

‘Help, educate, encourage?’: Geographical variations in the provision and utilisation of diabetes education in New Zealand

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Abstract

In New Zealand, as elsewhere, it is argued that a diabetes epidemic is underway. With careful management from individuals and professionals and appropriate levels of education, it is possible to prevent many complications of diabetes. The overall objective of the paper is to evaluate the role and impact of Diabetes New Zealand (DNZ), the key voluntary sector provider of diabetes education and support services, with respect to four criteria: (i) the extent to which DNZ is reaching groups most at risk of diabetes; (ii) the degree to which it has encouraged levels of member involvement; (iii) whether voluntary group provision of education is that most preferred by members; and (iv) the extent to which members see the voluntary sector model as being effective in combating the growth of diabetes. A survey of members of six of the 41 affiliated societies of DNZ suggests that such organisations, although having a high proportion of older members, have generally failed to target more deprived groups. While the societies generally score more positively in encouraging member involvement and being perceived as effective by their members, they do not always utilise the preferred form of educational provision. However, there are significant contextual variations by urban–rural location and according to the organisational structure of the societies. Rural societies and those with decentralised organisational structures generally score highest on the above criteria.

The results pose a problem for DNZ which, like many other voluntary sector organisations, is facing pressures of increased corporatisation and centralisation. We see this as an important challenge that DNZ needs to address if New Zealand is going to better cope with the emerging diabetes epidemic.

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Introduction

The growing prevalence of Type 2 diabetes (World Health Organisation, 2002) is placing health services under considerable strain. In New Zealand, for instance, the crude prevalence rate of 4.1% people affected by Type 2 diabetes places the

country in the top quintile on a global basis (Moore & Lunt, 2000; Rayner, Petersen, Buckley, & Press, 2001). The growing ‘diabetes epidemic’ has resulted in an overloading of hospital services, which in turn has prompted an increased devolution of diabetes care from secondary to primary settings together with a variety of innovative community approaches aimed at reducing the risk factors associated with the disease (Simmons & Voyle, 2003). While complications associated with diabetes can be life threatening, with careful management from

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individuals and health professionals, it is possible for them to be prevented and their impact reduced (Tilly, Belton, & McLachlan, 1995). Therefore, an important component of the diabetes management strategies adopted in New Zealand, along with many other countries, has been a focus upon improving the quality and access to primary health care and diabetes education among people with the condition.

Despite the increasing significance of diabetes as a public health concern, geographers have paid little attention to this emerging chronic health condition. This is surprising because of the importance of migration and acculturation in the development of the disease (Foliaki & Pearce, 2003), contextual differences in its treatment (Brown & Barnett, 1992) and the close links between the 'greying' of western societies and the emergence of this new critical health burden. Recently, attention has also begun to focus on the ecological determinants of obesity as key causes of diabetes with specific reference to the effects of urban sprawl and car dependence (Vandegrift & Yoked, 2004) or neighbourhood variations in the availability of healthy food (Reidpath, Burns, Garrard, Mahoney, & Townsend, 2002) on increased obesity rates. Although public health issues have not been ignored in the 'new' geography of health (Elliott, Jolin, & Walker, 2000; MacKian, Elliott, Busby, & Popay, 2003), with the exception of work on diabetes-related hospitalisation (Brown & Barnett, 1992) and rural–urban variations in the incidence of diabetes (Ryttonen et al., 2003), key issues relating to variations in incidence, problems of access to services and perceptions of diabetes as a disease condition have largely been the domain of other social sciences.

In view of this lack of attention, this paper explores the success of community diabetes education programmes in reaching at-risk groups in New Zealand. In New Zealand, the voluntary non-profit organisation Diabetes New Zealand (DNZ), and its 41 affiliated societies, has played an important role within the network of diabetes care and educational providers. It is the primary provider of educational resources, advice and support for many people with diabetes and, given its focus on health promotion, is an important advocacy organisation. Despite the importance of the local societies in delivering diabetes care and education and promoting a greater awareness of the risks of diabetes, there has been little research on the success of DNZ in terms of reaching at-risk populations. Given that

similar community-based health organisations have been active in many other national contexts (Liburd & Vinicor 2003; Staudt & Homedes, 2004; Taylor, 2000), an evaluation of DNZ is overdue especially given that the New Zealand Ministry of Health, as part of the New Zealand Health Strategy, has targeted diabetes as one of the 13 major health priorities (Ministry of Health, 2003).

The paper is informed especially by three sets of literatures; those relating to geographies of voluntarism, community development and social capital, and research on health promotion. First, with respect to the former, while a number of studies have indicated a discordance between the spatial distribution of voluntary sector resources and welfare needs (Bryson, McGuinness, & Ford, 2002; Mohan & Gorsky, 2001; Wolch & Geiger, 1983), little attention has been devoted to the extent to which health non-governmental organisations (NGOs) are actually utilised by deprived populations (Fyfe & Milligan, 2003a, b). Moreover, relatively few studies (Milligan, 1998, 2001; Milligan & Fyfe, 2004; Prime, Zimmeck, & Zurawan, 2002; Wardell et al., 2000) have examined geographical variations in service provision by voluntary organisations, especially between urban and rural areas. Thus, as Fyfe and Milligan (2003b) have argued, it is important to recognise that voluntary sector involvement may have quite different consequences in urban and rural environments and that it is important for policy makers to recognise that what works in one place may not necessarily work in others.

Second, much the same can be said about the role of social capital. Again, as Greiner, Li, Kawachi, Hunt, and Ahluwalia (2004) indicate, relatively few studies have examined interactions between the importance of social capital in affecting health and the use of health organisations and other community characteristics such as rurality. Two issues are important here. The first, is the increasing corporatisation of NGOs. Many voluntary agencies, especially the larger urban-based ones who are more likely to be dependent upon state sources of finance (Barnett & Barnett, 2006), have adopted a corporatist stance which is different from traditional grass-roots organisations emphasising local participation and citizenship (Mohan & Mohan, 2002). While such organisational changes are now well known (Owen, 2005), less evident is the effect of the growth of more bureaucratic organisational structures on the provision and use of the services

provided by such organisations. A second issue relates to the effects of social capital. While a considerable literature on social capital has stressed its beneficial effect on health via a number of different mechanisms (e.g. see Greiner et al., 2004), what is less clear are the downsides of social capital (Hawe & Shiell, 2000; Portes, 1998). For example, while social mechanisms, such as collective socialisation, realising shared goals through collective action, or transmitting health promotion messages more effectively through community organisations, may all be health promoting, they can also be highly exclusionary (Fukuyama, 1999; Staudt & Homedes, 2004). This will be the case if existing community organisations favour more powerful and articulate groups who already enjoy a greater capacity to engage with community development initiatives (Portes & Landolt, 1996; Shucksmith, 2000). We see such questions as important especially given the recent resurgence of interest in geographies of organisations (Del Casino, Grimes, Hanna, & Jones, 2000) and the need to evaluate the extent to which health NGOs are reaching socially deprived groups.

Third, the study is informed by recent work on health promotion. In many countries public health approaches have attempted to improve population health by refocusing health care systems to target preventive strategies and health promoting activity (Beaglehole & Bonita, 1997). While many studies have indicated that socio-economically disadvantaged persons appear to be slower to respond to such initiatives and engage in behavioural change (Gough & Conner, 2006; Honjo, Tsutsumi, Kawachi, & Kawakami, 2006; Melia, Harland, Moss, Eiser, & Pendry, 2000), what is less clear is whether health promotion strategies may be more effective in reaching disadvantaged groups in certain locations or organisational contexts.

In the light of the above questions, the objective of this paper is to evaluate the success of DNZ with respect to four criteria; (i) the extent to which DNZ is reaching groups most at risk of diabetes; (ii) the degree to which it has encouraged levels of member involvement; (iii) whether voluntary group provision of education is that most preferred by local society members; and (iv) the extent to which members see the voluntary sector model as being effective in combating the growth of diabetes. In addition, given evidence that both organisational structure and local context are important in influencing the development of voluntary organisa-

tions (Fyfe & Milligan, 2003b), we examine the extent to which the activities of DNZ with respect to each of the above criteria vary both by urban–rural location and organisational type.

To achieve these objectives, the rest of the paper is organised as follows. First, we briefly explore global responses to the diabetes epidemic and pay particular attention to the importance and limitations of diabetes educational strategies. Second, we then provide a background to diabetes in New Zealand by reviewing the socio-economic context of diabetes before describing the development of educational strategies adopted by DNZ. Third, we outline the methodology and results of our study. Finally, we conclude by first summarising the results and then discussing the theoretical and policy implications of our findings.

Barriers to diabetes education

The global growth in diabetes rates has resulted in health education programmes becoming an integral component of health promotion policies in many countries. The onus of health education within a New Public Health framework (MacKian et al., 2003) is to increase knowledge and empower people so that they can make informed decisions about their health issues (Bunton & Macdonald, 2002). Currently diabetes-related public health strategies have two aims; (i) to create an awareness of the key risk factors that are likely to lead to the development of diabetes and (ii) to provide education targeted at newly diagnosed patients with diabetes in order to help them better understand and manage their condition (Brown et al., 2002). Although risk factors such as obesity, unhealthy diets and physical inactivity, are reasonably well understood, the prevention and control of diabetes is far from straightforward due to the presence of a large number of barriers which serve to limit participation in educational programmes (Engelgau, Venkat Narayan, Saaddine, & Vinicor, 2003).

A large number of people with diabetes remain undiagnosed and even for those who are diagnosed there is a lack of awareness of diabetes and its potential complications (Simmons, Shaw, Kenealy, Scott, & Scragg, 1994). Patients diagnosed with diabetes are also often unaware both of the symptoms of diabetes and of the existence of diabetes educational programmes (Graziani, Rosenthal, & Diamond, 1999). In the past this has also been true of patients' own doctors (Lawton, Peel,

Parry, Araoz, & Douglas, 2005; Pricewaterhouse Coopers, 2001) and, in New Zealand, only recently have general practitioners (GPs) become more confident in dealing with the condition (Kenealy et al., 2002). Such gaps in awareness are problematic given that there is a wealth of information from international studies which suggests that 20 hours or more of diabetes education is needed in the 1st year of diagnosis. Diabetes education programmes have a significant impact in promoting long-term benefits in self-care, glycemic control and health status (Tilly et al., 1995) and appear to be most effective when they contain a strong element of social support (Gilden, Hendryx, Clar, Casia, & Singh, 1992; Norris, Nichols, Caspersen, & Glasgow, 2002).

In addition to the lack of public awareness of appropriate health information, research has indicated a wide variety of barriers in terms of accessing diabetes services. These barriers restrict access to services that would otherwise lead to increased diagnoses and delay complications that may arise. They also limit the extent to which patients can be involved in educational programmes and their ability to undertake self-management once diabetes has been diagnosed (Graziani et al., 1999). While it is beyond the scope of this paper to review all the factors which have limited participation in diabetes educational programmes, recent reviews (e.g. Brown et al., 2002; Zgibor & Songer, 2001) have indicated that the following barriers are significant; (i) psychological barriers including health beliefs and motivation to seek care; (ii) internal physical barriers, such as other health conditions, which may limit involvement in educational programmes; (iii) external physical barriers including problems of cost or access to services or (iv) psycho-social barriers involving issues of social capital such as a lack of family support or group pressure from others not to adhere to professional advice.

Research in the USA (Graziani et al., 1999) and UK (Lawton et al., 2005) has shown that two of the most frequently cited reasons for non-attendance in educational programmes are the low perceived seriousness of (Type 2) diabetes and the fear and denial of the condition. While lack of acceptance of diabetes as a chronic illness may be related to a reluctance to make significant lifestyle modifications (Brown et al., 2002), it is also related to the type of interaction that patients have with the health care system and the nature of the care they receive. Provider attitudes, level of competence, along with

the place of treatment all may affect whether patients interpret their condition as potentially serious or not (Lawton et al., 2005). Fear and denial of diabetes and issues of stigma may also be important in terms of whether or not people seek care (Broom & Whittaker, 2004).

While patient perceptions of the seriousness of their condition or a denial of that condition may affect levels of participation in diabetes education, other research has shown that structural barriers are also important. These include problems of physical access, time constraints or the costs of services (Simmons, Peng, Ara, & Gatlaand, 1999; Simmons et al., 1998). However, interestingly, while cost appears to be a minor factor influencing initial rates of participation in diabetes education, financial constraints are more likely to be important in whether patients are likely to adhere to recommended treatment programmes.

Diabetes in New Zealand

New Zealand is no exception to the global growth of diabetes as rates, especially of Type 2 diabetes, have risen consistently since the 1980s. From a basis of approximately 115,000 people diagnosed with diabetes in 2001, or a crude prevalence rate of 4.1% adult population, this figure is expected to rise by two-thirds by 2010 (Health Funding Authority, 2000). The financial costs of diabetes and its related complications are also predicted to rise in magnitude from 2–12 percent of national health expenditure in less than 20 years (Ministry of Health, 2002).

There are also important variations in diabetes rates between different social and ethnic groups. Rates of the disease are consistently higher for males than females and self-reported diabetes prevalence is twice as high in the most deprived communities in New Zealand compared to the least deprived. But it is among Maori and Pacific Islanders that the incidence of the disease is particularly strong with these two groups having a 2–4 fold excess prevalence compared to the European (Pakeha) population (Ministry of Health, 2003).

Given the rapid development of diabetes, a wide variety of stakeholders have become involved in the provision of diabetes services and education. Diabetes educators include; health professionals, most commonly GPs and practice nurses; diabetes specialists who are often located in hospital affiliated diabetes centres; voluntary sector agencies

catering for both the general population or selected ethnic groups; and dieticians either in private practice or part of local doctors' surgeries. In addition, public health agencies, while not directly involved in patient education, nevertheless play an important role in fostering diabetes awareness in the community. The importance of individual stakeholders has varied considerably over time. Prior to the establishment of DNZ in 1962, people with diabetes tended to rely on hospital outpatient departments, given the limited involvement of GPs in providing diabetes care. For those people admitted to hospital, patterns of care were very uneven with diabetes (public) hospital admission rates being more a function of the public bed supply than measures of population need such as ethnicity or age (Brown & Barnett, 1992).

DNZ is a nationwide non-government, non-profit organisation which aims to provide a 'positive, empowering and encouraging environment for those with diabetes and their families' (Diabetes New Zealand, 2003a). DNZ and the local societies are significant advocates on diabetes issues but are also the primary providers of educational resources for the prevention and management of diabetes in New Zealand (Diabetes New Zealand, 2005a). The societies also provide a network of support for people with diabetes to discuss their condition and to improve patient learning. Thus, as therapeutic organisations (Gesler, 1992), the prime focus of the societies is threefold: to encourage involvement in the Society by people with diabetes, to provide local educational classes for diabetes management and social support, and to play a local advocacy role in health promotion by increasing awareness of the risks of diabetes.

The establishment of DNZ occurred largely because of significant concerns about the very limited amount of diabetes education provided by GPs for their patients. The inception of DNZ also occurred at a time when there was a lack of state intervention and acknowledgement of diabetes. Despite difficulties in securing funding, DNZ nevertheless has evolved from an initial base of seven societies with 750 members in 1962, to a network of 41 societies with 13,500 members in 2004. Between 2001 and 2004 all but six societies increased their membership base. The growth in membership has not only been encouraged because of the increased advocacy role of DNZ but also because only a small annual fee of between \$20 and \$35 is charged annually for membership to a local society (Dia-

betes New Zealand, 2005a). While the head office of DNZ is, like many other health NGOs, highly reliant on government (Ministry of Health) contracts for most (59%) of its income, the various local societies are independent of the national body and raise funds themselves (Diabetes New Zealand, 2003b).

Today DNZ and its 41 affiliated societies are one of the most important components of the network of diabetes care and educational providers within the country. At a national level, DNZ interacts with the Ministry of Health, the New Zealand Society for the Study of Diabetes, and the National Diabetes Forum among others (Fig. 1). Regional representatives liaise with the DNZ council and executive, subsequently coordinating national matters with the local societies in their specific region. This is a two-way relationship, as individual societies can also use their regional representation to voice their concerns at the national level. The individual societies then work within their communities, and the network of diabetes care and educational providers, advocating on issues that affect people with diabetes. Each of the societies employ paid managers but also rely on a large number of voluntary workers (Price Waterhouse Coopers, 2001). DNZ is like many other voluntary organisations with a federal type structure. While the centre provides guidance and advice, the local branches are relatively autonomous with respect to the policies and programmes they pursue. Therefore, the local societies are likely to vary in their role and operation within the network of diabetes care and educational providers. Given the importance of DNZ as a provider of diabetes care, this paper evaluates the extent to which the Society



Fig. 1. The structure of diabetes New Zealand.

Table 1
Society types and survey response rates

Society	Society type	Number of members 2003	Number of questionnaires sent	Number returned	Response rate (%)
Christchurch	Larger urban	904	200	114	57.0
Waikato ^a	Larger urban	500	200	90	45.0
Nelson	Smaller urban	200	100	47	47.0
Gisborne	Smaller urban	78	78	34	43.6
Buller	Rural	83	83	34	41.0
South Waikato	Rural	46	46	16	34.8
Total			707	335	47.4

^aBased in the city of Hamilton.

has been successful in reaching the key at-risk groups in New Zealand. Further, the research will consider the extent to which the societies successfully engage with their members, as well as the satisfaction of the members with their society in terms of managing their condition. Before turning to these issues we first briefly outline the methodology of the study.

Methods

To examine how the individual diabetes societies were structured and operated, phone interviews were conducted with each of the 41 society presidents. The interviews provided insights into how individual societies operated within the network of diabetes care and educational providers in New Zealand, along with contextual information on the size and structure of each society. Six societies were selected for further investigation (Table 1) using two main criteria. First, the societies were chosen to provide a mixture of urban and rural regions which is important given overseas evidence of urban/rural variations in the rates of diabetes (Rytkonen et al., 2003). Second, importance was placed upon the model of regional health care organisation adopted by the societies to provide a mixture of centralised and decentralised structures. The organisational structure of the health care system has been shown to influence a range of health outcomes including the extent to which people access local services and rates of diabetes hospitalisation (Brown & Barnett, 1992). The Christchurch and Hamilton (Waikato) Societies are both located within larger cities and had different modes of organisation. Christchurch has a more centralised organisational structure and distribution of members compared to Hamilton. In contrast to the Christchurch Society which is

administered from one office, the Hamilton Society occupies a number of different sites in the city and surrounding rural hinterland and thus, because of greater outreach, there is much more local involvement in the way the Society is organised and run. Two societies, Nelson and Gisborne, are located in smaller cities. The remaining two societies, Buller on the West Coast of the South Island and South Waikato in the North Island, were based in small towns and had a distinctly rural focus.

To achieve the objectives of the study the following methods were used. First, in order to determine who belongs to diabetes societies the addresses of all members were obtained from each of the six selected societies. These were geocoded to the appropriate census meshblock¹ in order to obtain deprivation profiles of the membership of each society using the New Zealand Deprivation Index (NZDep 2001). In addition, an ecological analysis was undertaken of the key predictors of the spatial distribution of membership of one local organisation, the Christchurch Diabetes Society. This was selected because the neighbourhood location of its 1200 members was able to be compared to the register of the diagnosed population with diabetes in Christchurch. The latter was obtained from Pegasus Health, an Independent Practitioner Organisation which represents approximately 95% of medical centres in the city. Pearson and partial correlations were calculated between the percentage of people on the Pegasus Health database who were members of the Christchurch Diabetes Society and seven socio-demographic indicators (which included three measures of ethnicity (the proportion of persons of Asian origin, %

¹Meshblocks are the smallest unit of dissemination of New Zealand census data, with each meshblock representing approximately 100–150 people.

Maori and Pacific Island descent, and % European (Pakeha)), the New Zealand deprivation index (NZDep01), along with the % persons aged over 50, cars per household and the distance of a Census Area Unit (CAU) from the central city site of the Christchurch Diabetes Society). The importance of different socio-demographic predictors of society membership was analysed using stepwise regression in SPSS. Statistical significance was assessed at the $p < 0.01$ level using a two-tailed test.

The remaining objectives were attained through a questionnaire ($n = 707$) which was distributed to members by the presidents of the six selected societies. It was piloted with 10 members of the Christchurch Diabetes Society who were selected randomly from the Society's database. In addition, local health professionals, diabetes specialists, diabetes educators and Maori and Pacific Island health providers and public health professionals were also consulted about content and format. Questionnaires were distributed to all members of the societies that had a small number of members and to approximately 25–50% of the members of the three largest societies. An overall response rate of 47.4% was obtained with slightly higher responses from the more urbanised societies (Table 1). The response rate was generally higher than that obtained in other studies of voluntary sector organisations and in part this was possibly because the questionnaires were distributed by the offices of the different societies. The response rates were generally similar for most of the societies, but why the Christchurch and South Waikato Societies had the highest and lowest rates is unknown.

The questionnaire aimed to elicit members' levels of involvement in their societies, their preferences for diabetes education and their perceptions of the effectiveness of their society in health promotion and in helping people to manage their diabetes. Levels of involvement were measured via three Likert scales which addressed members' degree of involvement, for example whether they attended meetings or helped in promotional activities like Diabetes Awareness Week, how often members used the services of their society and their satisfaction with the level of support they received from family and friends. The preferences of members as to whom should provide diabetes education were elicited by two questions relating to the type of provider members actually saw for most of their diabetes care, and secondly the type of provider they most preferred. Finally, with respect to the fourth

objective, perceptions of effectiveness were based on three specific questions; (i) the extent to which members thought their society was effective in health promotion activities to combat the growth of diabetes in their area; (ii) the extent to which members took advantage of the services (especially nutritional, diabetes management and exercise advice) provided by their society and; (iii) the level of social support (e.g. sharing information) and community outreach provided by members. The questionnaire data was analysed using χ^2 in SPSS to test for significant differences (at the $p < 0.01$ level) in responses between members of the various societies.

Results

Who belongs?

The most commonly represented groups in the six diabetes societies were New Zealand European (95.3%), females (57.5%), persons over 60 (76.4%) and especially over 70 years of age (45.9%). Maori and Pacific persons were under-represented in the membership of the six societies, making up just 2.8% of the total. While the predominance of older persons is not unexpected, given the tendency for diabetes rates to rapidly increase with age, the predominance of female society members is noteworthy given that males are more likely to develop diabetes (Ministry of Health, 2005). The under-representation of Maori and Pacific persons is even more noteworthy, especially given the fact that in Christchurch, for example, these groups comprised 8.2% of all persons diagnosed with diabetes, a proportion that rose to 29.7% in the most deprived decile (Table 2). For New Zealand as a whole people of Maori or Pacific Island origin were 2.2 times more likely to develop diabetes in 2003 than non-Maori/Pacific persons (Ministry of Health, 2005).

While no significant differences existed between the age profiles of the six societies, this was not the case with respect to their deprivation profiles. Higher membership levels are found in the middle deciles and the lowest levels in the low and high deciles (Fig. 2). χ^2 tests indicated that there were significant differences between the deprivation profiles of the six societies ($\chi^2 = 195.3$; $p < 0.001$) especially between the urban and rural societies ($\chi^2 = 115.3$; $p < 0.001$), but also between the two metropolitan societies with different modes of

Table 2

Percentage of the adult population diagnosed with diabetes, by ethnic origin, and Christchurch Diabetes Centre members as % diagnosed persons with diabetes by deprivation decile

NZDep01 Decile	Pegasus Health		% persons diagnosed of Maori & Pacific Island origin	Christchurch Diabetes Society	
	Number of persons diagnosed with diabetes	% adult population		Number of Diabetes Society members	Diabetes Society members % persons diagnosed with diabetes
1 Low deprivation	471	1.7	0.8	90	19.1
2	492	2.1	3.7	96	19.5
3	678	2.4	3.2	118	17.4
4	693	2.4	4.2	136	19.6
5	652	2.5	6.0	102	15.6
6	738	2.5	4.7	123	16.7
7	625	2.8	7.8	82	13.1
8	763	2.7	13.8	100	13.1
9	582	2.6	17.5	69	11.9
10 High deprivation	384	3.2	29.7	27	7.6
Christchurch	6048	2.4	8.2	943	15.6

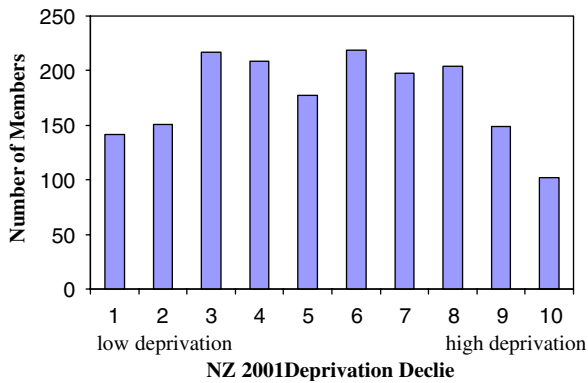


Fig. 2. The membership of the six diabetes societies in deprivation deciles.

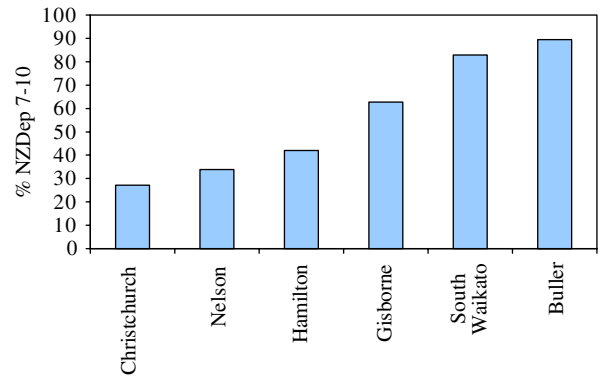


Fig. 3. % diabetes society members living in areas of higher deprivation.

organisation ($\chi^2 = 51.5; p < 0.001$). While three of the four urban societies (Christchurch, Hamilton and Nelson) had a membership profile which reflected members living predominantly in areas of middle and low deprivation, the reverse was true of Gisborne and the two rural societies, where most members lived in areas of higher deprivation (Fig. 3).

Similarly when the two metropolitan societies, with different forms of organisation were compared, it is evident that the more centralised society (Christchurch) had a more middle class membership (Fig. 4) than that of Hamilton. Here, although there were a large number of members from more affluent areas, this was counterbalanced by increasing numbers of members as deprivation levels increased

(Fig. 4). The middle class focus, particularly of the larger urban societies, is evident in a more detailed analysis of CAU variations in membership rates of the Christchurch Diabetes Society. While the correlations are not high, it comes as no surprise that more deprived CAUs, especially those with larger Maori and Pacific Island populations, had lower rates of membership (Table 3). The inverse relationship persists between ethnicity and membership rates after controlling for deprivation (partial $r = -0.31; p < 0.01$) and deprivation, age and sex (partial $r = -0.33; p < 0.01$). When a stepwise regression analysis was undertaken, ethnicity was the only variable to enter the equation at the $p < 0.01$ level ($R^2 = 0.17$).

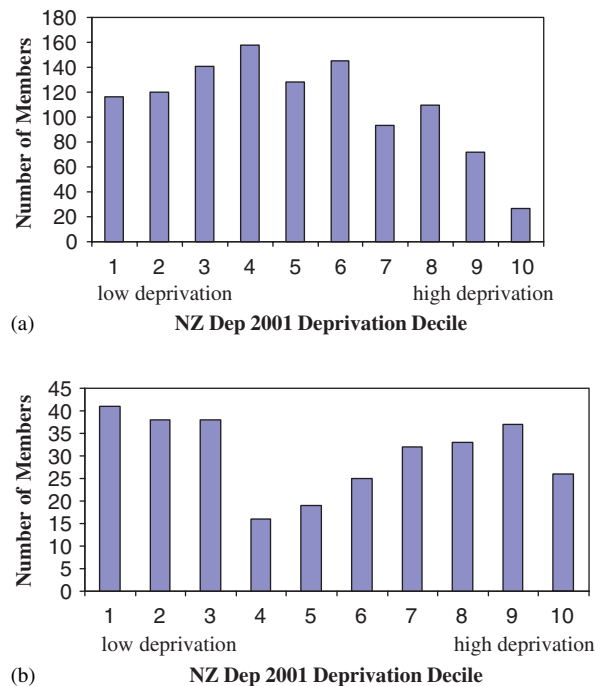


Fig. 4. The number of urban society members according to deprivation decile, Christchurch and Hamilton.

Table 3

Pearson and partial correlations between selected socio-economic characteristics and rates of membership of the Christchurch Diabetes Society 2003^a

	Pearson correlation	Controlling for age and sex	Controlling for age, sex and deprivation
% Asian	0.05	0.01	0.01
% European	0.06	-0.04	0.01
% Maori and Pacific Island persons	-0.41*	-0.33*	-0.33*
NZ Dep 2001	-0.29*	-0.14	—
Cars per household	0.20*	0.02	-0.25
% aged 50 and over	0.27*	—	—
Males/100 females	0.09	—	—
Distance to society premises	0.08	-0.08	-0.13

^aProportion of persons diagnosed with diabetes who were members of the Christchurch Diabetes Society.

* $p < 0.01$.

Levels of involvement in societies

Involvement with the diabetes society means attending meetings or assisting with the annual

Diabetes Week. Over half (55.3%) of the members from the six societies indicated that they were never involved with their local society. The levels of involvement for the remaining members ranged from being always involved (13.9%), sometimes involved (7.6%) and occasionally involved (23.2%).

However, while there was no significant association between age and gender and levels of involvement, there was with urban–rural location and organisational type. Members of the two rural societies displayed higher levels of involvement than their urban counterparts ($\chi^2 = 19.4$; $p < 0.001$). Members of rural societies also met more regularly and shared information with other people who had diabetes than urban members (50.0% and 31.6%, respectively) ($\chi^2 = 3.63$; $p < 0.05$). With respect to organisational structure, of the two metropolitan societies, Hamilton, with its more decentralised structure, had higher levels of involvement ($\chi^2 = 14.5$ $p < 0.01$) than Christchurch (13.8% versus 2.9%). Members of the Hamilton Society (28.4%) also met more regularly with other people who had diabetes than was true of Christchurch members (25.0%).

Preferences for diabetes education

As educational providers, the diabetes societies have an important role to play, but are not always the preferred source of education by their members. In this section the extent to which members preferred different sources of diabetes care are compared to the degree to which they actually used these sources for all or most of their care. While most members ‘strongly/usually’ preferred their GP or practice nurse as sources of education, the actual source of provision was often quite different. For example, while 87% of patients ‘strongly/usually’ preferred their GP as a provider of education, only just over 62% members received ‘almost all/quite a lot’ of their education from this source. Despite this trend more rural members ‘strongly/usually’ preferred their societies compared to their urban counterparts (62.5% versus 41.1%) as did members of the decentralised (Hamilton) Society compared to their Christchurch counterparts (53.8% versus 21.0%). However, given that many members who obtained ‘almost all/quite a lot’ of their education from their local society did not rank the continued existence of barriers limiting access to GPs (Barnett, 2001) prevented many people from obtaining

diabetes education from their most preferred source of care. In other words, urban members who relied on their societies for all or most of their care, were less likely than rural members to strongly rate their societies as preferred educational providers. Similarly, among urban members, those relying heavily on the centralised society for their educational needs were less likely to strongly prefer their organisation as an educational provider than people in similar circumstances who were members of the decentralised society. Consequently there was a significant difference between preferences and patterns of use for the urban societies but not the rural ones ($\chi^2 = 18.2$; $p < 0.001$) and the same was true in a comparison of the decentralised versus the more centralised Christchurch Society ($\chi^2 = 8.8$; $p < 0.01$).

Perceptions of effectiveness

In terms of members' perceptions of the societies, the majority of members felt that the societies were effective in terms of giving priority to health promotion to combat increased rates of diabetes in their local area (36.8% very effective, 44.1% somewhat effective). However, only 33.4% of members considered a diabetes society to be the best way of addressing increasing rates. Indeed more members indicated that medical centres, GPs, practice nurses and primary health organisations (PHOs) would be the best/most effective way of addressing growing diabetes rates (49.0%). This was closely followed by encouraging self-care and self-monitoring (46.6%) and advertising (40.6%).

There were significant differences between rural and urban society members' perceptions of the effectiveness of their society; 57.8% percent of rural members perceived their society to be very effective in health promotion activities to deal with the growth of diabetes in their area, compared with only 32.0% of urban society members ($\chi^2 = 10.2$; $p < 0.01$). In terms of managing the growth of diabetes, half of the rural members perceived the societies to be one of the most effective ways of addressing the growth of diabetes compared to less than one third (30.5%) of urban society members. By contrast, despite different deprivation profiles, there were only minor differences in perceptions of society effectiveness between the members of the two metropolitan societies (32.8% for Hamilton versus 28.8% for Christchurch).

Two other measures of effectiveness were also examined: (i) the extent to which members used the

services of their society and (ii) the level of social support and community outreach provided by the societies. With respect to the first criterion, while not all members were heavily involved in their society, many people nevertheless made good use of its services. Utilising the services of their society relates to accessing the diabetes supply scheme (supply of blood glucose monitors), purchasing items or receiving magazines or newsletters, rather than direct involvement. Over half (59%) of the members indicated that they utilised the services of their local society. Again important contextual differences emerged. Rural members were far more likely to use the services of their society than urban members (86.4% versus 53.9%) ($\chi^2 = 18.4$; $p < 0.001$), with both Christchurch and Hamilton having the lowest levels of service use compared to the other four societies. For example, rural members were more likely than urban members to utilise their diabetes society for nutritional advice (30% versus 22.5%) and diabetes management advice (30% versus 18.9%). Similarly, with respect to organisational type, members of the decentralised society were more likely to use its services more often. In Hamilton, 44.5% members used the Society's services at least once every month compared to only 11.6% of the Christchurch members ($\chi^2 = 21.4$; $p < 0.001$).

With respect to the second criterion, the societies have also played an important role in providing social support for members and outreach activities in their communities. While rural members were more likely to meet regularly and share information with other people about diabetes here the differences, while significant, were less marked ($\chi^2 = 3.6$; $p < 0.05$). Nevertheless, more rural than urban members (60.0% versus 48.0%) indicated that they were likely to help others with diabetes. Similarly a greater percentage of rural compared to urban members (63.0% versus 48.8%) spoke to family and friends about diabetes prevention as did members of the more decentralised Hamilton Society compared to their Christchurch counterparts (53.4% versus 31.6%). As the following comments illustrate, society members played an important role in providing information and outreach support within the wider community:

...given a talk on glucose intolerance and food to my men's group; talk to friends/workmates (Nelson member)

...talking to friends of my symptoms has helped (them) go and get checked—are *type 2 diabetics* (Christchurch member)

...in the small town I live in, others approach to ask questions and I am able to assure them all is not doom and gloom (Christchurch member)

...I've encouraged some who seemed lost and dithered. Taken some to doctors when it seems right. Take their GI with my equipment and, if they had a higher than normal reading, purred at them till they took doctor's advice (Christchurch member)

...I take a friend who otherwise wouldn't go (Gisborne member)

Discussion

This study has examined the role that the diabetes societies play in providing diabetes care and education in New Zealand. From the data collected through interviews with the society presidents and the questionnaires administered to members of six of the societies, it is clear that the societies have played an important, but limited, role in health education and health promotion in addressing rising rates of diabetes in New Zealand. For a while they were the only important provider of diabetes education. However, while this is no longer the case, the results of the study nevertheless raise a number of concerns over the operation and effectiveness of DNZ in coping with the diabetes epidemic. From the study a number of key themes emerged.

First, it appears that many of the local societies are not reaching the groups most at-risk from developing diabetes. While the societies had a predominance of older members, their socio-economic profile was predominantly middle class and there was a conspicuous absence of Maori and Pacific Island members. This distribution in the membership is not unexpected given the results of previous studies which have found that participation in voluntary organisations is dominated by middle income groups (Stafford, Bartley, Sacker, Marmot, & Wilkinson, 2003; Wolch, 1990). Our findings are also consistent with other studies which have noted that people from more deprived areas tend to be under-represented in health support networks (Bailey & Pain, 2001; Gillam, 1992) and in health screening (Melia et al., 2000; Simmons, Gatland, Leakehe, & Fleming, 1996). Similar observations have been noted for diabetes, as low-

income groups are more likely to forgo preventative health care including diabetes care and educational services (Zgibor & Songer, 2001).

Second, as evident in other studies of community health promotion (Elliott et al., 2000; Robinson & Elliott, 1999), there are important geographical differences in the way the societies operate and in their membership profiles. Particularly important here were the variations between urban and rural societies and between societies with different modes of organisation. Compared to the urban societies, the two rural societies had a higher number of members living in more deprived areas and appeared to be more effective in targeting the hard-to-reach social groups. The reasons for this are not clear but could reflect the influence of small size on member involvement (Olson, 1971), or the lack of health providers, such as GPs or other diabetes specialists, in rural settings, or problems of continuity of GP care, all of which may result in rural societies taking on a different role in diabetes management and education.

Third, there were also important differences which occurred between the two urban societies with different modes of organisation. The greater representation of persons from deprived areas in the Hamilton Society suggests that a decentralised structure, with a more community-focused approach, may be more effective in recruiting the hard-to-reach groups. This may be because of the greater priority given to local decision making by giving the public a greater voice, in turn leading to greater community involvement (Hurley, Birch, & Eyles, 1995).

Fourth, there were marked differences in the levels of member involvement in the societies. The level of involvement was far greater in rural societies where members were more likely to utilise the services of their society and meet more regularly than members of urban societies. Again, as Olson (1971) has suggested, small size may encourage greater levels of involvement and community outreach because members are more likely to be able to discern the results of their actions such as increasing the awareness of diabetes in the community. The higher level of involvement in rural societies is supported by a number of studies which have found that levels of social capital are often higher in rural areas (Greiner et al., 2004; Kawachi & Berkman, 2000). Similarly, levels of involvement were also higher in more decentralised societies. This suggests that decentralised organisations with a strong

community focus are more likely to attract local members and encourage greater use of their services. Variations in levels of involvement could also reflect differences in the level of professionalisation of the societies. The increased corporatisation of much of the voluntary sector, in particular the recruitment of more paid staff, has created tensions and affected the traditional base of volunteers (Milligan & Fyfe, 2004). Given that higher levels of professionalisation are more likely in larger and more centralised organisations, then such trends may well be affecting the performance of those particular organisations.

Fifth, the education preferences varied between members and between societies operating in urban or rural settings, and under different modes of organisation. Despite the importance of the societies to members, most members tended to prefer more individually based providers of diabetes education. However, given that members who obtained most of their education from their local society did not always rate the society as a highly preferred provider suggests that the continued existence of access barriers, especially in the cities, prevented many people from obtaining diabetes education from their preferred source of care.

Finally, there were important perceptual distinctions between members in terms of the effectiveness of the diabetes societies in helping people to manage the growing diabetes epidemic. Whilst the GP and practice nurse were identified as the key to addressing growing rates of diabetes, the societies were also felt to be important in tackling the epidemic. Members of rural societies felt that their organisations were more effective in diabetes education and health promotion than members of urban societies, however there was no significant difference by mode of organisation. Such perceptions are important, for despite much of the positive work done by local societies and their members, they nevertheless indicate that many society members themselves were sceptical of the ability of local societies to address the growing diabetes epidemic.

From a theoretical perspective the findings of the present study thus add to the three literatures discussed previously. First, with respect to research on the role of voluntarism we emphasise the importance of examining place-based differences in the actual utilisation of services provided by this sector and not just the spatial distribution of voluntary activity. The presence of this sector in a locality thus should not be equated with its

effectiveness in reaching groups most in need. The results also suggest that different types of voluntary organisations provide settings which can foster very different types of citizenship. The fact that rural and more decentralised diabetes societies, characterised by grass-roots organisational structures designed to encourage empowerment and participation, were more inclusive organisations and more effective in reaching those most in need raises questions about the equity consequences of the growing corporatisation of this sector. Second, with respect to work on social capital the study supports the view that social capital-rich communities, with strong elements of collective socialisation and collective action, are likely to be more effective in transmitting health promotion messages more efficiently via information channels such as the diabetes societies (Jack, Liburd, Spencer, & Airhihenbuwa, 2004; Petersen, 2002). The fact that rural societies in particular were characterised by greater member involvement supports other research which indicates higher levels of volunteering and other forms of community involvement in rural areas (Greiner et al., 2004; Prime et al., 2002; Wardell et al., 2000). However, the results also indicate the downsides of social capital (Portes & Landolt, 1996), in that the benefits of organisational involvement are often not evenly shared amongst those most at risk of diabetes and its complications. Thus as Fyfe and Milligan (2003b) have argued, while it is important to recognize that there may be place-based differences in the nature of social capital, we also need to be aware that its consequences may be divisive and not necessarily lead to more positive health outcomes which benefit the whole community. Thirdly, from a health promotion perspective, while the findings of the present study to some extent confirm other research which suggests that socio-economically disadvantaged people appear to be slower to engage in behavioural change (Honjo et al., 2006), the extent to which this occurs may well be context specific. For example, why the centralised Christchurch Society had the lowest representation of deprived groups among its members is far from clear. Thus future research, building on recent studies of geographies of health knowledge (Williamson, 2004), should attempt to identify the extent to which health promotion messages are ignored or actively resisted by certain groups (Crossley, 2002; Hughes, 1997) and in what locations and organisational circumstances this is most likely to occur.

From a policy perspective the results are important to the future direction of DNZ and the way in which it is attempting to address the question of the rapid growth of diabetes in New Zealand. At a national level DNZ has had an important advocacy role and, in part due to this, has been an important stimulus in the development of national initiatives to address diabetes such as the Diabetes 2000 implementation plan (Ministry of Health, 2003). However, as in the 1990s, when public health promotion was not seen as a priority area by government, since it often conflicted with the interests of important business lobbies (Barnett & Malcolm, 1998), diabetes health promotion still appears to remain undervalued. While DNZ has received increased government funding, particularly for the supply of blood glucose monitors, state support for advocacy, on the other hand, has been limited despite the fact that diabetes prevention is a key objective of the New Zealand Health Strategy. However, given DNZ's middle class focus, it seems that state funding for both advocacy and service development is being directed through other organisations, such as PHOs and Maori providers, which are seen to be more proximate to such vulnerable populations (Barnett & Barnett, 2004). As a consequence, this has restricted DNZ's national focus but has also placed greater burdens on localities to promote both advocacy and education.

At a local level, it could also be argued that the national impact of DNZ has been limited because of its decentralised organisational structure. On the positive side the independence of local societies from the national body has meant that they have had considerable autonomy in developing local educational programmes and have been a mechanism for democratic participation and social change. However, independence has also meant that local agencies have had to raise most of their own funds and partly because of this, like many other health NGOs, they have a heterogeneous nature and their local impact has been very uneven (Robinson & Elliott 1999; Wolch, 1990). This is recognised by the societies and has resulted in debate over the merits of retaining decentralised 'participatory' organisations or developing a more centralised business model along the lines of other health NGOs. However, despite the potential increase in effectiveness in dealing with the diabetes epidemic, a more centralised model is not currently favoured by most DNZ members (Diabetes New Zealand, 2005b).

To some extent the uneven outputs of DNZ's activities may be altered with the advent of the Ministry of Health Diabetes 2000 implementation plan. This has resulted in the formation of 'local diabetes teams' (LDTs), and a greater co-ordination of services between key stakeholders concerned with the identification and treatment of diabetes. Important here are new initiatives involving the development of diabetes registers and the free annual 'get checked' monitoring programme being developed by primary health organisations (Ministry of Health, 2003). While not all primary care providers are yet involved in the plan, it has the potential to develop a more reliable information base on diabetes prevalence rates and to provide a more integrated approach to patient care. It is expected that DNZ will play an important role in the operation of LDTs, but in so doing this is also likely to result in the development of key performance indicators to ensure that key objectives are being met.

While such developments may aid agencies such as DNZ and perhaps lead to a greater focus on the extent to which local societies are targeting at-risk groups, there are clear limitations to such an approach. First, without central financial support, local societies will be restricted in the extent to which they can address local needs. Second, there are also limitations associated with behavioural or lifestyle interventions such as education which are fundamental to the DNZ approach. Both constraints need to be kept in mind when designing educational programmes and attempting to reach at-risk groups. In such cases, while education may have some beneficial effects it needs to be recognised that sustained and significant improvements in limiting the growth of diabetes may only occur with the implementation of a broader-based prevention strategy and a more strategic approach on the part of DNZ in which issues of how to deal with health inequality become more prominent. This has already occurred among other health NGOs in New Zealand, where organisations such as the Heart Foundation have developed parallel organisations to deal especially with issues of Maori and Pacific health inequalities (Owen, 2005). Similarly, in the United States, as Liburd and Vinicor (2003) have argued, public health research and practice must address the social production of diabetes, broaden the boundaries of how diabetes risk and causation are understood and articulated, and establish new community health models that reflect

the changing complexion and socio-political dynamics of contemporary urban communities. Given that questions of how to address ethnic and social inequalities in health has become more central feature of national health policy in New Zealand, the relative neglect of such concerns by the main provider of diabetes education raises questions about the ability and accountability of the current voluntary sector model to deal with such issues. We would also like to thank the referees for their helpful comments.

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