care delivery system.

The second critical component of this model in that the system does not effectively work unless all the pieces are in place.

The third component is that a team is essential to provide the full complement of services needed for chronic disease management.

Staged Diabetes Management

Staged Diabetes Management (SDM) is a disease management program for providers of diabetes care that restructures the health care delivery system to address the shortcomings of the western health care system.[5] The SDM recognizes the significance of the patient in the management of his o own disease. The health care system needs to suppor patient in navigating the most effective course in total A critical element is recognizing and supporting the pati participation in determining the outcomes of his/her car second critical element is consensus of the support t comprised of the full range of services needed for diabetes management.

The health c support the the most eff care. A c recognizing patient's determining

SDM in Hawai'i

In the summer of 1995, two other groups committed to SDM. The Wai'anae Coast Comprehensive Health Center had received separate grant funds from the Office of Minority Health to implement SDM. They co-ordinated the SDM process through Papa Ola Lokahi. Kaiser Hawai'i had also been planning to "re-tool diabetes care to focus more on patient teaching and better patient management." They elected to use SDM as the vehicle to restructure diabetes care and through initial contacts made by Papa Ola Lokahi with Becton Dickinson, became a beta site for the Becton Dickinson SDM program. They received their training directly from the International Diabetes Center, but remained part of the Hawai'i SDM network.

care system needs to patient in navigating ective course in total critical element is and supporting the s participation in the outcomes of his/ her care.

Over the next two years, Papa Ola Lokahi provided training for an additional nine provider groups. At present there are three SDM sites on the island of Hawai'i, one site on Maui, seven sites on O'ahu (excluding Kaiser) and two sites on Kaua'i. More significant than the number of sites is the increasing number of physicians exposed to SDM. During the 1997 calendar year, providers with the Castle Hospital Physician group were trained and almost all of the physicians on the windward side of O'ahu were exposed to SDM. In addition, we are working with groups on Kaua'i, potentially rapidly eliminated when the International Diabetes Center agreed to have Becton Dickinson be the single source of distribution for SDM in the United States. The State of Hawai'i was specifically excluded from this contractual arrangement due to the previous commitment from the International Diabetes Center to have Papa Ola Lokahi distribute SDM.

The overall SDM implementation program started slowly. Managed care and the privatization of the Medicaid program (the payment for health care for the under-privileged) assumed increasing human resources on the part of physicians and other providers. Most groups were not interested in getting involved in more training and meetings even though they recognized the opportunity to improve care.

The Kauai's Native Hawai'ian Health Care System, Ho'ola Lahui Hawai'i, initiated a Staged Diabetes Program in conjunction with their traditional Native Hawai'ian diet program in the spring of 1995. Because two members of the core team completed the training from the International Diabetes Center, Papa Ola Lokahi obtained the material s from the International Diabetes Center, but did not get involved with the implementation of SDM. Ho'ola Lahui Hawai'i had six people with diabetes referred to the program. SDM had a foothold

Through a grant from the Hawai'i Community Foundation, Papa Ola Lokahi provided training in SDM for 20 health professionals in December 1994. The objective of the training was to develop a core of providers who could in turn train ot throughout the state in SDM. The two major health p Hawai'i Medical Services Association (HMSA) and Ka were included in the training activity. The Internati Diabetes Center encouraged the development of a si statewide network to implement SDM in Hawai'i co-ordin through Papa Ola Lokahi.

Limited additional support was obtained through HM and pharmaceutical companies to offset the costs of e training. The funds were requested and controlled by local provider group usually through the Native Hawa Health Care Systems and did not come to Papa Ola Lo to support the SDM network. This source of funding

making SDM the standard of care for patients on that island.

HMSA, the largest health plan in Hawai'i, has made a major commitment to developing disease management directed at diabetes and asthma. Papa Ola Lokahi will be working with HMSA in the implementation of their program and hopes to integrate the SDM activities with the program being developed by HMSA.

Discussion

Patients with elevated serum cholesterol, hypertension or glucose have little or no early symptoms related to the chronic condition. With asymptomatic disease, individuals would not usually establish chronic disease management as a priority in the activities of daily living until the course of disease leads to increased symptoms and/or disability. As a chronic disease progresses beyond the asymptomatic stage, patients pay more attention to disease control and take measures to alter their life style. By this time however, physiologic damage has occurred. There is limited effect of behavioral changes on the natural course of the disease process when secondary complications are clinically present.

Patient-centered care requires the focus on intervention that addresses the needs of patients. The physician is both rewarded and accountable in the western health care system. Most of Hawai'i has adopted a model based on the western model with a strong focus on episodic care related to acute illnesses and late complications due to chronic disease. The concepts behind SDM call for a re-structuring of the health care system to address the needs of those with chronic illness.

Another difficulty with the adoption of SDM relates to the coverage of services. Currently education and case management services provided by non-physician team members are not reimbursed by the major health plans with the exception of Kaiser. The SDM providers have made a significant effort to improve diabetes care. They have clearly made an impact on the coordination of services and care for patients with diabetes, but the impact is limited by existing insurance benefits. The limited services directly affect Native Hawai'ians who represent a disproportionate number of the economically disadvantaged. Where others can pay for the additional services, many Native Hawai'ians cannot afford to pay for essential services critical for effective diabetes management. The Native Hawai'ian Health Care Systems are able to provide partial support but there is a clear lack of financial incentives to improve the care of patients with diabetes using SDM.

The SDM network and individual programs continue to struggle, but now represent a substantial number of physicians and other providers who have a common training in the management of diabetes. The limited resources and lack of reimbursement for services by providers other than physicians discourage the use of a structured team approach to diabetes management.

The evaluation of SDM in other locations in the U.S. and the world show a substantial improvement in blood glucose control for the average patient. At the 1997 National American Diabetes Association meetings, Kaiser Hawai'i reported on the success of their program in improving diabetes care and the other Hawai'i groups informally reported improved patient involvement and control. Papa Ola Lokahi has not collected network wide results.

The success of the various SDM training has varied. Based on the experience of the authors, there are several critical elements that have lead to the success of selected sites. The most significant factor in developing a successful program is the commitment by a team of providers to learn the system and work together to improve care. The best results are seen when there are one or more "champions" on the team that take the initiative to coordinate regular meetings and move the implementation process along.

The most significant factor in developing a successful program is the commitment by a team of providers to learn the system and work together to improve care. The best results are seen when there are one or more "champions" on the team

A second important component is administrative support. To date, many of the SDM teams have initiated and sustained SDM on their own initiative and time, but the process needs to have a level of administrative support. The best situation occurs when the administration is solidly behind SDM and there is a commitment from the leadership of a provider group to support SDM. A program where a single physician from a group is the only participant is inherently weak. The physician usually does not get recognized by the other physicians for his or her efforts and the other team members must treat patients differently depending on who refers the patient.

A third component is the audit and feedback system. Completing a chart audit as an initial set in the implementation process gives the local providers their own data to measure quality and establishes the importance and methodology to access the success of the SDM program. The audit attempts to review 10 to 15 charts. This number is designed to show the patterns of care, but not to be an exhaustive study of diabetes care. Because the findings are for the local SDM provider team, there are no demands for sophisticated statistical analyses.

to show the patterns of care, but not to be an exhaustive study of diabetes care. Because the findings are for the local SDM provider team, there are no demands for sophisticated statistical analyses.

Conclusion

SDM was developed as a model for use with any chronic disease. The skills and structure of the program are easily adapted to other diseases. The major barrier to the use of SDM with other diseases is the lack of guidelines and decision paths that are essential to the implementation of SDM. Papa Ola Lokahi has developed decision paths for asthma based on the National Institutes of Health (NIH) guidelines for one group in Hawai'i and has shared this tool with others in Hawai'i and a group in California already using SDM. Over time, there are an increasing number of guidelines available for different diseases that are evidence-based and well developed. The ease in implementing a full complement of disease management programs will improve with time as these materials are developed. Papa Ola Lokahi has attempted to use a similar format for asthma decisions paths. Such an effort will minimize the need for providers to learn a new format for each disease.

There needs to be a paradigm shift in medical care to address the needs of patients with chronic disease.

SDM is in use in multiple settings and countries around the world. Most countries have health care systems developed around a western concept with a focus on acute episodic care. There needs to be a paradigm shift in medical care to address the needs of patients with chronic disease. The outcomes of chronic disease are patient dependent and require behavioral changes by the patient to complement any medical care. The health care system needs to support these behavioral changes and address the health care needs of patients over the duration of the chronic disease. The health care system needs to be adapted to local resources and not be based on standards developed in isolation from the actual local resources.

The evolution of the SDM project in Hawai'i has improved care for Native Hawai'ians and others in Hawai'i. Through the training and implementation program, Papa Ola Lokahi has established a network of providers all with a common interest in improving the care of patients with diabetes. The resource and service integration with providers continues to increase for the Native Hawai'ian Health Care Systems as the SDM systems evolve. By taking the leadership in improving the health care system, Papa Ola Lokahi assures an increased cultural awareness and recognition of alternative approaches to medical care as part of a new approach to patient care.

References

1. Etzwiler DD. Diabetes translation: A blueprint for the future. *Diabetes Care.* 17 (Suppl):1-4. 1994.
2. Hiss RG. Barriers to care in non-insulin-dependent diabetes mellitus: The Michigan experience. *Ann Intern Med.* 124:146-148. 1996.
3. Humphry JW. Outcome-oriented quality assurance in an ambulatory setting. *Hawaii Med J.* 54:552-55. 1995.
4. Orchard TJ. From diagnosis and classification to complications and therapy. DCCT. PartII? Diabetes control and complication trial. *Diabetes Care.* 17:326-38. 1994.
5. Mazze RS, Etzwiler DD, Strock E, et al. Staged diabetes management. *Diabetes Care.* 17 (Suppl):56-66. 1994. □

Hili hewa ka mana'o ke 'ole ke kūkākūkā.

Ideas run wild without discussion.

Discussion brings ideas together into a plan.

'Ōlelo No'eau #993