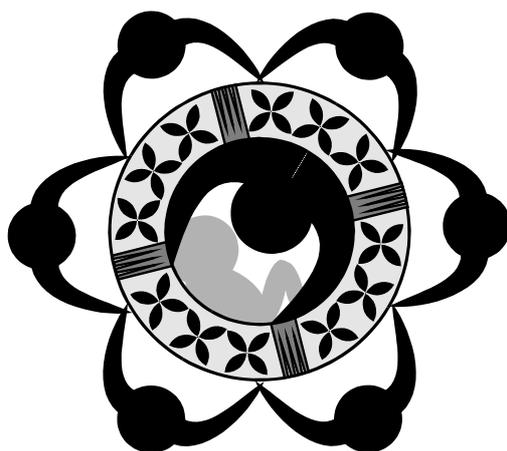


Pacific Islands Families: The First Two Years of Life Study



TECHNICAL REPORT 1

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1.0 BACKGROUND

Pacific people in New Zealand are characterised by high fertility, a high population growth rate and a youthful population (Cook, 1999). Pacific peoples tend to be disadvantaged in New Zealand society and are over-represented in adverse health and social statistics (Bathgate et al., 1994; Ministry of Health, 1998). Compared with national rates, Pacific children are at increased health risk with high rates of hospitalisation and high incidence of respiratory infections (Bathgate et al., 1994). These factors have implications for child health, development and wellbeing. Despite this, little epidemiological information on Pacific children's health and development is available to inform policy development. In response to this informational need, the Pacific Islands Families Study (PIF) was developed through a process of collaboration with Pacific communities, researchers, and relevant health and social agencies.

1.1 Setting of the study

The cohort was recruited from Middlemore Hospital, the largest Hospital under the umbrella of South Auckland Health. The maternity division of Middlemore has the largest number of Pacific births in New Zealand, and includes the main Pacific Islands ethnic groups. There are two small satellite maternity hospitals (Papakura and Botany Downs), connected to Middlemore Hospital. Mothers and infants who were transferred from Middlemore to these satellite hospitals after the birth were eligible for inclusion in the study. Use of a single large recruitment site has immediate theoretical and social benefits in terms of the epidemiological foundation (utility of findings for the respondents and a substantial identifiable source community), will enhance compliance and retention, and is logistically sound in terms of data gathering and information systems management.

2.0 AIMS

The PIF Study is following a cohort of 1398 Pacific children within their family environment over the first two years of the child's life. Extensive consultation within Pacific communities has contributed to the development of this multidisciplinary project and the inclusion of psychosocial and health concepts that are relevant to these communities. It is anticipated that this prospective, longitudinal study will generate important practical information on Pacific child and family health and psychosocial functioning over a critical developmental stage. The three overall objectives of the PIF Study are:

- (a) to provide information on Pacific peoples' health, and the cultural, economic, environmental and psychosocial factors that are associated with child health and development outcomes and family functioning,
- (b) to determine how such factors individually and interactively influence positive and negative child, parent and family outcomes over time,
- (c) to provide information that will help set quantifiable targets for Pacific peoples' health.

These three objectives are designed to inform policy development and programme implementation for a variety of end-users working towards maximising the potential of Pacific families and communities within New Zealand society.

3.0 METHODS

3.1 Design

The PIF Study employs epidemiological methods and a prospective design to follow a birth cohort selected from the Pacific population over the first two years of the child's life. The PIF Study is made up of respondents from a community population, and follows individuals and families *prospectively*. This design was optimal in that it satisfied the aims of the study by (a) allowing estimation of incidence rates; (b) providing relative and attributable risk statistics and causal pathways; and (c) largely eliminating recall bias and permitting analysis of bias through attrition and non-participation (Lilienfeld & Lilienfeld, 1980). Alternate possibilities regarding the start point for data collection (e.g., at an antenatal point), their advantages, disadvantages, costs and feasibility have been worked through extensively by the

scientific and community members. The present design is cost-effective (Fergusson et al., 1989), and is at a developmental stage that is optimal for intervention (Mrazek & Haggerty, 1994).

3.2 Statistical power

A cohort of approximately 1400 was recruited as it was estimated that with attrition, a final cohort at 24-months of 1000 would provide sufficient statistical power to detect moderate to large differences after stratification for Pacific ethnicity and other key variables (e.g., sole vs. two-parent families). Based on the non-differential attrition rate of 6% to date the projected cohort numbers at each of the follow-up data points will still have adequate power with 1314 at 12-months and 1235 at 24 months. The size of the cohort has adequate power for inter-ethnic comparisons. Intra-ethnic analyses will only be calculated for major groups such as Samoan, Tongan and Cook Islands Maori. It is recognised that power may not always be adequate for analyses involving smaller ethnic groups or for more complex analyses involving a greater number of categories (e.g. different feeding methods in Islands born versus NZ-born Tongans). Variables other than ethnicity may be collapsed if cross-tabulations are sparse.

3.3 The cohort

The cohort was drawn from Middlemore Hospital in South Auckland from 15 March to 17 December 2000.

3.3.1 Eligibility criteria

All potential child participants were selected from live births at Middlemore Hospital where the child had at least one parent who identified as being of a Pacific Island ethnicity and also a New Zealand permanent resident. There were no further eligibility requirements for participation in the Study. While in Middlemore Hospital, permission was sought from the mothers of potential participants to contact them six weeks later. At this initial approach 98% of mothers consented to a visit by an interviewer to further explain the study when their infant was six-weeks old.

3.3.2 Provision of information and informed consent

1. Promotional material was made available through numerous sources (e.g. media, community meetings) so that parents were aware of the study and had time to consider their involvement prior to admission at Middlemore. Information distributed via antenatal classes and Lead Maternity Carers also informed all potential participants.
2. Recruitment procedures occurred at Middlemore through the Birthing Unit in conjunction with the Pacific Islands Cultural Resource Unit that provided a daily printout of Pacific admissions. These were checked for Pacific births and crosschecked with the daily records held in the Birthing Unit.
3. Under the supervision of Middlemore Clinical staff, a Pacific Liaison Officer appointed by the Study made the initial approach to eligible participants within the hospital setting. This initial approach was for brief information giving and permission for later contact. Informed consent was not sought at this point. Each day of the recruitment period that ran from 15 March to 17 December 2000, was covered either by the Pacific Liaison officer (6 days) or a rostered replacement (1 day).
4. For potential participants who were either discharged home or to one of the two satellite hospitals prior to being seen by the Pacific Liaison officer, a secondary recruitment procedure was carried out. In these situations, the Pacific Liaison Officer visited the mother outside of Middlemore Hospital to make the initial approach.
5. Four-to-six weeks after birth, potential participants were allocated to a team of trained female Pacific interviewers fluent in both English and a Pacific language. In most cases the interviewers were ethnically matched with the potential participant.
6. The female interviewers visited the potential participants in their own homes and informed consent was obtained after full discussions had occurred with the parents.
7. Once informed consent was obtained the interview was carried out in the preferred language and returned to the office for coding and data entry procedures.

3.3.3 Response Rates

A high response rate of 93% was achieved with mothers who were contactable at six-weeks and who were confirmed as eligible (New Zealand permanent residents). When taking into account mothers that could not be contacted to confirm eligibility (a permanent New Zealand resident or whether they remained in the country six weeks after the birth of the child), the response rate remained high at 88%. In sum, the final cohort is made up from potential participants whose mother's met the eligibility criteria, were contactable and where the child survived to six weeks.

3.3.4 General description of the mother and infant participants of the cohort

Of the 1376 mothers of the cohort (1.7% gave birth to twins), 1365 were biological mothers and 11 were foster or adoptive/foster mothers. The mean age of mothers was 27 (SD=6.2) years, the range was 14 to 57 years, and 8% of mothers were younger than 20 years. The majority of mothers (n=1107; 80.5%) were living together in married or defacto partnerships, and 454 mothers (33%) were New Zealand-born. The majority (n=535; 38.9%) of mothers had no formal educational qualifications, 464 (33.7%) had secondary school qualifications and 377 (27.4%) had post-school qualifications. Just over a quarter of infants were first-borns and 1339 infants (97.3%) were discharged with their mothers from hospital. Middlemore hospital records revealed that the mean birth weight was 3584 grams (SD = 613) with a range of 650 to 5390 grams.

Ethnicity of Pacific mothers was self-identified and also coded according to the sub-groupings of the 1996 Census. The ethnicity of 1398 infants of the cohort was categorised by the mothers' ethnicity. Of the cohort mothers, 650 (47.2%) self identified their major ethnic group as Samoan, 289 (21%) as Tongan, 232 (16.9%) as Cook Islands Maori, 59 (4.3%) as Niuean, 47 (3.4%) as Other Pacific (this includes mothers identifying equally with two or more Pacific groups, equally with Pacific and Non-Pacific groups, or with Pacific groups other than Samoan, Tongan, Cook Island or Niuean), and 99 (7.2%) as Non-Pacific. The infants with a Non-Pacific mother were eligible due to Pacific ethnicity through the father.

3.3.5 Ethnic representativeness of the cohort

Comparisons of the ethnic representativeness of the cohort have been made with the Pacific data available from Statistics New Zealand 1996 and the 2001 Census. This is possible as data are recorded on the ethnicity of all possible participants, including non-participants based on eligibility (e.g., not permanent New Zealand resident, infant deaths etc) and non-participants due to refusals. The cohort was drawn from Middlemore Hospital, South Auckland and was not intended to be representative of the total population. However, Middlemore has the largest number of Pacific Islands births in New Zealand, and the ethnic groupings are broadly representative of the Pacific census figures. For example when comparing with the 1996 Census the figures are Samoan 50% (96 Census) and 47.2% (PIF cohort), Cook Islands Maori 23% (96 Census) and 16.9% (PIF cohort), Tongan 16% (96 Census) and 21% (PIF cohort), Niue 9% (96 Census) and 4.3% (PIF cohort).

Note: Our classification of infant ethnicity differed from that used by Statistics New Zealand because it was weighted according to the Pacific component of ethnicity not the Maori component. Within the Statistics New Zealand classification those infants who had a Maori mother were identified as Maori whereas the infants in this cohort have been classified according to their Pacific parent (mother or father).

3.4 ASSESSMENT METHODS

Information concerning the current and recent circumstances of the families is obtained through interviews conducted at three time points. The six-week measurement framework is presented in Appendix 1. The first measurement point was an interview with the mother six weeks after the birth of the child. Subsequent measurements are being carried out with mothers and where appropriate, fathers at

the child's first and second birthdays. Participants are given the opportunity to respond in their primary languages. At the 12-month interview mothers are asked for contact details for the father/father figure of the child. All fathers who are contactable are invited to join the study at the 12 and 24-month data collection points. Selected information has also been gathered from Middlemore Hospital birth-records and the Royal New Zealand Plunket Society's records from their routine home visits that occur six weeks after birth.

3.4.1 Interviewer Reliability

A number of systems are in place to check on interviewer reliability. These include manual coding of each interview to check consistency within the individual interview; random phone checks to participants to clarify specific details; repeat interviews with different interviewers to assess reliability across interviewers; and accompanying interviewers to check on rapport, informed consent and on the carrying out of standard procedures.

3.4.2 Development of the interview protocols

The interview protocol is primarily designed to gather quantitative data, however, several areas within the interview protocol are qualitative in order to explore some questions in more depth. In order to make a contribution to the understanding of Pacific child health and development in New Zealand, it was considered important to select content areas and employ measures deemed relevant and appropriate by both researchers and Pacific communities. To this end, there was extensive consultation with the Pacific communities. Furthermore, Pacific researchers within the PIF team have considerable input into the general measurement framework and specific measures used in the Study. The content and measures for the three measurement points are subjected to specific internal and external processes before inclusion in the interview protocol.

In order to gather scientifically rigorous data, due consideration is given to the employment of existing measures known to have acceptable psychometric properties. There are practical and theoretical reasons for applying internationally developed scales in the PIF Study: (a) to measure constructs that are universal across cultures (e.g. child motor development), (b) to elicit information that is considered to be important in terms of future child health and development, and (c) to demonstrate the appropriateness of existing scales and by analysis and review, further develop or reject them for ongoing research and/or clinical practice in a Pacific context.

From the outset, researchers recognised that employment of some existing assessment instruments may not be appropriate for these communities and that, ideally, the undertaking of discrete validation studies for these measures would be desirable. However, such a procedure was not practical for a variety of reasons including the extra funding that would be required, the burden on Pacific families and the amount of time needed to fully address validation issues. An alternative strategy was therefore adopted whereby standardised measures were employed in both the Pilot and the Main Studies and the appropriateness (reliability & validity) of these measures closely monitored. Where measures employed during the Pilot Study proved unsatisfactory (e.g., SF-12) they were removed from the Main Study. The psychometric properties of most standardised measures were at acceptable levels and modifications were not necessary. This is critical information in terms of the usefulness of these tools for clinical application in the Pacific context. Most measures demonstrated very satisfactory internal consistency and validity. Some measures have undergone a focus group examination to check wording of items and testing procedures (Fox, 1994; Kreuger & Casey, 2000).

The interview protocol was translated into Samoan, Tongan and Cook Islands Maori and was checked by fluent speakers of these Pacific languages to ensure that the translated versions matched the English version. In addition, the interview was individually administered by interviewers who were fluent in a Pacific language and were therefore able to clarify concepts verbally where necessary. All participants were given the opportunity to use a translated interview protocol, however only 174 mothers (13%) took up this option.

3.4.3 Secondary data collection

Additional data was collected from Middlemore Hospital birth records, together with reports from Plunket visits at six-weeks. This was collected from secondary sources to lessen the burden on cohort mothers and infants. Medical birth details were collected from Middlemore and the data from the comprehensive physical assessment carried out by Plunket at six-weeks meant that these dimensions did not need to be covered in the PIF interview and thus the interview length was minimised. Thus, four measurement points will be available for some key outcome variables. This will allow models to be fitted to individual developmental trajectories, incorporating individual, family, and environmental characteristics as covariates. The gathering of data from mothers, fathers and secondary sources allow the concordance between reports of child outcomes and parental functioning to be assessed. Testing for bias through differential attrition will be carried out at 12 and 24- months, and conditional analyses will be undertaken as appropriate (Rubin, 1976; 1987).

3.5 Data Analysis

All data, including that from open-ended questioning and interviewer observations, are coded and double entered into an electronic data base (SPSS Data Entry Builder 2.0) that employs comprehensive data validation and checking rules. Analyses will incorporate a) scale formation, including the evaluation of reliability and stability of measures, and (b) exploratory and confirmatory hypothesis testing and statistical modelling.

Cross-sectional analyses at each assessment time will be undertaken, which will allow the prevalence of key outcomes to be estimated, as well as the association between risk factors and key outcome variables. Several longitudinal analysis techniques will be used in the modelling of developmental pathways. Specifically, structural equation modelling will be used to investigate latent constructs (Willet & Sayer, 1994). Mixed linear models will be used to assess the individual developmental pathways, by analysing the data collected at the three interviews (six weeks, 12 and 24-months) (Bryk & Raudenbush, 1987). In the analysis of binary outcome variables, generalized estimating equations will be employed to incorporate the multiple observations from each participant (Liang & Zeger, 1986).

There were a small number of open-ended questions in the six-week interview protocol. Two researchers developed the codes for these questions based on the first 50 cases. The codes were checked on completion of this phase and collapsed or modified if necessary.

4.0 ETHICS AND CONFIDENTIALITY

Careful consideration was given to the ethical aspects of this longitudinal study with Pacific peoples. Ethical approval for the PIF Study was obtained from the Auckland Branch of the National Ethics Committee, the Royal New Zealand Plunket Society and the South Auckland Health Clinical Board.

4.1 Data security

The data from the study is coded and held anonymously in secure storage under the responsibility of the Co-Directors in accordance with the requirements of the New Zealand Privacy Act (1993) and the Health Information Privacy Code (1994). All reference to participants is by code number only. Identification information is stored on a separate file and computer from that containing the actual data. All interviews are confidential and only PIF Study staff authorised by the Co-Directors have access to computerised data. All information is treated as sensitive data. Provisions have been made for any participants who request that their data be disposed of at any time.

4.2 Emergency situations

As this is not a clinical trial but a community survey, low levels of emergency are expected however if the research unexpectedly identifies some condition unknown to the subject, they are advised to contact their usual adviser/practitioner. If any emergency situations arise such as suicidality, homicidality, abuse or neglect, a referral needs to take place with appropriate community services. Participants are always advised before a referral takes place. Confidentiality of respondents is preserved with great care and participants are informed of the legal limits of the confidentiality assurance given at the start of the interview.

5.0 THE RESEARCH TEAM

The PIF Study is being undertaken by a team of researchers under the leadership of the two Directors, Dr Janis Paterson and Dr Colin Tukuitonga. The two Directors are guided by the Pacific Peoples' Advisory Board who monitor the general direction of the Study. The Board is primarily set up to protect and enhance the Study in order to maximise benefits to the Pacific communities. The Management Group (Paterson, Tukuitonga, Cowley, Abbott, Feehan, Silva, Percival, Borrows, Butler, Giles and Williams) have responsibility for general decision making and policy development to ensure optimum running of the Study.

Pacific and Non- Pacific researchers share various responsibilities across the different layers of the study. This structure is optimal as it draws on research expertise and skills across disciplines and brings ethnically and culturally diverse perspectives to the Study. In addition the PIF serves as an excellent platform for the advancement and training of Pacific researchers and field staff.

5.1 Investigators

Dr Janis Paterson and Dr Colin Tukuitonga as Directors of the PIF Study share the scientific and management responsibility. They are directly responsible to the funders, the Pacific Peoples' Advisory Board and to the Pacific communities. In addition to his academic Pacific research role, Dr Tukuitonga is responsible for policy and strategic initiatives with government and non-government agencies at local and national levels. Dr Paterson is responsible for the daily running of the project relating to organisation and monitoring of all procedures. These roles are essential for effective co-ordination of the project and associated staff. In addition both Directors are principal investigators responsible for specific areas of investigation.

5.2 Co-Investigators

The co-investigators and the sub-contracted investigators all assume academic leadership for their respective areas. They are Professor Max Abbott, Dr Teuila Percival, Associate Professor Michael Feehan, and Professor Phil Silva. Their roles include management of measurement issues, data collection, data handling, analysis, write-up, publication and dissemination. These procedures are undertaken following policies set by the Management Group. Other investigators include Ms Esther Tumama Cowley (community liaison), Maynard Williams and Lynne Giles (data management and biostatistics), Sarnia Butler (Research Fellow) and Jim Borrows (financial and project grant management).

5.3 Field Staff

There are 3 male and 4 female Pacific interviewers who are fluent in English as well as a Pacific language. A South Auckland office provides a base for the interviewers and a collection point for completed interviews. All interviewers participated in intensive training sessions prior to the commencement of each phase of the study. Ongoing monitoring of the interview process occurs via checking of each interview protocol and regular feedback to each interviewer. In addition, regular individual and group meetings are held with all interviewers to ensure optimum accuracy of data collection.

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