SIDS or Sitisi: Plight and Response of Pacificans in New Zealand (Aotearoa)

Abstract: Sudden Infant Death Syndrome (SIDS) or Sitisi was considered a rare event among Pacificans worldwide. However, recent findings in New Zealand (Aotearoa) have shown that at least 33% of Pacific infant deaths in New Zealand since 1991 have been due to Sitisi, and the incidence of Sitisi among Pacificans has been on the increase since 1986. These findings have necessitated the development of a Pacific response, especially since a National SIDS Prevention Programme in Aotearoa, implemented in 1991, had led to decreasing rates amongst Pakeha (Europeans) only.

This paper reports the Pacificans’ experience with Sitisi and the response to the control of yet another epidemic amongst migrants. The response included research; community consultation; and training of Pacifically appropriate Community SIDS Educators. The importance and initiation of community-based strategies is central to the Pacificans’ response to Sitisi and its determinants. The success of this approach provides a model for intervention and health promotion, at least, among Pacificans globally. (Pacific Health Dialog 2003, Vol.10 (2); Pg 182-192)

Eseta Finau*
Sitaleki ‘A. Finau**
Nite Fuamatu*
Colin Tukuitonga*

Introduction

Sudden Infant Death Syndrome (SIDS) or Sitisi was considered a relatively rare event among Pacificans worldwide. In the Pacific proper, SIDS was not a reported cause of death even though Sudden Unidentified Nocturnal Death (SUND) among young men has been reported and deaths due to unknown causes is high in mortality reports of Pacific countries. The latter may be due to lack of post mortem, inadequate pathology services and antiquated health information systems.

The 1995 data from the National Maori SIDS Prevention Programme showed that SIDS among Pacificans in New Zealand (Aotearoa) has been increasing. A review of infant mortality data among Pacificans showed that SIDS accounted for at least 33% of infant deaths since 1991 and 36% of post neonatal death in 1992. In 1987-1990 birth defects (28%) and SIDS (22%) were the major causes of infant mortality among Pacificans. The rate of SIDS (2.1 per 1000 live births) was markedly lower than the national rate (3.6 per 1000 live births).

These findings highlighted the SIDS problem among Pacificans thus warranting a concerted and immediate response. This paper describes that response and examines its ethnic specific features. It describes a model for organizing a community-focused response to the issue of SIDS and its prevention among Pacificans. This Pacific experience and programme may provide approaches to other emerging health problems among Pacificans in Aotearoa, especially to new and unfamiliar phenomena like SIDS. It also provides a model for addressing similar challenges to health of Pacificans, globally.

The Pacificans Of Aotearoa

The Pacificans (people of Pacific descent) make up 6% of the total population of Aotearoa with 65% living in Auckland and 15.6% in Wellington, Samoans (50%) being the majority. About 19% of Pacificans have been reported to be unable to converse in English and more than 30% are living in extended families. More than 20% of Pacificans do not have access to telephones in their homes compared with the 12% national rate. The crude birth rate among Pacificans is double the national rate.

In the Auckland region, Pacificans (population 119,526) make up 9.8% of the population with more than 1/3 being children less than 15 years old. About 19.3% (population 1580) of all Auckland births are Pacificans. The Pacific total (3.3 per 1000 women) and age specific fertility rate are the highest in Aotearoa.
The life expectancy rate at birth for Pacificans (70.5 years) is higher than for Maori but lower than for Pakeha (Europeans). Pacificans are over represented at the lower end of the socio-economic spectrum. In 1994 23% of Pacificans were unemployed (18% national average), more than 80% earned less than NZ $20,000 and 26% were in households of more than seven people. The average household income per year was NZ$25,000 in 2000.

Discrimination in the health and housing sectors complicate the effects of unemployment, overcrowding and other socio-economic deprivations. The low socio-economic status of Pacificans has contributed to poor access to health services. Subsequently there is a need for existing health services to adapt, and for Pacificans to be encouraged and supported to develop more effective and innovative models of health care delivery. Reduction of reliance on hospital services and improvement of primary health care should be goals for addressing the health predicaments of Pacificans in Aotearoa. The Pacific SIDS Prevention Programme was formulated with these objectives in mind.

The Initial Response

The reporting of the new status of SIDS among Pacificans \textsuperscript{5} evoked the expected immediate response of “is it real?” \textsuperscript{7} This was not an unreasonable response since the increase in SIDS among Pacificans occurred during a decline in SIDS among Pakeha following a national SIDS prevention programme in Aotearoa. \textsuperscript{1,2} The Pacific responses was:

- A research project to confirm the increase noted from the National Maori SIDS Prevention Programme database;\textsuperscript{13} 
- Consultation with Pacific community child health workers to assess their knowledge of SIDS in Pacific communities and formulate a work plan;\textsuperscript{14} and
- Acquisition of resources to plan and implement a Pacific-specific prevention programme;\textsuperscript{14}

a. The Research Project

Police and coroners’ reports, which included routinely collected national data, were reviewed. These confirmed that SIDS among Pacificans had increased from 1 per 1000 live births in 1988 to 6.2 per 1000 live births in 1995 (see Figure 1). \textsuperscript{13} Under reporting and misclassification of SIDS cases among Pacific infants was identified. This was not unique for Pacific infants but it caused a wide fluctuation in the rate due to the small numbers involved. Nine parents of Pacific SIDS babies were interviewed. They indicated that the National SIDS Prevention Programme had not addressed nor explored key issues such as their grief, infant care practices or the appropriate prevention of SIDS among Pacificans. \textsuperscript{3} Some indicated negative experiences with the non-Pacific SIDS workers.

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure1}
\caption{Trend of the number of Pacific SIDS cases, Auckland 1988 - 1997}
\end{figure}

\textsuperscript{5,11} The Pacific SIDS Prevention Programme was formulated with these objectives in mind.
During the period of study there were no changes of diagnostic criteria. There was also an increased awareness of SIDS nationally and among all service providers. Thus it was unlikely to have variation and bias due to definition among ethnic groups because the SIDS diagnosis was undertaken through the same mechanism. The SIDS diagnosis was by exclusion of other causes after an autopsy. Under these conditions, there was a decrease in SIDS incidence between Pakeha, a flat pattern for Maori and increase for Pacificans.

b. Community Consultation

This forum was the first opportunity for about 50 Pacific child health workers to focus on SIDS. The forum was learning and planning opportunity. It concluded that Pacific infants' vulnerability to SIDS was increased by environmental factors in the womb, the sleeping environment of the baby, and the family situation. This forum suggested that the Pacific SIDS Prevention Programme must:

- Protect, promote and support family well-being;
- Enhance good communication between the generations; and
- Address the family responsibility for supporting parents and protecting children.

It concluded that Pacific infants' vulnerability to SIDS was increased by environmental factors in the womb, the sleeping environment of the baby, and the family situation.

This consultation concluded that any programme for Pacificans must address the social and behavioural risk factors for SIDS while at the same time enhancing the overall health development and survival of Pacific babies.

c. Resource Acquisition

The Pacific Health Programme, Division of Maori and Pacific Health, at the University of Auckland developed and presented a proposal for a SIDS prevention programme for Pacific families in Auckland." The proposal included strategies to:

- Increase community awareness of the SIDS risk factors;
- Produce suitable Pacific ethnic specific workers and resources for SIDS prevention;
- Improve collection of Pacific ethnic specific data on SIDS;
- Co-ordinate SIDS prevention activities among Pacificans in the Auckland region; and
- Contribute to SIDS prevention generally and in other communities.

The specific activities from this proposal constitute the Phase 2 of the Pacific response. These activities have been funded mostly by the Regional Health Authority (later the Health Funding Authority) in Aotearoa. Strong support from the Pacific community and other agencies (e.g. Cot Death Association, Plunket, Tongan Health Society Inc. and Pasifika Healthcare) has assisted programme development and implementation.

d. The Pacific SIDS Prevention Programme

This is based at the Pacific Health Programme, Division of Maori and Pacific Health, Faculty of Medical and Health Sciences at the University of Auckland. It is managed by a Pacific SIDS Co-coordinator who is assisted part-time by Pacific health staff consisting of one researcher, two public health physicians, one health promotion specialist and the National Maori SIDS Prevention Programme staff. The SIDS Co-coordinator is a nurse with sociology and management degrees. She was trained by the staff of the National Maori SIDS Prevention Programme in the various facets of SIDS project management and prevention. In 1997 the Pacific SIDS programme started implementing the plans that had evolved since the acknowledgement of SIDS as a priority problem among Pacificans in 1995. 5'14

A management group oversees the Pacific SIDS Prevention Programme and the Pacific Health Programme staff coordinate its operation (see Figure 2 for the organizational chart). The aims of the Pacific Programme are to:

- Develop and maintain an ethnic specific awareness program infrastructure;
- Initiate a SIDS research and information system for data collection;
- Analysis and dissemination of SIDS information-relevant to Pacific communities; and
- Report on Pacific SIDS activities.

Four progress reports on the Pacific SIDS Prevention Programme have been distributed and submitted to the funding agency. 1516,17,18 The SIDS Co-coordinator supervises the Community SIDS Educators and manages the day-to-day operation. She and the other Pacific staff have participated regularly in the retreats and continuing education activities of the National Maori SIDS Prevention Programme. The latter have also provided support for grief resolution activities.
Figure 2: Organisational Chart of the Pacific SIDS Prevention Programme

Pacific Community

PACIFIC SIDS MANAGEMENT COMMITTEE

PACIFIC SIDS CO-ORDINATION GROUP

MAORI SIDS PREVENTION PROGRAMM

PROFESSIONAL DEVELOPMENT AND PUBLICATIONS

SIDS CO-ORDINATOR

PLANNING AND MONITORING

RESOURCES DEVELOPMENT

SIDS RESEARCH AND DATABASE

COMMUNITY SIDS EDUCATORS

PACIFIC HEALTH PROGRAMM
The Second Phase

It was obvious from the community interactions that SIDS was a new and unfamiliar phenomenon to Pacificans. Therefore awareness, appreciation and ownership of this problem were minimal. The initial strategy had to be the development of community awareness and problem ownership within the context of Pacificans’ cultural realities. The approaches chosen were based mostly on the experiences and realities of the Pacificans involved in project development and implementation elsewhere. This was crucial because there was scarce objective evidence on effective health promotion among Pacific communities and of successful SIDS prevention efforts for Pacificans.

a. What is in a Name?

The name SIDS needed to be translated into the Pacific languages to enhance communication, understanding and ownership of the problem. Being a new phenomenon, the first question was how to translate SIDS into the 13 Pacific languages spoken by the Pacific communities in Aotearoa. A combination of staff intuitiveness and informal community consultations led to a phonetic translation of SIDS to Sitisi. Although this phonetic translation did not spontaneously convey any meaning about etiology and risk factors, it symbolically transformed SIDS to a Pacific specific derivative word similar to previous translation experiences of so many foreign words in the Pacific (e.g. spoon, typhoid, flu, AIDS, etc). This intuitiveness was based on experiences with working on AIDS in the Pacific countries where the South Pacific Commission AIDS Project successfully used the same approach to translate AIDS to various phonetic versions (e.g. Eitisi in Tongan).19

The phonetic translation of SIDS to Sitisi was incorporated into materials development and a jingle song with the tune of "This Old Man"16

**SITISI SITISI**
**SITISI HAVE HIT US HERE**
**HELP US FAST**
**WITH NO FEAR**
**TO RID AUCKLAND OF SITISI**

This jingle was derived from a Tongan version and has been translated into Samoan, Cook Island Maori, Fijian, Niuean, Tuvaluan and Tokelauan.

b. Printed Materials Development

The community forum suggested different types of printed materials. These also concurred with the project staffs’ assessments. The layout and colour scheme was the same for each item through the different translations. These Pacific SIDS educational materials have been distributed in Christchurch, Dunedin, Wellington, Levin, Gisborne, Napier, Nelson, Whangarei, Hamilton, Kerikeri, Auckland, and Sydney through different Pacific health and mainstream providers including Plunket, general practitioners and a variety of community health workers. (See Table 1)

<table>
<thead>
<tr>
<th>Type of Printed Materials</th>
<th>Ethnic Group</th>
<th>Auckland</th>
<th>Wellington</th>
<th>Christchurch</th>
<th>Other Areas</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Leaflets</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*Keeping your Baby Alive</td>
<td>Samoan</td>
<td>1000</td>
<td>300</td>
<td>100</td>
<td>200</td>
</tr>
<tr>
<td></td>
<td>Cook Island</td>
<td>500</td>
<td>100</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>Tongan</td>
<td>500</td>
<td>100</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>Niuean</td>
<td>550</td>
<td>100</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td>*Love me Tender</td>
<td>English</td>
<td>500</td>
<td>300</td>
<td>200</td>
<td>300</td>
</tr>
<tr>
<td>2. Poster</td>
<td>English</td>
<td>60</td>
<td>20</td>
<td>20</td>
<td>30</td>
</tr>
<tr>
<td>3. Video</td>
<td>English</td>
<td>10</td>
<td>2</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>3070</td>
<td>922</td>
<td>472</td>
<td>835</td>
</tr>
</tbody>
</table>

*Awareness* leaflet: This was formulated around the "Keeping Your Baby Alive" message listing the major risk factors as: lack of breastfeeding, sleeping prone, smoking, poor ventilation and dirty sleeping environments. The translation of these messages to Pacific languages were challenging, e.g. the translation of "Keeping Your Baby Alive" varied to incorporate appropriate ethnic specific cultural emphasis.
This resulted in wording changes and contextual shifts, e.g. in Tongan the message literally translated into "Protect Your Child from Death".

- **Poster:** This incorporated the content of the awareness leaflet with the Pacific translations on one poster. The staff developed other posters during training sessions. These posters were ethnic specific and distributed to the relevant ethnic and language groups.

- **Information Leaflet:** This provided details on SIDS diagnosis, risk factors and prevention. The information was built around the tune "Love Me Tender," which was suggested by the community forum." This is being translated into different Pacific languages.

- **Flip Chart:** To enhance small group presentations an eight page A3 size flipchart was developed. This covered SIDS, diagnosis, risk factors and prevention, incorporating images and texts from the leaflets and posters described above.

- **Transparent Overhead Slides:** These are for projection during large group sessions. These, too, incorporated the messages and images from the other educational materials described above in English and the vernacular.

c. Media Plan

This was developed using radio, audio-visual and print media. Radio programmes in different Pacific languages consisted of didactic presentations, talk back and short jingles/advertisements. The messages were built around "Keeping Your Baby Alive" and "Love Me Tender". A seven-minute national Pacific SIDS presentation in English was on Tangata Pasifika, a regular national TV programme. This tape is used for community education and staff training. The Pacific community SIDS workers and staff in different Pacific languages addressing the commonly asked questions produced about 15 ten-minute video presentations: *What is SIDS?* and *How to prevent SIDS?* These videotapes were developed through the SIDS training sessions for staff. Through the efforts of the staff, articles about Pacific SIDS were published in English language newspapers and newsletters read by Pacificans and some were in the Pacific language newspapers.

d. Health Professional Development

Resources and training were needed for SIDS prevention staff as well as for other Pacific health professionals who had largely ignored SIDS as a Pacific problem. The opportunity for a formal training programme for the health professionals was minimal. Therefore visits were paid to different Pacific health providers. Published papers on SIDS were distributed. Review articles on SIDS were requested from experts and published in *Pacific Health Dialog*, a journal for Pacific health workers. The staff and collaborators continue to develop articles on Pacific SIDS research for publication in professional journals. Other Pacific SIDS educational materials have also been distributed to many health providers in Aotearoa, Australia and Pacific countries to raise their awareness of SIDS. So far the staff have attended and presented on Pacific SIDS at four international conferences and at least 12 national meetings in Aotearoa. An important component of health professional development is the training of community SIDS educators. These educators have conducted educational sessions in the community, identified families with the history of SIDS, and facilitated the linkage of SIDS families to various community services.

e. Community Information Sessions

The Pacific Community SIDS Educators provided educational sessions in the vernacular to various Pacific community groups. The group session sizes have varied from 10 to 500 people per session. These have been conducted in homes, halls, schools, churches and other convenient community venues. Some smaller group sessions (<10 people) have also been conducted. So far over 200 sessions have been conducted for about 10,000 people, throughout the Auckland region, in seven Pacific languages (see Table 2). Information poster displays on Pacific SIDS were used on several occasions. The displays were strategically placed at various Pacific gatherings and festivals and were coupled with distribution of educational leaflets. At least one SIDS worker had attended the display and responded to public inquiries during these occasions. The information, posters and displays have been exhibited in at least 35 such sites to date.
Table 2. Number of Recorded Formal SIDS Sessions* and Participants by Ethnic Group

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>No. of Sessions Frequency</th>
<th>No. of People Frequency</th>
<th>No. in General Population Frequency</th>
<th>Rate of Participation Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Samoan</td>
<td>81 (35.4)</td>
<td>3,883 (49.9)</td>
<td>56,985 (47.7)</td>
<td>6.8</td>
</tr>
<tr>
<td>Cook Island Maori</td>
<td>41 (17.9)</td>
<td>1,023 (13.1)</td>
<td>2,1162 (17.7)</td>
<td>4.8</td>
</tr>
<tr>
<td>Tongan</td>
<td>40 (17.5)</td>
<td>1,090 (14.0)</td>
<td>2,1915 (18.3)</td>
<td>5.0</td>
</tr>
<tr>
<td>Niuean</td>
<td>40 (17.5)</td>
<td>1,152 (14.8)</td>
<td>1,2369 (10.3)</td>
<td>9.3</td>
</tr>
<tr>
<td>Fijian</td>
<td>17 (7.4)</td>
<td>336 (4.3)</td>
<td>4,266 (3.6)</td>
<td>7.9</td>
</tr>
<tr>
<td>Tokelauan</td>
<td>10 (4.4)</td>
<td>200 (2.6)</td>
<td>1,080 (0.9)</td>
<td>18.5</td>
</tr>
<tr>
<td>Other Pacific Islands</td>
<td>1,749 (1.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>229 (100%)</td>
<td>7,784 (100%)</td>
<td>119,526 (100%)</td>
<td>6.6%</td>
</tr>
</tbody>
</table>

* Many informal interactions took place but are not recorded here. ** 1996 Census

f. Research And Database Development

The Pacific SIDS team was involved in a multi-ethnic study of Infant Care Practices in Auckland. Support was provided for the collaborative project to establish a national SIDS database and monitoring system. Through the Pacific Health Research Centre participation in collaborative child health research projects, SIDS integration to child health is being fostered e.g. National Children's Nutrition Survey, First Year of Life Study, and Children Pneumonia Study.

The Community SIDS Educators

After reviewing Pacificans' realities in Aotearoa it was concluded by the Pacific SIDS team that the most efficient and culturally appropriate strategy to expedite the awareness of SIDS in the Pacific community was to train community health workers from the different language groups. Initially 15 participants were recruited from six Pacific ethnic groups (see Table 3). Another 15 were recruited and trained to replace dropouts from the initial group and to increase the number of Samoan educators.

Table 3: Number of Community SIDS Educators by Ethnic Group

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>No. Recruited and Trained</th>
<th>No. of Drop Outs</th>
<th>No. still Operating of Sessions per SIDS Educators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Samoan</td>
<td>13</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Cook Island Maori</td>
<td>3</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Tongan</td>
<td>4</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Niuean</td>
<td>4</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>Fijian</td>
<td>2</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Tokelauan</td>
<td>1</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>27 (100%)</td>
<td>9 (33%)</td>
<td>18 (67%)</td>
</tr>
</tbody>
</table>

The training was mostly in English, problem-based and practical, using the staff of the Maori and Pacific SIDS Prevention Programmes as facilitators. It is believed that this training approach for SIDS is the first of its kind. The details are reported elsewhere.

A brief outline as follows:

a. The Training Phases

The training was divided into four phases. Each phase had a clearly proposed outcome followed by practical sessions. The practical sessions were supervised actual paid work for the community workers, concurrently producing and testing educational materials. The phases were as follows:

Phase 1 - The training outcome was that the Community SIDS Educators would be able to plan and conduct community education sessions. This involved didactic lectures on SIDS and group work on community education. The increase of knowledge about SIDS was a primary objective as this is a new and unfamiliar problem.
• Phase 2 - The second training outcome was for the community educators to be able to review their experience to date and to maximize the use of training materials and technology for their community sessions. The context of the training included a review and update of SIDS knowledge from the first training four months before. The focus was on training techniques, planning of sessions and use of teaching aids.

• Phase 3 - The third training was conducted about six months later. This training focused on the community SIDS educators, reversing their trainee role to that of trainer. Each participant prepared a teaching presentation on a topic of their choice. They presented this to the class and this was followed by the usual discussion, questions and answers sessions. The whole session was videotaped. The participants in the next training day critically viewed the video. This generated discussion and critical comments. These tapes are being edited to be used as community education materials. Participants were also asked to develop SIDS posters for viewing during the training session. They presented this to the class and this was followed by the usual discussion, questions and answers sessions. The top three from each category were given cash prizes.

• Phase 4 - These sessions were for remedial or slow learners, continuing education, update and catch-up. The latter refers to training of new community SIDS educators, to replace or increase the number of workers. There have been two continuing education training's and two training's to replace and increase the number of Samoan SIDS educators since Samoans comprise the largest Pacific group and also have had a high drop out rate. There are now 18 trained Pacific Community SIDS Educators (see Table 3 on Page 15). More continuing education and training sessions are planned for each quarter in the future.

b. Training Format and Content

Each training session started with a review of the previous training, followed by a knowledge update session and a discussion on issues from their preceding experiential/practical community education sessions. Pre-and post-test questionnaires were used at each phase to show knowledge gaps and strengths, practical community education skills and to raise training issues from the trainees' viewpoints.

The analysis of these questionnaires showed a marked incremental increase in knowledge, improvement of community education skills, and a near 100% retention of the content of the previous training session.

Training was conducted mostly in English at about Form Two level, with translations where appropriate. Participants were provided with printed resource materials on SIDS and health promotion techniques, as well as a resource bag to store and carry their resource materials. The one day training started at 9.00am and finished at 5.00pm and each training session ended with at least two hours to address miscellaneous questions from the trainees on SIDS, general health, logistics, programme planning, local politics, project management or any other matters of consequence to their work. These free-for-all sessions always left the trainees enthusiastic owners of the problems, strategies and solutions.

c. Practical Sessions

Between each training the Community SIDS Educators conducted educational sessions under the supervision and support of other Pacific SIDS staff. Usually people of the same language groups worked together. Videotaping as an alternative supervisory and performance-monitoring tool has been useful. In this case the community education sessions were videotaped and reviewed at convenience by the supervisors and the other colleagues. This approach has resulted in: supervised rapid dissemination of SIDS information; real life training experiences; a record for quality assurance; and accumulation of videotape footage for further community SIDS education audio-visual training material. The incentives for the training were altruistic and also monetary, a potent combination for the motivation of poor communities. The incentives for the training were altruistic and also monetary, a potent combination for the motivation of poor communities.

An important component of the practical session was the recording of all the questions asked at each session. These questions were then used at subsequent follow up training sessions or on radio programs. This improved the Community SIDS Educators' responses to community inquiries, orientated the focus of the educational materials as well as dealt with the most important issues from the peoples' perspective. The most important questions from the community that were used for training were as follows:

- What is SIDS?
- Who gets SIDS most?
- How is SIDS diagnosed?
- What causes SIDS?
- What are the main risk factors?
- How is SIDS prevented?
- What should people do when SIDS occur?
Discussion

The Pacific SIDS Prevention Programme emerged in an environment of inadequate ethnic specific information for SIDS prevention. This initiative was rectified through the use of Pacific staff and the assistance of colleagues from the Maori SIDS Prevention Programme. The latter brought wide experience with SIDS prevention activities. The intuitiveness and community-based experiences of the Pacific staff from within these communities, ensured that the structure and strategy would be culturally and ethnically appropriate; a feature that was lacking in the previous National SIDS Programme. This is crucial in working with a new and unfamiliar phenomenon such as SIDS. Programme development in an information poor environment needs insiders and a concurrent deliberate information gathering approach. Proper use of research can empower poor communities like the Pacificans of Aotearoa.

The use of Pacific professionals from within the communities enhances the mechanism for early ownership of the problem by not neglecting community participation. In the Pacific SIDS Prevention Programme, SIDS information was repackaged for Pacificans to minimize the negative experience of the Pacific parents from overzealous (non-Pacific) SIDS workers, whose efforts result in culturally inappropriate support, especially during grieving.

The new materials allowed for a holistic approach to include aspects conducive to child health in general, even if they were of debatable importance to SIDS e.g. breast feeding, better ventilation, clean environment and hygiene, bed sharing, etc. The forum of Pacific child health workers also suggested this holistic approach. This approach elevated community needs and understanding over the primacy of science.

The use of Community SIDS Educators enhanced community participation. The training approach allowed the community at large to participate in their training as well as to anchor the educators in the realities of the Pacific community. The training content was deliberately broad to allow the community SIDS workers to comfortably respond to a variety of health issues, not just SIDS, e.g. nutrition. Experience with single-issue community health workers has indicated that deprived poor people spend an inordinate amount of time to earn very little and to just survive. Even after training some workers were too busy to continue SIDS education in their ethnic groups. However many continued to provide SIDS information informally as part of their daily interactions and continued to facilitate the activities of the Pacific SIDS programme. Thus attrition of Community SIDS Educators from the programme did not mean cessation of SIDS community education.

Although this programme was for SIDS prevention, it quickly identified the need for grief resolution for SIDS parents/families and personal assistance with other issues e.g. poverty, linking with other services, facilitating post mortem consent and funeral arrangements, etc. In addition, requests for SIDS materials and assistance came from throughout Aotearoa not just the Auckland area. Even non-Pacific groups requested the materials and the assistance of the Pacific SIDS staff. These requests taxed resources and also raised the need for nationalizing the Pacific SIDS Prevention Programme with the Maori SIDS programme and for funding to be provided for grief resolution.

Collaboration with other agencies mentioned earlier has enhanced programme development despite very limited resources. It has enabled the Pacific SIDS programme to maximize efficiency and expedite project implementation through materials production, information dissemination, and research and database development. In such collaboration it has been important for such a small project to stay in control of its direction, and act as a buffer between its community and any potentially damaging, albeit inadvertent, intruders, without malice and with good intentions. This programme has recognized and consciously attempted to do just that through its design.

Although the programme is yet to be formally evaluated, many issues have been identified. The need for a grief and social-economic support has been mentioned. The association of the risk factors with SIDS among the Pacific community needs further elucidation. The similarity of Sudden Unexpected Nocturnal Death...
(SUND) among young men and SIDS need exploring because of the potential similarity of risk factors. The use of experiences from the Pacific countries for project design and implementation in Aotearoa seems to have strengthened this programme. This suggests that Pacificans in Aotearoa will benefit from appropriate Pacific experiences without having to 'reinvent the wheel'. The importance of insider Pacific staff has enhanced this programme thus supporting the notion of ethnic specific service provision in Aotearoa initiated by Maori and later by the Pacific groups.

The rising trend of SIDS among Pacificans seems to have been curbed. This is highly suggestive of the impact of the Pacific SIDS Prevention Programme and other similar prevention programmes currently implemented in the Auckland region. This conclusion is encouraged by the fact that this is the only targeted and new effort in SIDS prevention among and for Pacificans. The combine effect of insider Pacific health professionals and Community SIDS Educators fostered a more appropriate and innovative approach to developing and implementing a Pacific-oriented strategy. The use of experiences from other Pacific countries has also contributed to this. Other pertinent issues have been identified through this strategy, such as grief, poverty, and lack of resources, retaining community educators and child health. Collaboration with the National Maori SIDS Prevention Programme provided a wealth of knowledge and experience in tackling SIDS. Although this is an Auckland-based programme with limited national reach, it does provide a model for organizing a national programme.

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