Greater Community-Clinical Linkages and Attention to Patient Life Stage: Recommendations to Improve Diabetes Self-Management Education in Hawai‘i

Catherine M. Pirkle PhD; Ngoc D. Vu MA; Lindsey S.K. Ilagan MS; Stephanie L. Cacal BA; David A. Stupplebeen MPH; and Blythe Nett MPH

Abstract

Patients with diabetes regularly carry out multiple disease-management behaviors—taking prescribed medications, following diet and exercise regimens, self-monitoring their blood glucose concentrations, and coping emotionally with the condition—that may require ongoing support from community and clinical resources. Diabetes self-management education (DSME) is an ongoing, patient-centered process that helps provide the knowledge, skills, and ability for self-care. Evidence suggests that DSME is most effective when reinforced by community resources, through what are called community-clinical resources. We conducted a series of qualitative key-informant interviews with DSME coordinators/managers from all counties in Hawai'i to document the landscape of DSME services in the state, focusing specifically on challenges and recommendations. We analysed the results using the socioecological model in order to chart these factors by levels of influence on health care providers, in terms of service provision, and on patients, in terms of DSME utilization. Many interviewees highlighted concerns about low utilization of DSME services, as well as practical implementation challenges (eg, group versus 1-on-1 sessions). Nonetheless, DSME coordinators/managers offered numerous recommendations to improve DSME across Hawai'i, highlighting opportunities for improved community-clinical linkages. Finally, emergent from the interviews were anxieties about increasing numbers of youth with diabetes and insufficient resources for them in DSME or other community-clinical resources. This paper offers suggestions to expand community-clinical linkages and to adapt services provided by DSME to meet patient and community needs. It is particularly timely as Hawai'i is rapidly increasing the number and diversity of DSME programs available.

Keywords

Diabetes Self-Management Education; Community-Clinical Linkages; Socioecological Model

Abbreviations

AADE = American Association of Diabetes Educators,
ADA = American Diabetes Association
CDC = Centers for Disease Control and Prevention
DEEP = Diabetes Empowerment Education Program
DSME = diabetes self-management education
DSMES = diabetes self-management education and support
DSMP = Diabetes Self-Management Program
HDOH = Hawai'i Department of Health
SEM = socioecological model
T2D = type 2 diabetes

Highlights

- DSME in Hawai‘i has grown rapidly in the past 5 years.
- Despite expansion, DSME is underutilized in the state.
- Greater community-clinical linkages may improve service provision and utilization.
- Adaptation of DSME to the varied populations of Hawai‘i affected by diabetes may improve services.
- Numerous recommendations to improve DSME in Hawai‘i are provided.

Introduction

Population aging, combined with increasing rates of overweight and obesity contribute significantly to type 2 diabetes (T2D), which is a serious and growing public health concern in the United States (US).[1] T2D is common among older adults, with more than a quarter of those aged 65 and older experiencing the condition.[1,2] It is estimated that diabetes costs the US over $300 billion each year.[3]

T2D is a significant concern in Hawai‘i. An estimated 5% to 15% of the state's population has diabetes.[4] This is based on self-report and underestimates the true disease burden, as diabetes is frequently undiagnosed. The Centers for Disease Control and Prevention (CDC) estimates that 1 in 4 adults with T2D are unaware of their condition.[5] T2D prevalence in the US and Hawai‘i is expected to increase as obesity trends continue to track upwards and the population ages.[6] Hawai‘i already has one of the largest proportions of older adults in the US.[7] Although recognizing that prevention of new diabetes cases is essential, given current epidemiological trends, effective treatment and management of the condition are also crucial.

Type 1 and type 2 diabetes are complex chronic conditions. Although diabetes intervention efforts often focus on clinical settings, most diabetes care happens outside of the hospital or clinic. Patients with diabetes regularly carry out multiple disease management tasks: taking prescribed medications, following diet and exercise regimens, self-monitoring their blood glucose, and coping emotionally with the condition.[8] Many patients face difficulties performing these tasks.[8] Critical timepoints in diabetes management—diagnosis, annual assessment, emergence of new complicating factors, and care transitions—often require additional medical, nutritional, educational and/or emotional resources.[9] Diabetes self-management education (DSME) is an ongoing, patient-centered process to address the needs of the individual with diabetes. The knowledge, skills, and ability

for self-care gained from DSME are important tools that help patients with diabetes to effectively manage the condition, prevent complications, and take control of symptoms such as fatigue, pain, and depression.[10]

Historically, DSME has been provided through formal outpatient services conducted at a hospital or other health facility.[9] It is now recognized that outpatient clinic and hospital-based support can often be insufficient for meeting ongoing patient needs, which may be better served by community resources.[8] In fact, community resources are one of the pillars of quality improvement in the original and Expanded Chronic Care Models and are important for disease self-management and self-management support.[11,12] The involvement of community groups in diabetes self-management activities and programs decreases costs to health systems and improves participants' knowledge and self-efficacy.[13] Provision of DSME has evolved considerably over time and now takes place in a variety of settings in and out of the formal health care sector.[9]

Despite recent expansion of DSME beyond the formal health care sector, at a 5% participation rate, DSME is underutilized in Hawai'i.[14] This may reflect insufficient linkages between clinical services and community resources; however, the landscape of DSME in Hawai'i is currently unmapped. The objective of this study was to chart DSME services in the state and to document challenges to and recommendations for DSME including those related to improving service provision and increasing uptake. In doing so, the study authors examined opportunities for greater community-clinical linkages using the Agency for Healthcare Research and Quality definition, which states that community-clinical linkages "help connect health care providers, community organizations, and public health agencies so they can improve patients' access to prevention and chronic care services."[15]

Methods

Context

This study emerged from an evaluation of DSME programs in Hawai'i as part of a 5-year CDC cooperative agreement: State public health actions to prevent and control diabetes, heart disease, obesity and associated risk factors and to promote school health (CDC 1305).[16] The Hawai'i Department of Health (HDOH) was awarded the agreement in 2013 and collaborated with numerous partners from across the state. HDOH implemented a wide variety of interventions, including the provision of technical assistance to providers of DSME. As part of a nearly 20-year collaboration, the HDOH requested an evaluation of its activities by the Office of Public Health Studies at the University of Hawai'i. The work described here is part of those evaluation efforts.

Examples of DSME in Hawai'i include programs led by licensed health-care professionals and recognized by the American Diabetes Association (ADA) or accredited by the American Association of Diabetes Educators (AADE). These are known as diabetes self-management education and support services (DSMES). Other examples of DSME include the Diabetes Self-Management Program (DSMP) and Diabetes Empowerment Education Program (DEEP).[17] The text box summarizes the various diabetes self-management acronyms and programs included in this evaluation study.

Text Box

DSME: All-encompassing umbrella term for general diabetes self-management. There are three main types of DSME in Hawai'i: DSMES, DSMP, and DEEP.

DSMES: Delivered by licensed health professionals, DSMES is either AADE-accredited or ADA-recognized and is covered, at least in part, by almost all types of insurance. DSMES is often held in traditional outpatient settings.

DSMP: Originally developed at the Stanford Patient Education Research Center, DSMP is currently housed under the Self-Management Resource Center. DSMP is community-based and is provided by a pair of lay educators.

DEEP: Developed at the University of Illinois at Chicago and delivered in community settings, DEEP is covered by the Centers for Medicare and Medicaid Services and delivered by the state's Quality Improvement Organization.

Study Design

This is a qualitative evaluation, informed by the socioecological model (SEM). The SEM is popular in the field of health promotion and applied to research on program implementation in public health.[18] The visual metaphor for the SEM is a series of concentric circles, similar to the layers of an onion, representing the levels of influence on the outcome.[17] The SEM conceptual framework draws attention to individual and environmental determinants of a behavior, including service provision and utilization.[18] Of specific interest were issues related to DSME coordinator/managers' perceptions about the provision of DSME and patient utilization of their services. The SEM has been applied when examining macro- (eg, societal structures including policy), meso- (eg, institutions and communities), and micro-level (eg, personal networks and behaviors) activities related to implemention of diabetes self-management strategies across Europe[13] and has been recommended for the surveillance of chronic disease self-management programs.[11]

For this study, evaluators conducted 17 in-depth key-informant interviews with DSME coordinators/managers across all counties in Hawai'i. Interviewees were selected because of their involvement in daily DSME operations and leadership roles in their organizations' self-management programs. Interviews ranged from 45 minutes to 1.5 hours and employed semi-structured interview guides. Because the key informant interviews served explicit evaluation purposes for the HDOH, the questions aimed to: (1) record services provided by each DSME program, (2) learn about the relationship between the program and the HDOH, and (3) document successes and failures. General questions about the resources needed for people living with diabetes, at both the DSME site and community levels, were included. The SEM framework was applied to better understand challenges to DSME provision and uptake by patients, as well as opportunities for improved community-clinical linkages given the recognized importance of these linkages to DSME success.

Data Analysis

Interviews were transcribed verbatim using a professional transcription service (Rev.com, San Francisco, California) and thematic analysis applied. Two authors (NV and SC) coded the interviews deductively by challenges and facilitators and organized the results according to levels of the SEM. CP reviewed the codes and further organized the findings with the assistance of DS. Interviews were also coded inductively to capture emergent themes.

Ethics

This study was approved by the Institutional Review Board of the University of Hawai'i at Mānoa (2018-00180). All participants provided informed consent.

Results

Landscape of DSME Service in Hawai'i

At the time of manuscript submission (May 2019), there were 18 ADA-recognized and AADE-accredited DSMES organizations in the state, spanning all 4 counties. Four coordinators/managers representing 5 sites on O'ahu (4 hospital/clinical sites and 1 federally qualified health center [FQHC]), did not respond to our request for interview. Among DSMES service providers, 7 are based in large hospital systems and 5 are at FQHCs. Also, 3 are provided by community pharmacies, and 3 are in specialized settings (eg, for pregnant women). DSMES services are concentrated on O'ahu and Kaua'i and absent on Maui, as 1 provider recently retired and another site no longer has accreditation. On Hawai'i Island, services are concentrated in the north, but 1 pharmacist commutes regularly to Kona/Kailua. There is also a pharmacy DSMES on Moloka'i. Hospital systems tend to provide 1-on-1 services, whereas pharmacy and specialized providers often opt for group sessions. FQHCs offer a combination of 1-on-1 and group service programs. Additional community-based DSME include DSMP and DEEP. Originally developed by the Stanford Patient Education Research Center and now housed under the Self-Management Resource Center, DSMP is delivered by lay health workers under the coordination of non-profit organizations including the National Kidney Foundation of Hawai'i and Alu Like, Inc., as well as the HDOH's Office on Aging in all 4 counties. DEEP was originally developed at the University of Illinois at Chicago and is delivered in Hawai'i by Mountain-Pacific Quality Health, the state's Quality Improvement Organization. We interviewed several coordinators/managers of the DSMP and DEEP services.

Challenges to DSME Provision and Utilization

Table 1 presents challenges, across levels of the SEM, identified by the DSME coordinators/managers. These were divided into 2 broad categories: clinical service provision and community/patient utilization. Clinical or service-provision challenges covered issues from overcoming patient fatalism about diabetes to health systems' challenges related to reimbursement structures and payment models. Interviewees brought up concerns about how DSME programs are structured, including the composition of the program (group versus 1-on-1 classes), classes/visit frequency, and the duration over which services are offered. Some program implementation concerns, such as scheduling, echoed those also categorized as community/patient challenges to DSME utilization. One person said, *"That's another reason why group sessions cannot work, because you're trying to accommodate their schedule with the times that we're here."*

Patient/community challenges to service utilization largely reflected perceived issues with the potential or actual DSME user. Most of the challenges raised encompassed uptake issues, such as a lack of interest in the program or family support to participate, limited transportation options, and scheduling difficulties. As one key informant put it, *"…how do you translate, 'I know there's plenty of people who have diabetes,' into getting their asses into the chairs [for diabetes self management]?"* To a lesser extent, the program coordinators/managers discussed barriers to patients following DSME behavior-change recommendations, should they enroll in the program. Some of these included misconceptions about the cost of healthy foods, challenges to adopting healthy behaviors like exercise, and competing priorities.

Further examining challenges through the 5 layers of the SEM (individual, interpersonal, instititutional, community, and policy), the majority of community/patient utilization challenges were concentrated in the individual and interpersonal layers of the SEM, while service provision challenges were well-represented across all layers. Key informants frequently highlighted institutional issues, especially getting sufficient referrals to financially support their programs and enough patients to provide group classes:

> It's [referrals] fallen off mainly because I think the [physician association] case workers have been focusing on something else.

> *We're trying to create relationships with the American Diabetes Association and physicians and stuff like that. Referrals, themselves, from doctors … I think that's something we could definitely work on.*

Although institutional issues reflected challenges getting patients into DSME programs, most key informants did not make explicit linkages between referrals and enrollment challenges and low patient utilization of DSME. And although insufficient referrals from other health care providers were mentioned by numerous key informants, when asked further about the topic, many key informants were unaware of the actual numbers of patients referred to their services. Some informants also felt that referrals and enrollment could be improved with awareness campaigns run by the HDOH. There was a general sentiment that awareness of DSME was lacking in the health care sector and broader community.

Table 1. DSME Coordinator/Manager Perceptions of Challenges to Service Provision and Utilization of DSME, and Supporting Quotes, According to Levels of the SEM

	Explanation	Clinical (Service Provision)	Community/Patient (Service Utilization)
Individual	Refers to patient-level beliefs or behaviors that may be reflected in or affect service provision and/or utilization	**Patient Fatalism** *I guess just getting the word out there, how diabetes can be managed because it is something that a lot of people, some cultures think that they can't do anything about it and just accept the fact.* **Frequent and Sustained Visits to Support Behavior Change** *So it's really to up that frequency…give them enough time so they can develop healthy habits and healthy lifestyle modification.* *It's lifestyle change. It's behavior change. And over the span of a month, it's not going to happen. Even with our current structure, for three months. I think that's enough time for it to happen.*	**Generating Patient Interest in DSME** *…the biggest challenge is getting people interested and come to the classes, right?* … how do you translate: I know there's plenty of people who have diabetes, into getting their asses into the chairs? **Patient Knowledge on Healthy Behaviors Such As Diet** *…patients always tell us, "Health food is expensive." ... But it doesn't have to be. But it perpetuates the idea that, you know, like a pile of broccoli is going to cost you 3.69 versus you get a whole box of saimin for like $1.99 kind of thing.* **Competing Priorities** *… or they feel it's not important or they have other issues going on and they can't make it to their appointment. So it might be childcare or taking care of elderly parents.* *Sometimes it's a matter of patients coping with problems at home …*
Interpersonal	Refers to the effects of family, partners, or friends on service provision or utilization	**Assuring Interpersonal Support** *"You need to bring a support person." You can bring a couple of support people if you want, but we consider it a family issue …* *Yes. We really encourage care givers to come as much as we do the older adults.*	**Lack of Support from Family and Partners** *… Dad is out there sitting in the car. We have the pregnant girl in here and the father is in the car. Having a cigarette…with our juveniles, a parent at least is required to be in with them, but we can't force [adults] to ...* *The barriers…It could be numerous reasons, a lot of times, babysitting. It could be just not enough support at home, various things.*
Institutional	Refers to factors that directly affect the delivery and uptake of DSME at the site in which it is delivered (hospital/clinic, pharmacy, etc)	**Insufficient Referrals to DSME from Other HealthCare Providers** *We have flyers at our pharmacies. And really word of mouth. We're trying to create relationships with the American Diabetes Association and physicians and stuff like that. Referrals, themselves, from doctors ... I think that's something we could definitely work on.* *It's [referrals] fallen off mainly because I think the [physician association] case workers have been focusing on something else.* **Getting Newly Diagnosed Patients into DSME** *I don't know if it's a matter of money really, but I wish we had a way to capture those folks who are newly diagnosed, and to hook them up more quickly.* **Large Enough Class Size for Group Delivery** *You know, after we pay the rent, we pay the manpower and all that stuff. We don't need big classes. To keep it going, we just need constant, I guess, attendance. That's the other thing too. I think, yesterday, only one person showed up.* *I hear that statewide, and nationally, they struggle with getting small groups. So I've just decided, just to go on one on ones.* **Accommodating Patient Schedules** *That's another reason why group sessions cannot work, because you're trying to accommodate their schedule with the times that we're here.* **Institutionalized Peer Support** *One thing that's coming to mind is that, in talking to you, one thing that the patients have expressed a lot of interest in that we're not really able to supply … at least not at this point, is support classes. Basically, that just comes down to having a place to meet and maybe somebody with some knowledge of diabetes being able to coordinate it.*	**Finding Resources for Non-Clinical Activities** *The problem comes in on the business side of things when ... How can you pay someone to go with this patient for an entire week to do an exercise? But I think that's the kind of patient-specific care that's really needed.* **Busy Schedules** *The barriers, I think it could be the date, the wrong day that it doesn't fit them.*

Table 1. DSME Coordinator/Manager Perceptions of Challenges to Service Provision and Utilization of DSME, and Supporting Quotes, According to Levels of the SEM (Continued)

	Explanation	Clinical (Service Provision)	Community/Patient (Service Utilization)
Community	Refers to factors that affect the availability and accessibility of DSME, as well as supportive services outside of the healthcare sector	**Support Groups in the Community** *We get calls quite a bit about support groups asking for support groups.* *It's a chronic disease that every day you deal with. The most, I think, we get asked for is support. Why is there no support groups?*	**Unaffordability of Diabetes-Friendly Foods** *So, they need access to cheaper and healthier foods because patients always tell us …* **Getting To and From DSME** *Transportation is one of the barrier …*
Policy	Refers to county or statewide facilitators (or barriers) to DSME provision or utilization, including activities or efforts to change social norms about the program	**Legitimization of DSME Promotion** *It's a different message when a private organization like us are trying to "Come to our class." Compared to the Department of Health making an overall awareness campaign saying how important the issue of taking care of your diabetes is, and then here are the resources.* **Reimbursement/Payment for Services** *the payment model isn't really there. We have to work through some of these other hoops … I think we have the structure and the network and the ability to provide education on a huge scale. It's just the payment's not always there.* *Unfortunately, at the end of the day, the concept that I keep running into is ... We could teach as much as want or we could ... We want to spend time with the patient and we do create these good relationships with them, even after a month. But after that, unfortunately, the financial part limits what we can do.* *So, basically, this reimbursement we get, it's just a subsidy.*	**Limited Ppromotion of DSME** *Well I think… I think a lot of people don't know about these programs that exist.* *… public education, you know, issues where we don't see everybody. I'm aware that… even though in our world we see a lot of the diabetes patients, that there's a bunch out there that we're not hooked up with.*

Community-Clinical Linkages

Key informants offered a number of recommendations to improve service provision. At no point were interviewees asked to identify community-clinical linkages explicitly and yet, many of the recommendations addressed this topic:

I think [the patients] need a peer group. They seem to take advice from peers more liberally than they do with professionals. I think that's kind of already known, but, more so in this rural environment, you know. So, getting together peer groups, that is facilitated by a health professional… But the health professional, actually, I take that back. It can be a health professional or paraprofessional…Community health worker…Like, a community health worker [CHW]*, because there's some models out there, I think, that they're using CHW used to do this. They've done it in the past, and they seem to get good outcomes from it... Yeah, they seem to do well when they have groups, with CHW's facilitating it.*

Table 2 summarizes recommendations made by the DSME coordinators/managers who identified community-clinical linkages as a means to improving service provision. In this table, we indicate the levels of the SEM addressed by each recommendation. Notably, most recommendations to improve DSME incorporated 3 or more levels of the SEM. For example, one participant stated, *"I know a lot of the senior citizen centers they offer exercises. I think it's run by the county Enhance Fitness program, right? Those things are great for diabetes patients."* This recommendation explicitly acknowledged a community resource being offered by the county that addressed a clinical need (eg, improved diabetes outcomes) and incorporated both interpersonal and individual levels of the SEM, as the program targets individual behavior (ie, physical activity) in a group setting.

Life Stage Specific Issues

Worries about increasing numbers of youth with T2D emerged as a theme from the interviews. Concerns were raised about the enduring effects of diabetes, especially among at-risk youth or those who already have diabetes at a young age. Additional concerns were raised about the lack of DSME services for young people.

Diabetes can start at a very young age. All these people, all these young folks that I'm seeing that are like 10 years old that are going to be your 40-year-old dialysis patient but recognizing that diabetes is a lifespan of disease…

However, they only take them from 18 years old and over. There's really nothing for kids. I think there needs to be more health education for kids too…

In addition to concerns about diabetes in youth, especially growing numbers with T2D, key informants discussed barriers to addressing the varying needs of participants according to life stage. These types of barriers were largely interpersonal, reflecting the home environment and relationships between family members: *"Somebody who is elderly can't sit through with diabetes class or it doesn't grab their interest enough. Maybe the person I really should be talking to is the caregivers, the people that are involved in their care."*

The intersection of life stage specific issues and community resources was less discussed by participants, with the exception of older adults. Some informants implied that greater community resources were needed for kids and working-age adults, but specifics about what was missing or should be done were lacking: *"There's no support for these kids and the parents."*

Table 2. Quotes of Participant-Identified Community-Clinical Linkages, According to the Levels of the SEM that They Address					
Quotes	**Ind**	**Int**	**Ins**	**Com**	**Pol***
They're really trying hart to reach out to the patient, but the other half of the story is the patient needs to do their part, too. Yeah. Just I feel that we're trying really hard here and we're promoting it as a class, offering it as often, especially in between classes, we're trying to offer it to them and yeah, if they have excuses or if they can't make it for any reason, that is on their part where they need to make that decision, my health comes first or not. I think as a provider, we're doing a lot and I hope that we can do a lot more and just to push the issue, but sometimes, it takes the other half to do their part.	X				
So for the support group they do...we give them time to you know peer to peer socializing, talk to the teacher about how things are going.	X	X			
For our population I think it's getting the...like it would be nice to have classes for them in their language. I think that would be really helpful.					
Resources…Probably like more group education in their language, that would be helpful.	X		X		
I think they need a peer group. They seem to take advice from peers more liberally than they do with professionals. I think that's kind of already known, but, more so in this rural environment, you know. So, getting together peer groups, that is facilitated by a health professional…But the health professional, actually, I take that back. It can be a health professional or paraprofessional…Community health worker…Like, a community health worker, because there's some models out there, I think, that they're using. CHW used to do this. They've done it in the past, and they seem to get good outcomes from it...Yeah, they seem to do well when they have groups, with CHW's facilitating it.	X	X	X		
…experience with the nurse that did the visits. I think that was really important for the patient and I find that a really huge value…Someone goes there and they feel cared for and it might give them a little more motivation to take care of themselves.	X	X	X		
Someone who could put the patient, bridge a patient provider and the program and the patient.		X	X	X	
I know in San Francisco, where I saw it work phenomenally, it was the doctor...So this one pharmacist had great relationships with, let's say 10 doctors, 10 endocrinologists or whatever it might be, in the area. And basically the doctors would tell their patients, they would write them out a prescription, "You need to go take this class from this pharmacist." And so it was really the physician directing it. Because the patient had so much respect for the physician, there was no question. They went. And then the physician and the pharmacist had a really great working relationship too. And so they were helping each other, to manage the patient.	X	X	X		
I think people ask for cooking classes a lot. …but they're always asking about food.	X	X	X		
And so we have a program called Double Bucks, but that's only for people who have SNAP. And a lot of the patients that have diabetes don't have SNAP because they're the Micronesians. They don't qualify for food stamp[s]. So I'm not sure how we're going to be able to, but having the food bank in our community is helpful.	X	X	X	X	
We actually have a van?…that will hopefully decrease that barrier [transportation].	X	X	X	X	
I know a lot of the senior citizen centers they offer exercises. I think it's run by the county enhance fitness program, right? Those things are great for diabetes patients.	X	X	X	X	
Maybe potentially more exercise events? Like community exercise events? A lot of the patients I see, they'll go to the mall here.	X	X	X	X	
Public education, you know, issues where we don't see everybody. I'm aware that...even though in our world we see a lot of the diabetes patients, that there's a bunch out there that we're not hooked up with. And I think that ... just public education, you know, public service announcement kinda things, where if you have diabetes and you haven't seen a diabetes educator, contact your local whatever.	X	X	X	X	X
Yeah. We see how the media affects everything, whether it be positive or negative. I think any type of campaign like that, while it might not help in the moment, at least it catches the eye of participants who don't know the program exists.	X	X	X	X	X
So, okay, I have some ideas. So one is, community awareness.	X	X	X	X	X
I guess community collaboration. I remember...I guess it was the DOH. I forget exactly. But, they had a seminar here in Maui, where they were talking about diabetes, and got a whole bunch of definitely people together…But that was really helpful. The content of the presentation was really, really good. They were just talking to other people in the community, other Directors and executives. I guess I'm just a big collaboration type person. So, I think getting people together in one room and having types of seminars to bounce ideas off each other. Hear barriers and suggestions, things like that, I benefit from.	X	X	X	X	X

*Ind- individual, int- interpersonal, ins- institutional, com- community, pol- policy

Discussion

This paper examined the DSME landscape across Hawai'i, challenges to service provision and utilization, and recommendations for greater community-clinical resources. Service utilization is affected by both provider/health system characteristics and patient perceptions. By applying the SEM to examine factors perceived to affect DSME utilization, opportunities for programmatic improvement are highlighted across multiple levels of influence on both DSME service providers and their patients. Finally, emergent from the interviews were anxieties about increasing numbers of youths with diabetes and insufficient resources for them.

As previously mentioned, at a 5% participation rate, use of DSME in Hawai'i is low, as it is across the United States, where it rarely exceeds 10%.[14] DSME coordinators/managers highlighted numerous challenges to attracting enough patients to use their services. At the individual level, DSME service providers were concerned about the lack of interest expressed by potential participants, while at the policy level, they highlighted a broader lack of knowledge about the program by both physicians and the population at large and related this lack of awareness to insufficient public advertising. The implications of these challenges are clear. At an organizational level, low recruitment of patients into DSME is perceived to threaten program sustainability, while at a population level, it impacts public health and health system functioning. One potential solution, as indicated by several key-informants, is greater use of awareness campaigns. Increased engagement of community resources such as CHW to directly reach out to potential DSME participants and assure services are culturally adapted to meet participant needs may be another solution. Additional tailoring or adaptation efforts might include addressing participant demographic characteristics, such as age. DSME managers highlighted concerns about service provision for both extremes of the demographic spectrum: older adults and youth. DSME for youth appears to be a signficant gap in the repertoire of diabetes management tools available in Hawai'i. Overall, limited research has been conducted on diabetes self-management for youth. Current studies indicate that providers are uncertain of the appropriate management guidelines for youth with T2D, and the few existing guidelines appear to be inferred from research on adults.[19]

Challenges to service provision were more commonly mentioned by respondents than patient utilization issues. This should be expected because health care providers know best the challenges facing their workplace, but may be less knowledgeable about broader patient and community concerns. Moreover, providers' discussions with patients likely focus on clinical challenges to diabetes management rather than interpersonal, organization, or community ones. However, research on diabetes self-management indicates better success for patients in these programs when integrated with community resources.[13] One large study of self-management activities and programs across 6 European countries found, compared to formal services alone, community groups' involvement resulted in better reach through networking and referrals, improvements in meeting practical patient needs (diet, foot care, physical activity, transportion, etc.), and greater perceptions of humanized and holistic care by patients.[13] This is consistent with the Expanded Chronic Care Model, which places self-management support at the intersection between the health system and larger community, recognizing productive interactions and linkages between the two result in better clinical outcomes.[12]

This study has limitations and strengths. Because the key-informant interviews were designed to respond to program evaluation needs, the study did not explicitly examine community-clinical linkages or life stage specific issues related to DSME. These were emergent themes, largely discussed when participants were asked about successes and failures and the resources needed for people living with diabetes in their communities. As such, this study may not capture the totality of participant reflections on these topics. Despite this limitation, participants provided rich information on both topics. A particular strength of this study was the sample of DSME coordinators/managers interviewed. Interviewees represented diverse DSME sites and had strong representation from all counties in Hawai'i. However, it should be noted that those who did not respond to the request participate were exclusively from O'ahu, which may affect the generalizability of our findings to that island.

Practical Implications

Diabetes is one of the most pressing public health issues facing the state of Hawai'i and the nation. Rates of diabetes are expected to climb in the foreseeable future and people with this condition will require ongoing support in order to effectively manage their condition and prevent complications. DSME, which is cost-effective, limits hospital admissions and readmissions, and reduces lifetime healthcare costs;[9] is important to helping patients control their diabetes, but often works best when supported by strong community-clinical linkages. Work that highlights areas for improvement in DSME service provision and offers suggestions for improved community-clinical linkages is particularly timely as the state of Hawai'i is currently and rapidly increasing the number of programs available, as well as diversifying the contexts in which these are provided. This trend is mirrored across the US, as the CDC continues to promote DSME through more recent cooperative agreements.

Conflict of Interest

None of the authors identify any conflict of interest.

Acknowledgements

We would like to thank all of the key informants for this study. Every one of them was very generous with their time and insights and all are passionate about providing diabetes care.

Authors' Affiliations:
- Office of Public Health Studies, University of Hawai'i at Mānoa, Honolulu, HI (CMP, NDV, SLC, DAS)
- Chronic Disease Prevention and Health Promotion Division, Hawai'i State Department of Health, Honolulu, HI (LSKI, BN)

Correspondence To:
Catherine M Pirkle PhD; 1960 East West Road, Biomedical Tower 102, Honolulu, HI 96822; Email: cmpirkle@hawaii.edu

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