

The New Zealand experience in peer support interventions among people with diabetes

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Background. Peer-to-peer support has the potential to assist people with diabetes, or at risk of diabetes.

Objective. To review the development of diabetes peer support initiatives in New Zealand.

Methods. A systematic review of diabetes peer support publications from New Zealand, supplemented by unpublished records from Diabetes New Zealand (DNZ, the national diabetes patient organization) and the two major regional initiatives in South Auckland and Waikato.

Results. DNZ, which has 40 societies and 71 diabetes support groups, delivers a range of services to members and non-members. The membership is mainly older European New Zealanders with diabetes, with some Maori and associated societies for Pacific and Youth. While demand exists, no quantitative evaluation of health impact by these organizations has been undertaken. Other peer support groups have developed in South Auckland and Northland. Common themes that emerge relate to leadership, organization and balancing the different needs of people with diabetes at different stages (e.g. newly diagnosed versus others) and with different personal needs. In South Auckland and the Waikato, lay educators have been trained to provide 1:1 and group sessions for people with, or at high risk of, diabetes. A range of training, management, funding and organizational barriers existed in the implementation of these lay educator programmes.

Conclusions. Peer-to-peer support and education programmes in diabetes have been considered useful in New Zealand. Knowledge regarding training, management and organization is nearing a level, which would allow formal evaluation of a strategy for both the prevention of diabetes and in supporting people with diabetes.

Keywords. Diabetes, HbA1c, prevention, psychology, support.

Background

A high prevalence of Type 2 diabetes among New Zealand Maori and Pacific people (and now Asians) has been known since the early 60s.¹ Maori and Pacific people not only have a higher prevalence of Type 2 diabetes than Europeans but also a younger age at diagnosis, more complications and greater premature mortality.¹ The aim of this article is to review the different approaches to peer-to-peer support for people with, and at high risk of, diabetes in New Zealand.

Methods

A systematic review was undertaken using all databases within the ISI Web of Knowledge using the

keywords New Zealand, diabetes, 'peer support', 'self-help', 'support group', 'mutual support' or 'lay educator'. Records were also available from Diabetes New Zealand (DNZ) including newsletters, the South Auckland Diabetes Centre (SADC), South Auckland Diabetes Project (SADP) and Te Wai o Rona: Diabetes Prevention Strategy. A search using the same keywords in Google yielded no further information.

Results

The literature review yielded 33 articles, of which 5 described diabetes peer support activities in New Zealand. The others were either unrelated or mentioned peer support without it being the subject of research. Overall, activities were diabetes peer support

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activities run by those with diabetes (DNZ and affiliates, Whangaroa Club), peer worker services in the community (SADC) or research-supported activities (SADP, which included both peer support and peer worker, and Te Wai o Rona: Diabetes Prevention Strategy which was only a peer worker strategy at closure).

The DNZ

DNZ founded in 1962 (as the Diabetic Association of New Zealand) is the umbrella organization for 40 local societies across the country (Fig. 1). Under the 40

societies are 71 support groups, 22 of which are in Auckland (Benton P, personal communication). The membership includes those with diabetes and their families. It is decentralized, with differences between the activities of each society. The role of the organization includes support, education and advocacy, although these cover a range of specific activities in some local societies (Table 1). The monthly society group meetings are usually led by a person with diabetes, have an invited speaker/discussion topic and no health professional was present. The societies receive documentation from DNZ on set up and executive

Local Diabetes Societies - 2006

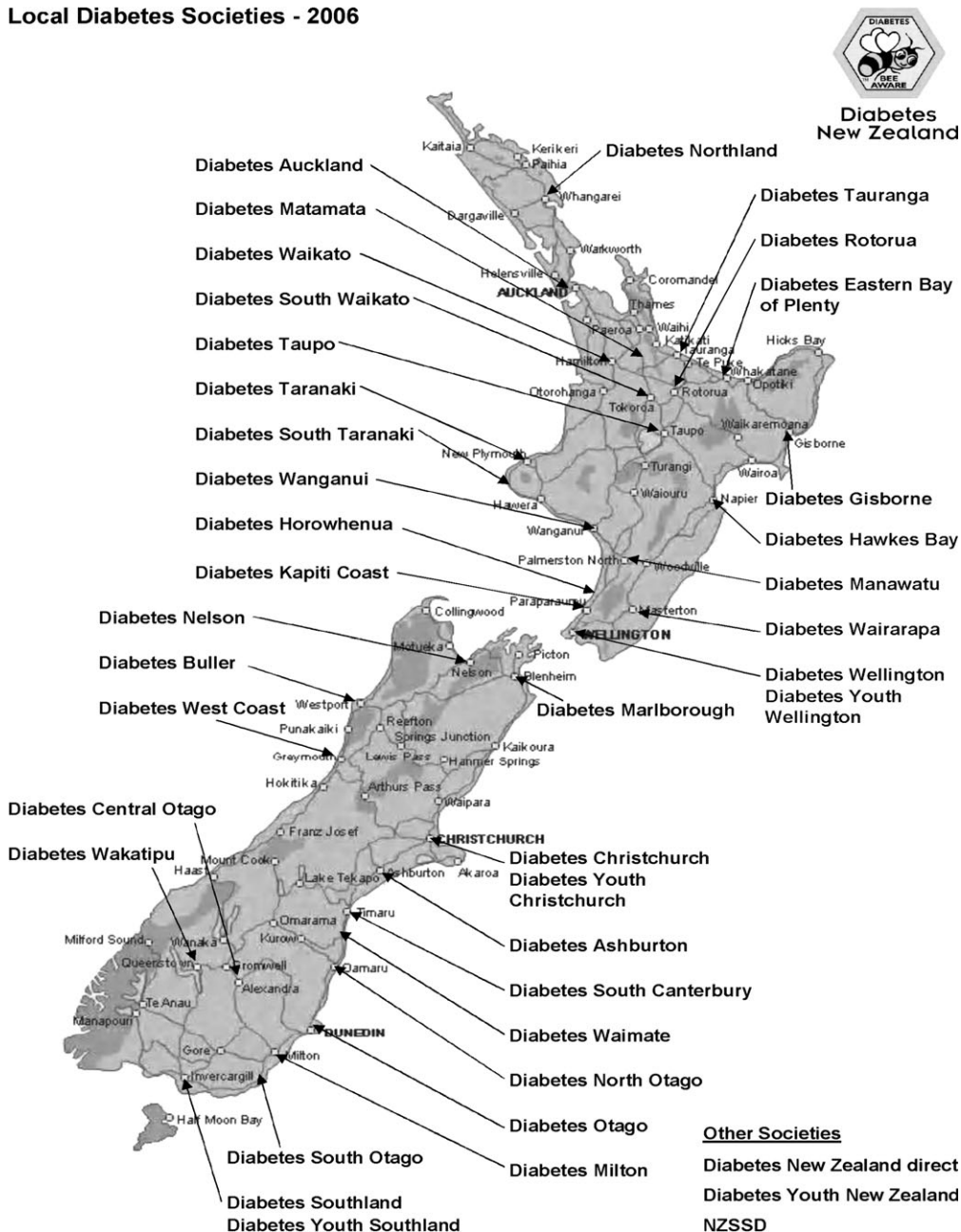


FIGURE 1 Distribution of DNZ Societies 2006 (<http://www.diabetes.org.nz>; accessed on October 28, 2007)

TABLE 1 *Activities of Diabetes Auckland* (<http://www.diabetes.org.nz>; accessed on October 28, 2007)

Education and help
Introductory courses for newly diagnosed, supermarket tours, healthy eating advice and guidance, physical activity—keeping you fit, training courses for practice nurses.
Information
Dia-Log (quarterly magazine), website—see above, videos/books lending library, automatic membership of DNZ and receipt of quarterly magazine 'Diabetes'.
Support
Phone helpline open daily, information centre with flyers, pamphlets and other detailed information. Support groups across Greater Auckland, children's and teenager's camps, Silver Medal Club celebrating those 50 years on insulin.
Shop
Purchase of blood testing equipment and training help, recipe books, foot care, other diabetes supplies including food and treats, gift baskets (open weekdays 9–5 p.m., Saturdays 9–12 noon, except bank products holiday weekends).
Advocacy
Representing the interests of those with diabetes.
Other member privileges
Quarterly members' meetings with qualified speakers.

members participate at a national level, but no formal training is received.

While no quantitative evaluation of the clinical or psychological impact of DNZ has been undertaken, it is successful in terms of national advocacy, distribution of societies, survival and membership.² The majority of members have Type 2 diabetes, are of European descent, aged ≥ 60 years and are retired. Members are less likely to be in the top and bottom two deprivation deciles.² DNZ is a provider of education and information, although the GP and literature are seen as more important modes for education. Support, and potentially through this, 'better diabetes management', is seen as 'an integral part of the education'.³

Other diabetes patient organizations

Young people with diabetes (predominantly Type 1 diabetes) established their own national diabetes organization in 1995, although this became affiliated to DNZ in 2004. In 1995, in recognition of the increasing prevalence of diabetes among Maori and Pacific people, the New Zealand Ministry of Health funded DNZ to carry out consultation with Maori and Pacific people. Subsequent to this, Maori decided to establish their own national patient organization, Te Roopu Mate Huka o Aotearoa.⁴ A constitution and a number of branches existed, although the situation today is unclear. Pacific diabetes support groups do not have a national organization. DNZ Pacific Wellington was established in 2007 and has been accepted by the DNZ Board as a local society. No evaluation of these organizations has been known to be undertaken. While there may be other peer support groups unaffiliated with DNZ, there is no formal documentation regarding this.

SADC: lay community health workers

Auckland is New Zealand's most populous region. South Auckland is noted for its ethnic diversity, and of the 433 083 residents in 2006, 47.3% self-identified as European, 15.7% as Maori and 24.3% as Pacific.⁵ In the 1970s and 1980s, there were no Pacific or Maori diabetes educators in the area, despite the size of these communities and recognition that the patients' understanding and adherence were poor. As a result, an independent charitable trust was created to provide a lay community health worker (LCHW) service.

Initially, there were six women volunteers from the Maori and Pacific communities (Samoan, Tongan, Niuean and Cook Islands) employed as LCHWs in South Auckland.⁶ Women were chosen as Pacific men were thought not to approve of other men counselling women (Thornton A, unpublished data). Tables 2 and 3 show the characteristics required and training received. The women were based at a marae (a Maori meeting place) in Otara, a suburb with 95% non-European residents. The marae community also comprised Pacific families who belonged to a church sharing the same site. The six LCHWs were trained by a diabetes specialist nurse and medical staff and supervised by two nurses. Patients were referred from primary and secondary care. Self-referrals also occurred. The LCHWs provided both education and counselling for the patient and their families at the marae, at home, within the hospital diabetes in pregnancy clinic and elsewhere.

By 1988, there were 7900 patient contacts each year. These were reported to be associated with increased knowledge and acceptance of diabetes, turnaround of patients resistant to management, increased community awareness of the risk from diabetes and heightened sensitivity of medical and nursing staff in primary and secondary care to ethnicity and the difficulties of life with diabetes.⁶ A 1990/1991 study comparing LCHW services, specialist services and general practice demonstrated that diabetes knowledge was generally low, particularly among Pacific people with diabetes.⁷ It was appreciated that no comparison of, e.g. glycaemia or knowledge was possible as those attending the service were also seen by other health professionals. However, the study did show that the LCHW service monitored 26% of Pacific people and was the preferred venue for diabetes education among 55% Pacific people and 41% Maori (particularly in group sessions).⁸

The service moved to a community house to increase access to patients and in the mid-1990s was absorbed into the hospital diabetes service. LCHWs largely moved into primary care as Maori and Pacific Diabetes Nurse Educators were employed within the specialist diabetes service.

TABLE 2 Components of selection and management process for community health workers in Diabetes (lay people undertaking educate/support in diabetes prevention/patient care)

Component	Whai ora marae/ SADC training ^a	SADP	Te Wai o Rona: Diabetes Prevention Strategy
Selection	People orientation	Previously long-term unemployed (22+ weeks)	Working with/within Maori community
	Fluency in own language and English	Literate but minimal qualifications	Depended on Maori Health Provider management: most respected within the Maori community, many already MCHWs
	Able to work as team member	Non-English Language skills an asset	
	Interest in learning and self-growth	Preferably with diabetes or diabetes close family member	
Training objectives (at the end of the training will be able to)	Accountability Female	From local community	
	Show accurate in-depth knowledge of diabetes/complications, how it affects health/lifestyle, methods to prevent complications	Provide culturally appropriate diabetes education in the community especially in the group/family setting.	Provide culturally appropriate 1:1 education relating to nutrition, physical activity and diabetes prevention including weight management in an allocated local caseload.
	Work autonomously but accountable work habits	Serve as link workers between the medical/nursing workforce and their Maori/Pacific patients, families and communities.	Undertake diabetes screening, anthropometric measurements as part of a wider team
	Show sensitivity to other ethnic groups	Be prepared for future employment in diabetes, other health and non-health sectors	Facilitate group, family and community interventions
	Work in a team	Influence their families and co-workers with choosing a healthy lifestyle. Increase employment opportunities for those with diabetes.	Understand food and physical activity venue access in their area Be able to use strategy tools (educational materials, desk file, PDA)
Training time (hours)	2 weeks (70 hours) initially 2 weeks (70 hours) close supervision	22 weeks full time including community placements	104–114 hours in class 12 days (community)
Training location	Community-in-service	Polytechnic	Hospital/community
Training funding	Service	Service/research/employment	Service/research
Report to	Diabetes specialist nurse	Diabetes doctor or specialist nurse	Matrix management—mainly to service manager

^aThornton A, personal communication.

The SADP

Background

The SADP ran between 1991 and 1998 as a research programme linked with community action and service development. It developed from a house-to-house census and survey of known diabetes among 100 000 residents (91% response) in inner urban South Auckland.⁹ Besides demographic and clinical data, information was gathered relating to barriers to diabetes care¹⁰ and possible community venues for intervention. The survey was undertaken by specifically trained local long-term unemployed people with cultural and community knowledge, networks and shared languages. The community venues identified were prioritized for a primary prevention programme, with the intervention provided largely through community diabetes educators (CDEs).^{11,12} These venues were also often the

site of new diabetes support groups run largely by those with diabetes. The impact of the household survey itself was assessed after 2.4 ± 0.9 years in a survey of 1644 randomly selected participants.¹³ Those who recalled the survey (versus those who did not) were 12.71(5.75–28.11)-fold more likely to have changed their lifestyle and 10.09(4.94–20.64)-fold more likely to have changed their perspective of diabetes. The survey experience involved a face-to-face explanation of the purpose of the survey and collection of census information. Specific factors influencing the lifestyle changes and revised perspectives were not enumerated.

A rural programme was also commenced and included various surveys^{14,15} and the formation of support groups.

The work of SADP led to a local plan,¹⁶ a range of service developments for those with diabetes, the development of a district-wide diabetes control

TABLE 3 Components of training for community health workers in diabetes (lay people undertaking educate/support in diabetes prevention/patient care)

Whai ora marae/SADC training ^a	SADP	Te Wai o Rona: Diabetes Prevention Strategy
Orientation to the service	Diabetes theory and practical skills: Pathophysiology and classification Treatment including medication Emergencies and sick day planning Complications and their prevention Monitoring diabetes including glucose monitoring Diabetes in pregnancy Group and 1:1 education methods Prevention of Type 2 diabetes Diabetes resources	Nutrition Physical activity Psychology
Observation of on site, group education and house visits	Anatomy and physiology	Anatomy and physiology
Provision of back ground materials	Nutrition	Other health issues
Experience finger prick testing, blood pressure measurement and weight	Communication skills Written Oral Written and oral interview skills	Diabetes/epidemiology Screening principles Screening/measurements
How to do self-blood glucose monitoring using metre and home practice	Community work experience: private homes, factories, schools, marae, hospital obstetric clinic, church	Te Wai o Rona: Diabetes Prevention Strategy and its tools including educational materials, desk file and palmtop/programme
Letter writing to patients and GPs	Cultural awareness	Maori culture/Maori health
Case study	Adult learning theory	Professional behaviour
Formal teaching	Class/group problem solving time	Assignment allocation/quiz
Food		Review, evaluation (reflective learning)
Exercise		
Treatment	Community health issues: asthma, child health, sexually transmitted diseases and mental health Future focus: employment skills Computer skills First aid	Motivational interviews Role playing Groups First Aid Community experience

^aThornton A, personal communication.

programme ('Let's Beat Diabetes': <http://www.letsbeatdiabetes.org.nz>) and transition to the Diabetes Projects Trust (<http://www.dpt.org.nz>), which continues to deliver many of the service-related functions in the community.

Barriers to care framework

More than 1800 people with diabetes were interviewed in the household survey about barriers to diabetes self-care, with responses mapped to a framework developed from in-depth interviews with 50 people with diabetes and their carers.¹⁰ Key barriers to care relate not only to education and knowledge but also to the need for support and addressing psychosocial and psychological barriers to care (Fig. 2). A range of interventions was subsequently developed to address some barriers.

CDE course for the unemployed¹⁷

In 1992/1993, some field workers who implemented the household survey opted to train as CDE. Selection, training outcomes, management structure and

course content are shown in Tables 2 and 3. In all, 31 students (9 male and 22 female) commenced the courses including 7 (23%) Maori, 15 (48%) Pacifica, 8 (26%) Europeans and 1 (3%) South Asian. Age ranged from 18 to 53 years (average 34 ± 15 years). Most students lived within 15 km of the polytechnic. In all, 8 (26%) of the 31 students had known diabetes (4 insulin treated). Learning was participatory, visual and practical. Service and community visits were mandatory. All participants who completed the course received educator certificates and certificates in first-aid and food hygiene.

Assessment of CDE trainee presentations among 265 community participants showed that the CDE were able to present on diabetes prevention in an understandable, well presented, interesting and culturally sensitive manner, were able to answer questions and were considered friendly and helpful.¹⁷ A more formal (controlled) assessment was undertaken among hospital ancillary staff¹⁸ who attended a session conducted in groups of 5–15 by 2–3. The presentations lasted approximately 1 hour, with the CDEs utilizing their

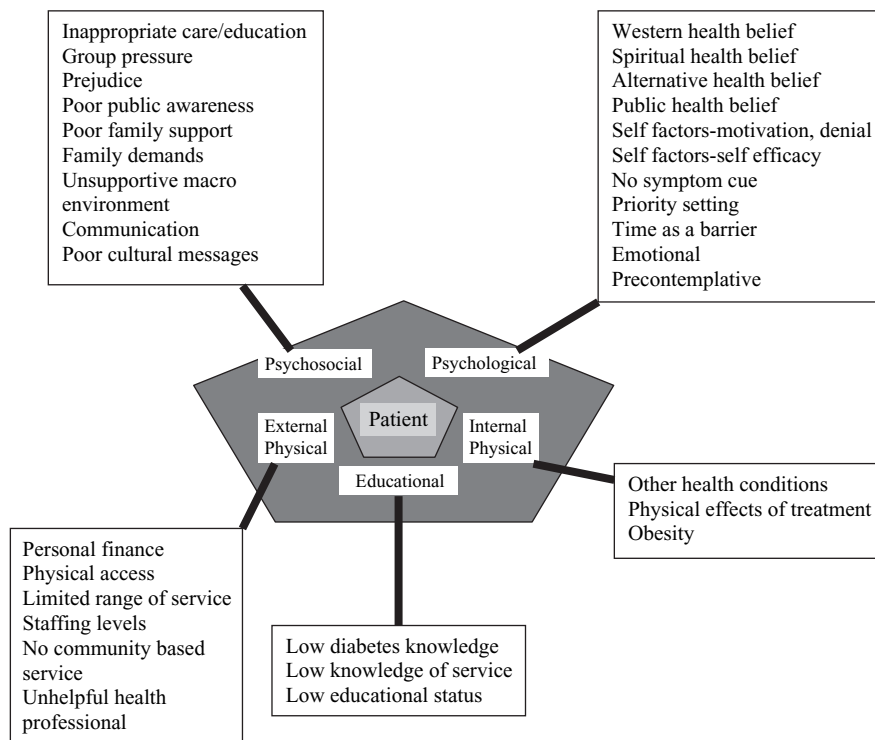


FIGURE 2 Barriers to diabetes care framework¹⁰

personally designed and illustrated flip charts and a video.¹⁹ A diabetes knowledge score assessed before and 6 months after the presentations increased from 26% to 35%. There was no change in knowledge of the control group ($P < 0.001$).

Subsequently trained CDE were either employed by the diabetes services, by the SADP, employment elsewhere or went on to further training (e.g. to become nurses).

CDE and the primary prevention programme

The SADP diabetes prevention activities included church and marae-based education supported by community action in Pacific and Maori communities, respectively. Actions included community organization-wide screening for diabetes, group education sessions, facilitated exercise sessions, with the programme order and process decided by a committee from within the community. The CDE served as link workers, delivered the education, led the exercise groups, with varying success organized other community members to lead exercise sessions and generally stimulated the community to participate and organize their own additional activities (e.g. a health expo on a marae,¹² purchase of exercise equipment by a church.¹¹ Comparison of the lead pilot Pacific church with a matched control church showed gains over 2 years in the lead church in uptake of physical activity and healthy

eating, prevention of weight gain and a shift to the action phase within the transtheoretical model.²⁰ Another, larger pilot church, did not achieve such health gains: the link worker there was not a CDE, the church was significantly larger and other differences existed.¹¹

CDE and the follow-up of those defaulting from diabetes clinics

A short project for three CDE was undertaken to assess whether home visits to Pacific patients who had defaulted from the diabetes services would be useful in identifying the reasons for default and to persuade the defaulters to attend. Over a 6-month period, 146 patients who had defaulted for at least 3 months were contacted by letter and 113 (77%) agreed to the educator visiting their home. It was found that most (66%) required a second visit to obtain the agreement to attend the service and make an appointment. Time per visit ranged from 15 to 150 minutes, excluding travel. Supervision during the pilot was by the diabetes specialist. The main reasons for default included transport, language, appointment letters not being received, fear, expectations of long wait times, work commitments, childcare, forgetting the appointment, wet weather and illness. Three patients had died, and a number had already been seen between the default being registered and the visit.

Diabetes support groups

At the time the SADP was established, there were no branches of the Auckland Diabetes Society (later Diabetes Auckland) in South Auckland, even though the area was one-third of the region. In response to requests for support groups from patients and the identified need from the house-to-house survey, the SADP began to stimulate the establishment of support groups. Ten support groups were built upon the framework developed from the Coventry Diabetes Asian Support Group in Coventry,²¹ which had demonstrated knowledge and glycaemia benefits among the South Asian attendees. They included two marae-based groups (one urban and one rural) with predominantly Maori memberships, three groups that met in urban Samoan/Tongan churches, a Samoan language group that met in an urban community centre, an urban mixed ethnic group that met in school community education facility and three rural groups comprising European and Maori memberships that met in community halls. All the urban and two of the rural groups were in suburbs/towns characterized by socioeconomic deprivation.

Most of the groups were developed in association with the diabetes prevention and rural programmes.^{11,12} Groups were nurse led, with interpreter assistance and were learner centred. Evaluation was through a general inductive approach using observation and interviews. A major challenge for membership stemmed from the asymptomatic nature of diabetes. Socioeconomically disadvantaged people had other more immediate priorities than worrying about possible complications from their diabetes in the future. Other significant challenges were around group self-determination and creating a context-specific balance between experiential knowledge of group members and the professional knowledge of the nurse leader.

Whangaroa Club

Patients in a rural community in Northland, working closely with the local GP established a 'club' for patients.²² The club involved weekly morning meetings including exercise, shared morning tea and lunch and open to family members (in recognition of diabetes as a family 'problem'). Patients governed the club, which originally emerged from a community consultation. The club met in a villa in the hospital grounds, with sufficient space for there to be side rooms to meet doctor, educator, dietician, podiatrist and/or retinal photographer. Consultations were conducted privately or as a group. Audit and benchmarking was provided by the SADP.²³

Te Wai o Rona: Diabetes Prevention Strategy

Te Wai o Rona: Diabetes Prevention Strategy was an Australasian Controlled Trials Registry registered

(ACTRN012605000622606), randomized cluster, controlled, participatory research trial established to demonstrate the efficacy of a combined intervention to prevent Type 2 diabetes among Maori families in New Zealand. The interventions were to include (i) Maori Community Health Worker (MCHW) coaching and support (ii) group activities with MCHW and other peer-to-peer support (iii) community action and (iv) enhancement of local access to healthy food and physical activity venues.²⁴ Educational materials, a desk file with detailed guidance on activities and training materials and a Personal Digital Assistant (PDA) with a novel program were developed and piloted. The pilot of the MCHW intervention was associated with significant weight loss, particularly among those with impaired glucose tolerance/impaired fasting glucose.²⁴ The Strategy was not funded after the first 3 years. The selection, management process and initial training for the MCHWs are shown in Tables 2 and 3. Of particular importance was the matrix management which involved District Health Board (DHB) funding with DHB monitoring and direction to 11 pre-existing Maori Health Providers who then managed the MCHW programme. The Strategy team had limited influence over this framework, but had responsibility for content development, dissemination and training. In future, shared responsibility would be more effective.

Discussion

From the 1960s, New Zealand has developed a range of peer-to-peer interventions for diabetes including support for people with diabetes, their families and prevention of diabetes through lifestyle change.

The more traditional support group approaches for those with existing diabetes, run by the national patient organization, DNZ, have been supplemented by additional groups for youth, Maori and Pacific people. While no studies have investigated the clinical impact of support groups in New Zealand, their continued survival suggests that some patients benefit. The roles of such groups are complex and variable, but the broad themes that emerged from the evaluation of the South Auckland groups are likely to apply in others settings.

The second set of peer-to-peer intervention involved recruiting lay people, with preference for those with diabetes, to provide education and support for those with diabetes or at risk of diabetes. The evidence for effectiveness for primary prevention remains reasonable, although the randomized trial testing of this in a robust manner was not continued for funding reasons. Use of lay educators in the diabetes service setting for those with diabetes continued for many years until nurses from non-European ethnic groups

were able to take over the education functions. Addressing the needs of specific ethnic groups and relatively deprived communities is important as the prevalence of diabetes and other chronic conditions continues to increase²⁵ in these populations.

The various Funding and Management systems clearly made the ongoing use of lay educators difficult, although a small number remain in niche areas. In some locations, diabetes specialist nurses were very supportive of lay educators, while in others, were involved in their replacement by other nurses. Management of lay educators is a key theme in all the experiences described. The need for clinical governance over the education role emphasizes the importance of having line management through an individual with clinical knowledge. Whether such line management is required in the 'support' role remains a point for discussion. From our experience, differentiation between the motivational support role, advisory role to assist them in navigating complex health systems and educational role needs to be clear.

We place the peer-to-peer support role within strategies to overcome motivational, self-efficacy and other psychological barriers to diabetes self-care within our overarching model.¹⁰ Such barriers are common²⁶ and perceptions of barriers are often discordant between patients and health professionals.²⁷ It is in this setting that peer-to-peer support may be able to provide the psychological support that can assist patients to overcome some of their fears and perceptions. If the lay educator also has accurate knowledge and can deliver this concurrently, there may be additional benefits in patient self-care and possibly clinical outcomes. This clearly needs to be tested in different settings.

In conclusion, while peer-to-peer interventions have been widely used in New Zealand, are in demand by patients and appear to be of quantitative benefit in primary prevention, further work is required to demonstrate efficacy. Such efficacy would need to be considered not only in terms of immediate clinical outcomes but also the longer term benefits of reducing barriers to self-care and improving quality of life.

Declaration

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Ethical approval: All the studies were approved by their respective local ethics committees.

Conflicts of interest: None.

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