

Sudden infant death syndrome among the Auckland Pacific communities 1988-1996: is it increasing?

Nite Fuamatu, Research Training Fellow, Pacific Health Research Centre; Sitaleki Finau, Senior Lecturer in Pacific Health; Colin Tukuitonga, Senior Lecturer in Pacific Health; Eseta Finau, Pacific SIDS Prevention Programme Coordinator, Department of Maori and Pacific Health, University of Auckland, Auckland.

Abstract

Aims. To define ethnic origin and verify the diagnosis of sudden infant deaths among Pacific peoples in Auckland 1988-1996, and to elicit socio-economic and demographic characteristics.

Methods. Police (P47) and coroner reports were analysed for an ethnic classification and diagnosis. Postneonatal and sudden infant death syndrome (SIDS) register and New Zealand Information Services data were analysed for additional Pacific cases. Rates of Pacific SIDS in Auckland were calculated. A Pacific SIDS database was developed and families were tracked. Face to face interviews covering the SIDS event were undertaken with selected families. Data were coded, stratified and a thematic approach to analysis was utilised.

Results. There were 52 cases of SIDS and the ethnic origins were: thirteen Samoans, nine Cook Islanders, seven Tongans, fifteen multiple ethnicity, and eight could not be verified. The annual rates of Pacific SIDS varied from less than one (in 1989) to 4.5 (in 1995) per 1000 Pacific live births. 34 cases (65%) could not be contacted and eighteen were traced. Nine

in-depth interviews were conducted with caregivers of these cases. All babies had slept in the supine position, seven were breastfed, and five of the mothers were non-smokers. Eight babies slept in the same room with their primary caregiver, with seven sleeping in their own bed. All of the mothers had had continuous access to childcare and support from their families, and seven had had previous children. Grief counselling for partners and children was identified as necessary by almost all the mothers.

Conclusions. This preliminary study concludes that the rate of Pacific SIDS increased in 1995 and remains a serious problem. Ethnic misclassification and under reporting of SIDS cases is apparent among Pacific infants. There is a need to establish a national infant mortality database that collects accurate data incorporating standardised ethnic specific categories. Official routine and data sources also need to incorporate standardised ethnic specific categories. A national prospective study is required to study SIDS in Pacific communities as a basis for effective prevention strategies.

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The New Zealand Cot Death Study (1987-1990) identified the Pacific population as having a lower rate of infant deaths than their Maori and European counterparts.¹ The National Maori Sudden Infant Death Syndrome (SIDS) Prevention

Programme has been collecting coroner and police (P47) reports to monitor Maori SIDS cases, and observed a number of non-Maori names.² This led to an increased recognition of Pacific infant death from SIDS, the

inadequate systematic collection of SIDS data in Pacific communities, and inaccurate reporting of SIDS cases.³

A list of names and addresses of Pacific SIDS cases was identified by the National Maori SIDS Prevention Programme database. This showed an increasing trend of SIDS among Pacific infants during 1988-1996.³ This finding was questioned, especially because of the widely held belief that SIDS is not a problem among Pacific infants.⁴ This paper reports an effort to establish definitively the ethnicity and cause of Pacific infant death. Qualitative research methods were used to examine some of the socio-economic and demographic aspects of these Pacific families.

Methods

The names of Pacific SIDS cases, and the police (P47) and coroner reports were obtained from the National Maori SIDS Prevention Programme. These reports and SIDS cases were cross-referenced to check ethnic origins of the child and each parent, accuracy of contact information, age, address, and place and cause of death. The Postneonatal and SIDS register, which is a National Maori SIDS Prevention Programme register that collects all SIDS deaths (up to two years) and infant deaths (from one month to one year), was examined for additional Pacific names and the ethnicity of both mother and father. This required an awareness of the diversity of Pacific cultures, and the ability to identify Pacific names, its ethnic origins, and Pacific names with European origins. A database of these Pacific SIDS cases was created to record: the baby's names, gender, date of birth and death, place of death, name of mother and father, ethnic origins of mother and father and baby, address, phone number, file number, and date of registration. Classification of ethnicity in the database was based on the ethnic origin of both mother and father as recorded on these reports.

Fetal and infant deaths data provided by the New Zealand Health Information Services (NZHIS) 1988-1994 were examined for official numbers and rates of Pacific SIDS cases in Auckland.⁵⁻⁷

Qualitative data were collected through face to face interviews. The families for interview were selected from the database of Pacific SIDS cases and tracked using contact details on the police (P47 forms) and coroner reports. The P47 is the police death scene report. The coroner's report is a record of the post-mortem. Figure 1 shows the flowchart for tracking families. The telephone directory, the Post Shop, and Housing New Zealand were employed to track telephone numbers and addresses and personal networks and home visits were also employed.

A suitable time for an interview and consent was arranged with the main caregiver. A letter of introduction about the project and SIDS team, and consent form was prepared in English and translated into the Samoan, Tongan, Cook Islands, and Niuean languages. Ethical approval was obtained from the University of Auckland Human Subjects Ethics Committee. The interview consisted of nine key areas. 1) General questions such as age, current work status, number of children, 2) ethnic origin of the parents and grandparents, description of lifestyle practices, 3) infant care practices and support network, 4) the incident, 5) risk factors, breastfeeding and bottle-feeding, sleeping position, and smoking, 6) bedding and bedsharing, 7) housing such as heating and ventilation, 8) grief, and 9) types of SIDS information recollected and needed. In-depth audiotaped interviews of 60-90 minutes were conducted with the SIDS families in their homes. These were held in English and/or Samoan. The interviews were analysed by coding their responses and drawing on common themes.

Results

The original list of Pacific SIDS cases from the National Maori SIDS Prevention Programme contained 69 names. After these were cross-referenced with police and coroner reports, 25 deaths (36%) were found to be due to other causes such as bronchopneumonia, meningitis, and haemophilus infection, and 44 deaths were SIDS cases. The Postneonatal and SIDS Register was analysed and eight additional Pacific cases were found, therefore identifying a total of 52 Pacific SIDS cases from 1988-1996 (Table 1).

Ethnic origin and demographic information (Table 2). There were thirteen (25%) Samoan, nine (17%) Cook Islands, seven (14%) Tongan, fifteen (29%) multiple ethnicity and eight (15%) with no ethnicity or gender information. The multiple ethnicity category contained fifteen cases (29%) of which the mother and/or father came from two or more different ethnic groups eg Samoan/Tongan, and Samoan/Maori/European. There were more males (48%) than females (36.5%).

32 (61.5%) cases died between seven and twenty weeks after birth (Table 3). Most cases occurred in South Auckland (38.5%) and Central Auckland (32.7%), the least occurring in the Northern and Eastern parts (1.9% respectively). The number of SIDS by season were: winter (28.8%), summer (25%), autumn (21.2%) and spring (19.2%).

Tracking SIDS families for interviews. Initial attempts to contact SIDS families was through using the telephone numbers and addresses provided on the police and coroner reports (Figure 1). A total of eighteen families (35%) were ultimately traced, with nine being interviewed while the others declined.

Interviews of Child Carers with SIDS. Nine interviews were conducted with Pacific families in 1997-1998; three from 1996, four from 1995, one from 1991 and one from 1990. The interviews were conducted with seven mothers, one couple, and one mother and grandmother. At the time of the interview, the fathers were working, caring for the children, or had since left the relationship when the baby died.

1) *General.* The mothers' ages ranged from 21 to 42 years, and the fathers from 21 to 39 years. For seven families, the baby that died was not the firstborn. Six of these women had gone on to have more children. The age of the baby at death varied from two weeks to five and a half months, and six of these occurred in the home and three at Middlemore Hospital. The mother's occupations were: caregiver (4), beneficiary (2), employed full-time (2), and doing a training course. The father's occupation were employed full-time (6) and beneficiary (2). The number of people living in the households ranged from four to thirteen people.

Table 1. Number and rate (per 1000 live births) of Pacific SIDS in Auckland 1988-1996.

Year	Total Pacific live births	NZHIS number	NZHIS rate	National Maori SIDS prevention programme number	National Maori SIDS prevention programme rate	Pacific SIDS research number	Pacific SIDS research rate
1988	2873	7	2.3	3	1.0	3	1.0
1989	3164	6	1.7	2	0.6	2	0.6
1990	3473	6	1.7	5	1.4	4	1.1
1991	3590	10	2.8	6	1.7	6	1.7
1992	3488	10	2.9	5	1.4	8	2.3
1993	3351	2	0.6	5	1.5	4	1.2
1994	3173	6	2.0	12	3.8	5	1.6
1995	3087	NA*	NA*	19	6.2	14	4.5
1996	3137	NA	NA	12	3.8	6	2.0
Total	29 336	47	14.0	69	21.4	52	16.0

*There was a change in classification of ethnicity in 1995. This is consistent with the concept of ethnic self-identification aimed at providing more detailed statistics and encompass a broader range of ethnic options.⁸ NA=not applicable. NZHIS=New Zealand Health Information Service.

Table 2. Number of SIDS cases by ethnicity and gender.

Ethnic Origin	Male	Female	Total
Samoan	7	6	13
Cook Islands	5	4	9
Tongan	6	1	7
Multiple Ethnicity	7	8	15
Unknown	NA	NA	8
Total	25	19	52

NA=not applicable

Table 3. Age at death of SIDS cases.

Months	Number	Frequency (%)
<1-1.5	7	13.5
1.6-3.1	21	40.4
3.2-4.7	11	21.1
4.8-6.3	4	7.7
6.4-7.9	3	5.8
8-9.5	2	3.8
9.6-11.1	1	1.9
Unknown	3	5.8
Total	52	100

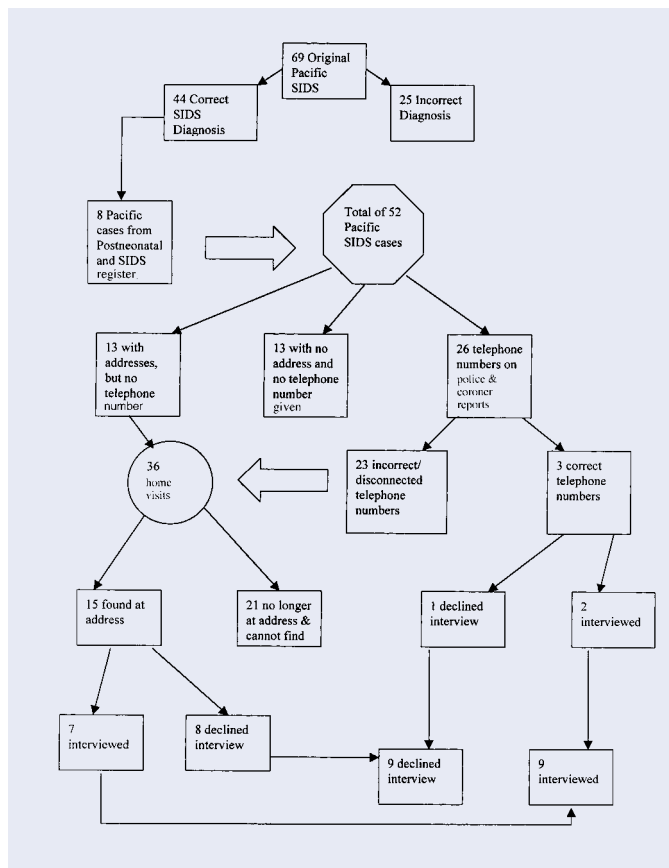


Figure 1. Flowchart to tracking Pacific SIDS families.

2) *Ethnic Origin of Parents.* The mothers were Samoan (5), Samoan/Maori (1), Cook Islands (1), Maori/European (1) and European (1). The fathers were Samoan (5), Samoan/Maori (1), Cook Islands (2) and Tongan (1). The ethnicity of the parents was based on the ethnic group that their parents came from. Those with mixed parents identified their ethnicity according to all the ethnic groups their parents came from. This was used to determine the ethnicity of the baby.

3) *Infantcare.* Childcare and support was received from the parents' mothers, in-laws, families, and from their own children. This was dependent on living arrangements eg

living with in-laws, and other considerations, such as whether they had a good relationship with their kinsfolk. Childminding eg bathing, feeding, were the main activities performed by their families. Seven of these women had had previous children and had no cause to change their infant or childcare practices.

4) *Incident.* Seven babies were healthy prior to death. One had been to the doctor and another was awaiting a bowel operation. Four of the mothers had performed activities which were different from their usual; one baby slept with his parents for the first time and was started on solids foods on the day of death; another baby slept unsupervised in the prone position; another baby slept in bed on an adult pillow; and yet another baby had been taken out late that night. The remaining mothers had gone about the usual routine.

5) *Risk Factors.* All nine mothers normally had put their babies to bed on their back or side. Babies were only put on their stomach if they were supervised or could independently hold their heads up. Five mothers were non-smokers, and four were smokers who did not smoke near or around the baby. Three babies slept in a cot, two slept on a single bed, two in a bassinet, and two slept with their caregivers on a double bed. Eight of the babies slept in the same room with their caregivers. Seven were breastfed and two were bottle-fed, and they were fed every three to four hours or on demand.

6) *Bedding and Bedsharing.* The babies had slept on a single/double bed, bassinet or in a cot. These were placed next to the wall to prevent drafts from the window and door. The bedding consisted of a sheet, plastic or underlay covering the mattress, a duvet, blanket or bumper pad, another sheet (optional), a baby pillow, and a duvet or baby blanket/quilt. Woollen blankets were not used because they were considered too heavy, too hot, or caused itchiness. The babies usually slept in a singlet or t-shirt, skivvy (optional), stretch-n-grow or nightie, and nappy. Four babies slept with their mothers, and one with a grandmother, because they had either grown too big for their bassinets, or the caregivers wanted the baby close by.

7) *Housing.* A total of eight families lived in three bedroom houses, and one family of five lived in a two bedroom flat. Six families lived in rented dwellings, and three owned their houses. Ventilation and fresh air for children was considered very important and windows and doors were frequently left open. Houses were vacuumed regularly because baby was crawling on the floor. Oil and fan heaters were used during winter to warm up the house or room. One family preferred to use more blankets and wear warm clothes.

8) *Grief.* None of the nine mothers had any SIDS personnel visit them and the Pacific team was the first time contact had been established about their loss. However, all of the mothers had taken action to work through their grief. Family, church, and peer support were the main sources that they drew on. Children and male partners were identified as needing support and counselling also. Their male partners were a major concern because they had not openly grieved, did not talk about it, and refused to seek professional help. A support group for grieving SIDS parents was viewed positively.

9) *Information.* The level of knowledge about SIDS differed amongst the mothers. Some had heard of SIDS and there was uncertainty and curiosity about its cause and prevention strategies. Television advertisements about Red Nose Day were recollected. Current SIDS information and materials translated into Pacific languages were requested.

Discussion

This research shows 52 Pacific SIDS cases for 1988-1996 in Auckland, which is less than the information provided by

NZHIS. This discrepancy in Pacific cases highlights two important points; the under reporting of SIDS, and the need for a monitoring mechanism. Mounting interest from various sectors led to the inclusion of the 'Pacific Island' group in post-1992 fetal and infant deaths publications. Such an interest in this group suggests formal monitoring of SIDS incidence has been established, particularly when previously identified as having the lowest SIDS rate. This is evidently not the case.

Scrutiny of official sources show inaccurate recording of Pacific names. The correct spelling of Pacific names assists in identifying ethnic origin, ensures appropriate contact and minimises repetition of names on the register. One SIDS case was counted twice because the baby's name was entered under both parents' surnames. Ethnic classification assists the development and implementation of appropriate prevention strategies. A two-day forum on SIDS held with Pacific communities (November 1996) concluded that the collection of reliable Pacific SIDS data and the formulation of guidelines for ethnic specific programmes to Pacific people were essential to addressing the problem of SIDS.⁹

25 cases listed as SIDS were, in fact, not related to SIDS. Causes of death, as determined at post mortem, included bronchopneumonia, meningitis and haemophilus influenza. To improve data accuracy post-mortem, mortality review and a formal register of Pacific infant mortality could be established. This register should incorporate: baby's names, gender, date of birth and death, age at death, place of death, name of mother and father, ethnicity of mother and father and baby, address, and telephone number. A national infant mortality database that includes such information would improve data accuracy for every ethnic group in New Zealand.

Given the lack of data and systematic collection of SIDS in Pacific communities, the task of tracking families proved cumbersome. This study showed a high number of disconnected or incorrect phone numbers (90%) supplied on official reports, and families (40%) that had moved and left no forwarding address. The low number of families that consented to participation (17.3%) in the interview may represent a negativity derived from the SIDS experiences. The validity and representativeness of our findings is affected by insufficient sample size. These data will be useful, however, for developing prevention strategies, and in formulating research questions. The experience in tracking families highlights the barriers to data collection and service delivery to Pacific peoples whom are mobile and difficult to contact.

Undertaking this research with Pacific communities required a level of knowledge about Pacific cultures and

protocols, fluency in English and a Pacific language, and access to community networks. The ability to communicate in a Pacific language fostered a rapport that enabled a better dialogue between the researcher and participant. Inherent in this primary medium of communication is a value system that underlies a particular worldview and responses to it.¹⁰ Unnecessary anxiety and mistrust were alleviated, prompting a favourable reception to the project from the outset. The low response rate from the families tracked however, may be an indication of peoples perceived inadequacies of dealing with grief and death. As a study, these preliminary findings show rich data not seen previously, and associated limitations with the study. This offers valuable insights to developing prospective research, both locally and nationally, for assisting in prevention strategies.

Based on this preliminary study, SIDS in the Pacific communities appeared to increase in 1995, and might still be increasing. Routine and official data sources are currently insufficient for reporting accurately and monitoring Pacific infant mortality. A national infant mortality database that incorporates standardised ethnic specific categories is needed. Official routine data sources also need to incorporate standardised ethnic specific categories. From the qualitative phase of this study, the insights gained are useful in developing prevention strategies, and can better assist the design of a national prospective study.

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Correspondence. Nite Fuamatu, Pacific Health Research Centre, Department of Maori and Pacific Health, Faculty of Medical and Health Sciences, University of Auckland, Private Bag 92019, Auckland. Fax: (09) 373 7074; Email: n.fuamatu@auckland.ac.nz

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If you are going to be ill, the best place to be is France - the country ranked first in an analysis of the world's healthcare systems carried out by the World Health Organisation (WHO).

Among major countries, France was followed by Italy, Spain, Oman, Austria and Japan, with several small countries (including San Marino, Andorra, Malta and Singapore) rated among the top ten healthcare providers.

Despite spending more of its gross domestic product on health than any other country (13.7%), the United States ranked only 37 out of 191 WHO member states; the United Kingdom, which spends just 6% of gross domestic product on health services, came out 18th. France spends 9.8%.

Zosia Kmietowicz. *BMJ* 2000; 320: 1687.