

“Ethnic community stakeholders as partners in primary and secondary diabetes prevention”

Abstract

Recently renamed as “Listening to Ethnic Communities about Diabetes” this project was a winner of the *2003 Innovation and Excellence in Primary Health Care Award, Community and Consumer Participation category*. The project is also being promoted as a model of best practice in culturally and linguistically diverse (CALD) community engagement. *Listening to Ethnic Communities about Diabetes* focused on Type 2 diabetes by developing, piloting and evaluating culturally appropriate primary and secondary prevention health promotion strategies with Maltese, Filipino and Vietnamese communities in the municipality of Brimbank, Victoria.

One of the critical success factors for the project was that, while the project was grounded in a health promotion framework, the lead agency did not have a great deal of health expertise. Rather the focus of its expertise was on relationships with ethnic communities. This allowed for a shift in traditional power structures as the communities were given a real voice and decision-making powers. While the health service providers had the clinical and practical knowledge and expertise in diabetes, it was the involvement of the ethno-specific organisations and ethnic community representatives that enabled the project to develop and pilot models of service provision which had relevance and accessibility to the target community.

The project also demonstrated the value in utilising a diverse range of strategies which reflect the cultural practices and preferences of the target communities through being developed and tested in partnership with the communities.

Introduction

The project was situated in the Western Metropolitan region of Melbourne and targeted three local ethnic communities, Maltese, Vietnamese & Filipino, in the municipality of Brimbank. The health promotion project, led by the Migrant Resource Centre North West and supported by ISIS Primary Care (local community health centre), facilitated strong collaboration with peak bodies and ethnic community agencies representing the three target groups.

To encourage engagement and active participation in the initiative, the interests of all the stakeholders had to be managed. Expertise was not seen as being held solely by the health agencies involved. The project engaged ethnic community members and ethno specific agency workers and involved them in the research and pilot project phases where their input was held in the highest regard. It was this genuine engagement of community members and ethnic agencies that led to the project’s success through a high level of ownership of the project by the communities involved.

Some of the limiting factors of the project were the budget and short-term nature of the funding for the project, which put a strain on resources and the ability to further progress the successes of the project to ensure sustainability. Another impact of the time limitation was the inability to produce the final report for public distribution and to implement a dissemination strategy for the resources produced as a result of the pilot projects. There was recognition given to the importance of ensuring that resources once developed remain accessible to the target community to avoid duplication and strain on limited resources. However, time limitations did not allow for these structures and systems to be further supported after being established.

The consumer participation approach¹ of the project, while it focused on developing specific strategies for different communities, can be applied to other work, provided it is understood that the approach is about being specific to communities in order to be appropriate. The strategies described

¹ Consumers in this instance are defined as individuals with and without diabetes who identify with particular cultural groups. This also means they are members of particular communities, though they may not identify themselves as such. They are users of services or potential consumers of services. For this reason, the terms ‘consumer’ and ‘community’ are used interchangeably throughout the paper.

here would need to be reviewed and adapted or fully redeveloped to have the same success in health promotion with other CALD communities.

Context

Diabetes Mellitus is one of the fastest growing chronic health conditions in Australia (Dunstan et al, 2000). With the proportion of overseas born population with Diabetes mellitus being twice that of the Australian born population, (National Health Survey: Diabetes Australia 1995) it is important that diabetes awareness and service development projects are focussed in areas of high need. Data on incidence and prevalence of diabetes mellitus in ethnic communities is limited. However, the prevalence of Type 2 diabetes is considerably higher in certain ethnic groups residing in Australia, especially those of Mediterranean descent, people from the Indian subcontinent, Pacific Islanders and people from some Asian countries (Colagiuri et al, 1998). The rates of morbidity have been shown to increase with duration of residence in Australia for migrants. Reasons for this are unknown but thought to be related to changes associated with adopting a Westernised lifestyle (Schofield, 1995).

The Diabetes Prevention and Management Initiative is a Victorian Department of Human Services initiative aimed at raising awareness of diabetes and developing sustainable models for the prevention and management of diabetes at the local level. Several three-year Primary Care Partnership projects were funded as well as a two-year Koori project and a one-year project targeting CALD communities. The *Listening to Ethnic Communities about Diabetes* project was funded for one year as a result of this initiative.

Method

The aims of the project were deliberately broad to allow for stakeholder input to determine the direction of the project. The aims were: to improve the delivery of diabetes prevention and management services to CALD communities in the Brimbank local government area (LGA), to enhance self management of diabetes amongst people from CALD communities in the Brimbank LGA and to engage the CALD communities in increasing understanding and access to diabetes prevention and management strategies and services in the primary care sector.

A steering committee was formed upon appointment of a project officer with the primary role of overseeing the development of the project and the provision of ongoing guidance and direction for the project. The committee, which represented over ten different agencies, was responsible for input into the project parameters, decision-making processes and for prioritising project directions. A major component of the role of this committee was to provide guidance in the development of strategies to address identified gaps for the three target communities. The key to the strategies was that they needed to be culturally appropriate and lifestyle relevant for the communities being targeted.

The committee was comprised of representatives from the CALD communities: Maltese Community Council of Victoria, Australian Vietnamese Women's Welfare Association, Vietnamese Community in Australia/Victoria Chapter, Filipino Community Council of Victoria and key health stakeholders from community health, general practice, Primary Care Partnerships and relevant peak bodies within the Brimbank and Western Metropolitan region. The presence of ethnic community organisations in this committee ensured genuine community involvement being facilitated in the early planning stages of the project. Community involvement throughout the project was considered to be genuine as it was sustained and determined the direction of the project, rather than only to collect information at the research phase or ensuring uptake of the initiatives in the implementation stage. Many of the relationships created between ethno-specific agencies and health care providers were sustainable beyond the project's life. An example of this was the seeding grants offered to the Filipino community, which ensured links were made with dietitians from the local community health service that implemented information sessions with community groups.

Three main phases characterised the project's approach. Phase one looked at identifying the particular and generalisable needs for each community group, in relation to diabetes prevention and management, as well as general issues with diabetes health care access and provision. (Summaries of these results can be found below in the 'Results' section.) Instead of employing researchers to conduct the needs assessment it was preferable to offer the consultancy to the ethno-specific agencies involved in the steering committee. They were supported by formal training in focus group

methodologies, and ongoing support from the lead agency. By doing this, the utmost value was placed on the cultural understanding and links with community groups that the ethno-specific agencies possessed, rather than formal research experience. This served as an excellent capacity building tool and offering paid contracts to do the work further demonstrated that their contributions were highly valued. The research undertaken by the ethno-specific agencies included conducting focus groups with members of their communities with and without diabetes and development of a final report with recommendations for the strategic planning team to consider implementing as pilot projects.

Phase two analysed the results from the needs assessment. This was done through a prioritisation and strategic planning exercise. However, the emphasis was not on how clients from the communities could be engaged to use existing diabetes health services. Instead, the community and health service representatives discussed ways in which they could be responsive to the identified needs by creating culturally relevant responses through service reorientation or program development.

Phase three saw the piloting of at least one intervention for each of the targeted ethnic communities. These were drawn from the needs assessment and prioritisation phases of the project. Pilot projects included a 5-week education program with a focus on exercise and using pedometers for the Maltese community, a dietary resource developed and launched for the Filipino community and a state-wide Vietnamese radio campaign using a CD produced by the project containing culturally and linguistically appropriate diabetes messages in the form of short narratives/stories in the Vietnamese language and supported by the establishment of a Vietnamese phone information line linked to Diabetes Australia Victoria.

Evaluation of *Listening to Ethnic Communities about Diabetes* was ongoing and utilised a variety of evaluation strategies during the consultative process to ascertain broader components of evaluation such as quality, appropriateness, feasibility, and restrictions or limitations to current diabetes service provision.

A final report containing all resources produced and with key recommendations was submitted at the end of the project to the Department of Human Services (DHS) for consideration and dissemination to the sector. The report is being considered for production as a DHS report¹ and is being promoted as a model of best practice for CALD community engagement.

Results

Focus Group Findings:

Eleven focus groups were conducted with over one hundred twenty three participants in total.

The Maltese Community saw diabetes as a sugar disease, "Sugar gets into the blood, it happens when you get old", and it is "fatal, no control". There was no real sense of understanding of the different types of diabetes and the complications that can arise as a result of lack of good diabetes management. There was a degree of shame associated with having diabetes. There was a definite lack of knowledge by consumers of services, roles and resources that health professionals provide in the care of diabetes. This was attributed to language barriers and inappropriate targeting of strategies.

The Filipino Community saw diabetes as disease of the rich, "from over indulgence". They felt it was important to be "responsible for your own management of diabetes". The GP was the important health provider with very few other health providers ever being consulted for diabetes care (possibly due to lack of knowledge of available services). The community believed that medication was a cure: "the drugs for diabetes fix it". There was little understanding about the relationship between diet, exercise, medication and self-management.

The Vietnamese Community generally had a low awareness of diabetes and displayed "shock, fear and sadness at a diagnosis of diabetes". After diagnosis there is a very concerted effort to prevent the diabetes worsening. Family support in managing diabetes was found to be paramount in this

community. Vietnamese speaking GPs provide the main care source for the community. Little information is sourced from other health care providers for diabetes care. Verbal information is the preferred method of education as literacy levels are low in the elderly and the greatest barrier to the provision of diabetes services for this community is seen as language.

Health professionals interviewed showed they were collectively in agreement with the identification of issues faced by the three CALD Communities in addressing diabetes self management although awareness of cultural issues and their impact in general was quite low.

Pilot Project Findings:

FILIPINO: It was noted by both the community, and health professionals working with the community, that there was a lack of current dietary resources that were specific to the cultural and eating preferences of the Filipino community in Victoria. The pilot intervention selected was to develop and disseminate a 'healthy eating' dietary resource, essentially a shopping list of healthier choices of Filipino and 'Western' foods. The resource was developed by health professionals (dietitians from ISIS Primary Care and Diabetes Australia Victoria) in partnership with peer leaders from the Filipino Community Council of Victoria (FCCV). Awareness of the resource was raised with the Filipino community through community radio (3ZZZ) and newsletters. Following resource development, a number of dissemination 'grants' were made available to Filipino organisations to promote the resource and diabetes services to their community members. Over sixty members of the public attended the launch of the resource.

MALTESE: The rationale for selecting this intervention came from the focus group findings that physical activity was difficult for people in the Maltese community, and the observation that a group format is well accepted. The concept of a peer leader or educator appealed to the focus group participants, and it was felt that this would help to de-stigmatise the disease if a Maltese person with diabetes was prepared to openly discuss the condition in a group environment. The project leaders in partnership with the Maltese Community Council of Victoria (MCCV) purchased pedometers to encourage physical activity. Peer leaders from the Maltese community were identified, with the program co-facilitated by health professionals and the MCCV. The 5-week education program focused on improving levels of physical activity via the activities of daily living and through the use of pedometers by approximately sixteen participants (including carers). Sustainability was addressed through the establishment of a 'pedometer bank' with the MCCV, and the establishment of formal links between the MCCV, Diabetes Australia: Victoria (DAV) and ISIS Primary Care.

VIETNAMESE: The first strategy used was to collaboratively develop a diabetes radio narrative for broadcast on Vietnamese radio programming. Key diabetes messages based on research findings were developed and used to formulate scripts for the radio narrative. The narratives contained basic diabetes information, explained the need for regular screening and check ups, risk factors and self management, and promoted the services available for people with diabetes. The scripts were recorded on to compact disc and agreements were entered into with five independent ethnic radio stations to play the narratives at various times of the programming format.

A second strategy, for DAV to offer linguistically appropriate telephone services for people from a Vietnamese background, was also implemented. As the radio narrative included a phone number at DAV for people to call, this enabled DAV to effectively pilot the use of a telephone interpreting service. The radio narratives were played on radio for several months beyond completion of the project and remain a resource for radio use.

The project also resulted in the collation of a CALD Diabetes Resources Directory², for use by health professionals working with people from CALD communities. It is envisaged that this directory will be disseminated through networks, both formally and informally, and will include focus group findings and recommendations for working with the CALD communities in diabetes prevention and management.

² The Centre for Culture Ethnicity and Health was approached after the project was completed to further develop this resource and assist in its distribution to health professionals.

Discussion

This case study highlights some methods for achieving effective intersectoral collaboration by working on shared goals and objectives and by actively attempting to meet the needs of all stakeholders. Community needs were held in highest regard as was the genuine involvement and capacity building of people from the targeted ethnic communities throughout the planning, implementation and evaluation phases of this project.

The health and ethnic community sectors have traditionally operated in parallel to one another. The project attempted to bridge this gap by working intersectorally and building knowledge and understanding between agencies by working together on common goals. Key issues and ideas about the direction of the project were explored from a number of different perspectives; this in turn created an environment of collective responsibility and a commitment to work together in a highly productive way. This commitment was further evident in the fact that the project was completed within its nominated timeframe and all steering committee responsibilities were completed.

The project built the capacity of each of the three CALD communities through involvement of community members throughout the project. This included input during the needs assessment and involvement in the development, implementation and evaluation of the pilot projects. These communities worked in close partnership with the Migrant Resource Centre North West Region to develop initiatives which were culturally appropriate, lifestyle relevant and proved an asset to streamlining diabetes self management and diabetes services within health care systems. Informal meeting structures such as chats over lunch in community venues were used as ways to engage and seek input from ethnic community members.

The relationship building that occurred as a result of the consultative methodology undertaken demonstrated an approach to creating genuine and sustainable partnerships. Local health service providers including ISIS Primary Care, Diabetes Australia Victoria and ethnic agencies continue to be involved in the outcomes beyond the project including the direct involvement in establishment of a Maltese Diabetes Support Group, Ongoing Diabetes Awareness Campaign via Vietnamese radio and uptake of seeding grants offered to Filipino associations and groups for promotion of the Filipino dietary resource produced. Due to this approach, the project has been able to demonstrate improvement in the delivery of diabetes prevention and management initiatives to the three targeted CALD communities in the Brimbank Region.

Conclusion/What can be learnt from this case

The outcomes of this project demonstrate that a stakeholder-oriented approach to health promotion can work with culturally and linguistically diverse communities. The key to success for this approach, however, is to have genuine community involvement throughout the project and to hold community stakeholders' input in the highest regard.

Even though most community health agencies in Victoria are still coming to terms with embedding consumer participation for the wider community into planning, implementation and evaluating health services and programs, this project has shown that consumer participation can work well with CALD communities. However, it should be noted that at least part of the success of this project was in the way that it targeted particular communities, rather than trying to reach everyone. This makes for culturally and linguistically relevant initiatives that are not based on cultural stereotypes or generalisations.

With limited resources and a need to reach particular community members within certain ethnic groups, the project developed a steering group that contained representatives of *all relevant stakeholders*. This meant that the interests of a wide variety of groups needed to be managed – from peak bodies, to health services, to ethno-specific agencies, to community members. And while one of the critical success factors for the group was much public relations work done behind the scenes by project leaders, the more important indicator was that the group was used as a forum for discussion, debate, decision-making and action. Rather than just providing advice that the project worker could then take away and prioritise, the group had a strong, hands-on involvement in all practical stages of the project. Furthermore, community input to the group was prioritised within the

forum as being the most authoritative source of information about the needs of the communities involved. This wasn't always an easy process and was quite time consuming.

Outside of the steering group, communities were closely engaged throughout all stages of the project. This meant approaching each community in a variety of ways, rather than utilising one method of consultation, such as a focus group. It's important to be aware that as much diversity may exist within one CALD community as there is between communities. In order to reach consumers from a variety of age groups, socio-economic backgrounds and migration histories, health promotion workers need to utilise a number of different approaches. Existing structures should be looked to first as these will require fewer resources to access and using established channels will make it easier to connect. Specialist agencies, such as ethno-specific health and welfare bodies, can be used as community partners who may also have expertise in health and community work. They can act as an introduction point to community members and through their involvement can legitimise the work of mainstream organisations. However, it is important to direct resources, preferably reimbursement, towards these agencies so that they have the capacity to adequately respond to the demands of partnership.

Finally, it is extremely important to have the flexibility to adapt to community feedback throughout all stages of planning, implementation and evaluation. This will contribute to cultural appropriateness of the methods of consultation, ongoing engagement, implementation of initiatives and even the evaluation measures. Regarding CALD community members as collaborators and joint partners in all aspects of their health care has in this instance been incredibly successful. While the resources to do this are generally located within agencies, attempting to distribute these more evenly across the community has here resulted in a high level of appropriateness, community ownership and capacity building for each of the communities.

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