

**Sudden Unexpected Death in Infants
(SUDI) and parental infant care:**
perspectives of general practitioners, nurses and
parents living and working in the multicultural
community of Western Sydney

Leigh Wilson

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FOREWARD

I, Leigh Wilson, was primarily responsible for the following: development of the research proposal and research questions; selection of research methods; data collection; data management; data analysis; interpretation and presentation of findings; and the development of recommendations.

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The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material previously for a degree at this or any other institution.

Candidate Signature..... Date.....

DEDICATION

This thesis is dedicated to

A grand lady who dedicated her life to improving infant and maternal health

Dr Clair Isbister

(1915 - 2008)

and

to all infants who have died suddenly and unexpectedly;

may your numbers continue to decrease.

ABSTRACT

For many years the major cause of infant mortality in NSW has been the result of Sudden Infant Death Syndrome (SIDS). Statistics show the area defined as 'Western Sydney' is no exception, and in 2002, a report prepared by the Epidemiology, Indicators, Evaluation and Research Unit (EIRE) in Western Sydney presented data indicating SIDS rates in the area were higher than the state average. In particular, two Local Government Areas (LGAs) had clusters of SIDS deaths. Previous Australian research identified a higher risk of SIDS and other causes of infant mortality in Aboriginal and Torres Strait Islander populations. The areas of Western Sydney where SIDS rates were higher than expected were home to Aboriginal, Torres Strait Islander and Pacific Island residents. The number of SIDS deaths in Aboriginal infants did not explain the higher than expected rate of SIDS in the areas under investigation. Studies undertaken in New Zealand and the Pacific Islands have identified higher than expected risk of SIDS in Maori and Pacific Island communities in those countries, although this has never been studied in Pacific Island residents living in Australia. The reasons for these communities exhibiting a higher than normal SIDS rate is not completely understood, but can be partially explained by behavioural practices which are known to impact adversely on the risk of SIDS.

This study sought to investigate the level of knowledge concerning the prevention of sudden and unexpected death in infants (SUDI) in three key groups of infant caregivers: general practitioners, nurses and parents living or working in the area geographically defined by Sydney West Area Health Service (WSAHS). In addition, the study sought to identify any variation in knowledge of SIDS reduction strategies in the three groups under study, and to investigate factors influencing knowledge and practice in these participants. The study findings were then used as a basis on which to develop strategies and recommendations to enhance the delivery of safe sleeping messages through the health care system.

Using a combination of qualitative and quantitative methods, this cross-sectional study highlights a number of issues around infant care practices and the major influences on new parents living in a multicultural community. Results of the study showed there is a

large variation in knowledge around safe sleeping practices (including SIDS reduction strategies) in all the groups studied. Although educational campaigns are conducted regularly, many general practitioners and parents are confused about the key SIDS reduction messages and still place infants in sleeping positions considered unsafe. While nurses and midwives were aware of the SIDS reduction strategies, they still occasionally used infant sleeping positions considered unsafe. General practitioners born overseas in a country where English is not the first language were less likely to be familiar with safe sleeping messages, including SIDS reduction strategies. Families from a Culturally and Linguistically Diverse (CALD) background were less likely to have seen SIDS information in their own language than families who spoke English, and as a result were more likely to use traditional methods of infant care, including co-sleeping with siblings and parents and side or tummy sleeping. CALD parents were more likely to rely on herbal remedies and friends and family for assistance, than English speaking parents who accessed health professionals as the first point of call when infants were unwell.

The study identified a relatively recent practice, which until reported in this study, has not been documented in the literature. The practice of draping infant prams with blankets originated from the Cancer Council of Australia guidelines which recommend covering a pram with a light muslin wrap to protect infants' skin from the sun. It appears parents have misinterpreted this message and are covering infant prams with blankets to encourage sleep, even when sun exposure is not an issue. Research suggests that poor air quality around the head of an infant may affect an infant's arousal response. While no research has been conducted on the air quality around an infants head when covered by a heavy blanket in a pram, it is possible based on research into air quality around infants, that that this practice may increase the risk of sudden and unexpected death in an infant.

In conclusion, this study found that multiple changes to the SIDS reduction messages since the initial 'Reduce the Risks' Campaign have led to confusion about ways of preventing SIDS in GPs, nurses and parents in Western Sydney. The study makes seven recommendations aimed at improving knowledge of safe sleeping practices in these groups, and optimizing health outcomes for infants using a collaborative approach to service delivery and future initiatives.

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ABBREVIATIONS

CALD	Culturally and Linguistically Diverse
CDRT	Child Death Review Team
C&FHN	Child and Family Health Nurse
ECHN	Early Childhood Health Nurse
GP	General Practitioner
LGA	Local Government Area
RTR	Reduce the Risks Campaign
SIDS	Sudden Infant Death Syndrome
SUDI	Sudden Unexpected Death in Infancy
SWAHS	Sydney West Area Health Service

CHAPTER 1 - INTRODUCTION

“A journey of a thousand miles begins with a single step”

Lao-tzu, Chinese philosopher (604 - 531BC)

1.1 BACKGROUND

The original concept for this research project was developed in 2003, following the publication of a report prepared by the Epidemiology Indicators Research and Evaluation Unit based in Western Sydney Area Health Service. The report, titled ‘The Health and Wellbeing Status of Children and Youth in Western Sydney’ examined in detail the demographic characteristics of the Western Sydney population aged less than 24 years, and key indicators of health status including morbidity and mortality (Wilson et. al, 2003).

Although Western Sydney as a whole compared favourably with NSW on key indicators of health status, investigating the data at a Local Government Area (LGA) level indicated higher than average rates of infant mortality in some LGA’s and not others. Further investigation of the data in these LGA’s identified the major cause of infant mortality as Sudden Infant Death Syndrome, commonly referred to as ‘SIDS’. Although the absolute number of deaths due to SIDS has decreased dramatically since the implementation of health promotion campaigns to educate families and professionals about ‘safe sleeping’, there appeared to be a recent upward trend in infant deaths classified as ‘SIDS deaths’ in Blacktown and Penrith LGA’s.

The reason for this finding was unclear, however Blacktown and Penrith Local Government Areas were known to have culturally diverse and socially and economically

disadvantaged populations and were home to large numbers of Aboriginal and Torres Strait Islander and Pacific Island residents.

Evidence has identified Aboriginal and Torres Strait Islander populations as being at higher risk of SIDS and other causes of infant mortality (Eades et. al, 1999: NSW Health 2001b). Studies undertaken in New Zealand and the Pacific Islands have also shown that Maori and Pacific Island communities in those countries have a higher risk of SIDS although this has never been studied in those from the Pacific Islands living in Australia (Everard et. al, 1998; Fa'lau et. al, 2003; Finau et. al, 2003). The reasons for these communities exhibiting higher than normal SIDS rates are not fully understood but can be partially explained by behavioural practices which are known to impact on the risk of SIDS (Tipene-Leach et al., 1999).

Whilst there has been much research into the parenting practices of Australian parents there have been limited studies into the influences on behavioural practices of parents, relating to infant care (Department of Family and Community Services, 2004). Recently, studies investigating the impacts of culture on parenting have highlighted the difficulties experienced by women from different cultural backgrounds when they give birth in a country other than their home country (Rice, 1994; Liamputtong and Naksook, 2003;Chalmers, 2006). The difficulty of the birthing experience is often compounded by isolation from family members and limited skills in the local language.

Similarly, there have been a few small-scale studies highlighting the difficulties for women who feel the need to practise traditional cultural methods of parenting, but are given conflicting advice from local health professionals (Rice, 1994; Barclay and Kent, 1998; Chalmers, 2006). Until these recent studies it has not been clear how women from differing cultural backgrounds care for their infants in a new environment.

There is a vast amount of literature, information, education and electronic and print media aimed at informing parents of a newborn infant. Although much of the written information for parents is available in a range of languages, it is widely recognized that parents (particularly mothers) from culturally and linguistically diverse (CALD)

backgrounds do not access health care services to the same extent as their English-speaking counterparts. This is due to a number of factors including, but not limited to: poor English skills, limited literacy in both their native language and English, cultural inappropriateness of available services, reliance on traditional methods of care, lack of trust in health care providers, lack of transport and differing social expectations of health care services (South East Health Women's Health Unit, 2002).

Western Sydney has, since the days of early settlement in 1788, been home to young families, providing low cost land to families from a wide range of countries. The families who come to Western Sydney from a variety of differing cultural backgrounds bring with them their own traditions, experiences and ideas on infant care practice and child rearing.

At the commencement of this study it was anticipated that the research would include tracing the historical context of parenting in the area of Western Sydney, a location rich in the social history of early Australia. Although insights on aspects of infant care through the years could have been gained through a historical study, the breadth of investigation necessary to complete this was beyond the scope of this study. This does not mean however that an historical investigation has been forgotten...merely put on hold for future study. This thesis does however include a historical dimension by reflecting on the changes to practice over time, predominantly since the early 1900's, and discusses the cyclic nature of many infant care practices.

Based on these observations and experiences, the final study sought to identify whether there was variation in knowledge between health professionals and parents who lived and worked in Western Sydney around the prevention of sudden and unexpected death in infants. The study sought to investigate the major influences on 'new' parents and whether there were any cultural practices, which conflicted with current locally recommended practices, related to infant care. Recommendations developed from the findings of this study will help inform health service agencies deliver services aimed at preventing sudden and unexpected death in infants.

1.2 DEFINITION OF TERMS

There are a number of terms used in this study which are defined below:

1. **Sudden Unexpected Death in Infancy (SUDI)** - SUDI is a broad classification for all Sudden Unexpected Deaths of a Child in Infancy. SUDI deaths are from both identified and unidentified causes.
2. **Sudden Infant Death Syndrome (SIDS)** – the sudden and unexpected death of an infant under one year of age, with onset of a lethal episode, apparently occurring during sleep that remains unexplained after a thorough investigation, including performance of a complete autopsy review of the circumstances of death and clinical history’
3. **Culturally and Linguistically Diverse (CALD)** – Culturally and Linguistically Diverse Communities are those born overseas and with a native language other than English and was previously termed ‘Non English Speaking Background (NESB)’. For the purposes of this study the CALD classification does not include the Australian Indigenous community.
4. **General Practitioner** – in this study all General Practitioners recruited worked in general practices located in the Sydney West Area Health Service (2004)
5. **Nurses** – for the purpose of this study Child and Family Health Nurses (C&FHN’s), Paediatric Nurses (PN), Neonatal Nurses and Midwives were recruited. Unless specified, ‘nurses’ refers to the all of the above.
6. **Parents** – refers to parents, grandparents or paid and non-paid care providers who care for infants aged 12 months or less.

7. **Sydney West Area Health Service (SWAHS)**– This refers to the geographical boundary (following Local Government Area boundaries) used by NSW Health to define areas for service delivery. In 2004, following major governmental restructure Western Sydney Area Health Service (WSAHS) merged with Wentworth Area Health Service (WAHS) to form the now Sydney West Area Health Service (SWAHS).
8. **Western Sydney** – a term used to refer to the area covered by Sydney West Area Health Service, and includes the Local Government Areas (LGA's) of Parramatta, Holroyd, Auburn, Blacktown, Baulkham Hills, Penrith, Hawkesbury and the Blue Mountains.
9. **Safe Sleeping messages** - (formerly referred to as SIDS reduction strategies) – for the purposes of this study the safe sleeping messages to be identified are those listed by SIDS and Kids as the main messages of their SIDS reduction campaign and include:
 - 1) put baby on the back to sleep from birth,
 - 2) sleep baby with face uncovered,
 - 3) cigarette smoke is bad for baby,
 - 4) have a safe cot, safe mattress, safe bedding and safe sleeping environment for baby night and day
 - 5) Sleep baby with the feet to the foot of the cot

1.3 THESIS STRUCTURE

This thesis is divided into six chapters, including this Introduction (Chapter 1).

Chapter 2 (The Big Picture) is a review of selected literature informing each of the major content areas relating to this research. These include the population characteristics and social context of Sydney West Area Health Service (SWAHS); the history,

demographics, classification and definition of sudden unexpected deaths in infancy; and the history and context of services for parents regarding infant care.

Chapter 3 (Methods) outlines the reasons qualitative methods were used in this study, and discusses the decision to interview three select groups of people involved in the care of infants: 1) general practitioners, 2) nurses and 3) parents, living and working in SWAHS area. This chapter provides a detailed outline of the way participants were recruited for the study; the methods used to collect data on each of the three groups, and the process used for data analysis in each of these groups.

Chapter 4 (Results) presents the results of the research as provided by the participants. This chapter includes demographic data about the participants, and outlines the key themes identified through analysis of data relating to infant care practice. Much of the data collected is presented in narrative form, spoken verbatim by study participants. Key findings are presented in relation to the data collected.

Chapter 5 (Discussion) reflects on the results of the research and discusses this in relation to the literature, and the research questions.

Chapter 6 (Conclusions and Recommendations) summarises this research in the present social context and presents recommendations for changes to service delivery, and professional practice to assist parents and others to optimize the health of the infants in their care.

CHAPTER 2 - THE BIG PICTURE

'Children, their health and welfare, their morbidity and mortality, necessarily offer a most sensitive reflection of the social and physical environment in which they find themselves'

Bryan Gandevia. Tears Often Shed, p 7. 1978

2.1 RATIONALE FOR A LITERATURE REVIEW

Prior to this thesis there had been little research into the key influences on infant care practice and the relationship of these influences to actual practice. While much research has been undertaken into sudden unexpected deaths in infants (SUDI), the relationship to infant care, and the factors contributing to an increased risk of infant death, research into the *reasons* why caregivers carry out certain infant care practices is limited.

Prior to the commencement of this study a literature review focusing on three main areas of this research was conducted: 1) the social context of parenting and infant care practices; 2) infant mortality in Western Sydney; and 3) sudden and unexpected death in infants, specifically Sudden Infant Death Syndrome (SIDS). In each area of literature, an historical context was identified and changes over time reviewed and documented.

Throughout the course of the study the literature continued to be reviewed, and as the study progressed newly published literature was added to the literature review to ensure accuracy and currency. Much of the newly published literature supported the thesis findings, thereby adding weight to the study findings. During the time the study was conducted Western Sydney Area Health Service (WSAHS) amalgamated with Wentworth Area Health Service (WAHS) to form Sydney West Area Health Service (SWAHS) and where possible statistical data and literature has been recalculated and reviewed to reflect this administrative boundary change.

This chapter discusses in detail the social setting in which the study was conducted, the area geographically defined by SWAHS, and also reviews the literature around sudden unexpected death in infancy and infant care practices.

2.2 THE SETTING – SYDNEY’S WEST

Introduction

Sydney is the largest metropolitan city in Australia, with a population of approximately four million (ABS, 2001). To the west of the city is the geographical heart of the Sydney basin, a region colloquially referred to as 'Western Sydney'. This large and socially diverse community includes the smaller cities of Parramatta, Penrith and Blacktown. The region is made up of nine LGA's, each with its own unique social characteristics. The population of Western Sydney is increasing, with the current population of over 1 million people expected to reach 1.24 million by the year 2016. The area is one of the fastest growing in NSW, and the growth is driven primarily by the release of land in Blacktown, Penrith, Hawkesbury and Baulkham Hills LGA's (Boyages, 2006).

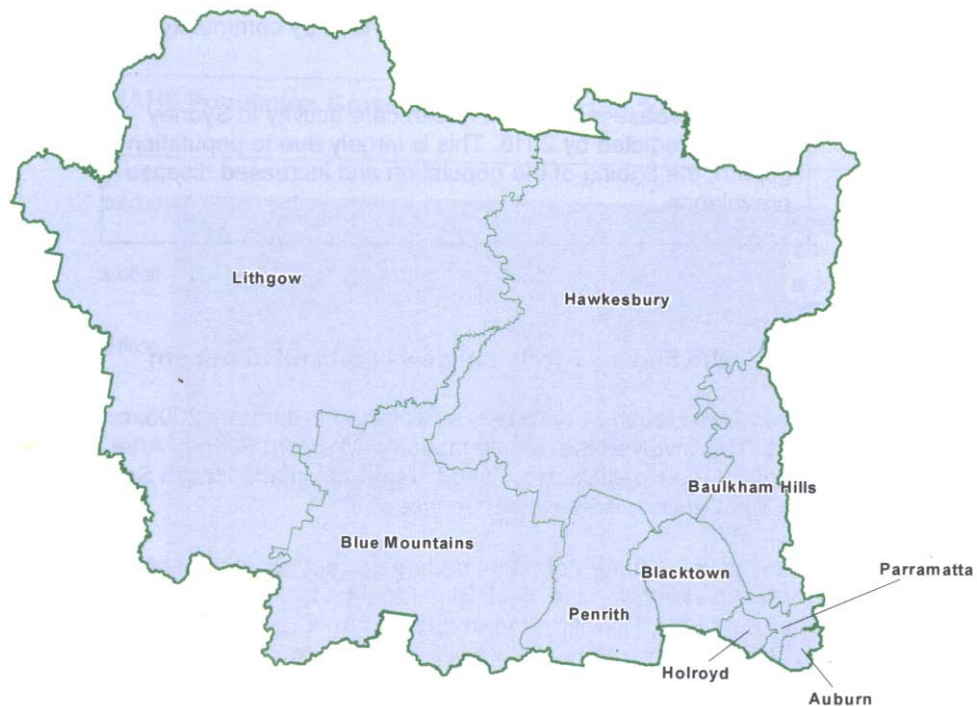
The Area Health Service (AHS) – historical snapshot

At the commencement of this study in 2004, NSW was divided into seventeen Area Health Services, including Western Sydney Area Health Service and Wentworth Area Health Service. Each Area Health Service operated independently, responsible directly to NSW Health and included varying numbers of LGA's within their designated boundary. Western Sydney Area Health Service included the LGA's of Auburn, Baulkham Hills, Blacktown, Holroyd and Parramatta and Wentworth Area Health Service included Penrith, Hawkesbury and the Blue Mountains LGA's (Boyages, 2006).

In 2005, under a major restructure by NSW Health, Area Health Services around the state were amalgamated, reducing the number from 17 to 8. The new 'Sydney West Area Health Service' (SWAHS) is an amalgamation of the former Western Sydney and Wentworth Area Health Services and Lithgow/Portland Health Services (formerly a part

of Mid Western AHS). Now covering the LGA's of Lithgow (in the west), Blue Mountains, Penrith, Hawkesbury, Blacktown, Baulkham Hills, Holroyd, Parramatta and Auburn, the AHS has an area of 8,904 square kilometers and provides health care services to over 1 million people (Boyages, 2006) (Figure 1).

Sydney West Area Health Service



¹ Boyages S. CAREFirst. Sydney West Area Health Service, 2005.

FIGURE 1: Sydney West Area Health Service (2005).

Sydney West Area Health Service is diverse geographically, socially and culturally, with a mixture of densely populated urban and more sparsely populated semi-rural areas. Some LGA's are rated by the Socio-Economic Indices of Families Australia (SEIFA) (Australian Bureau of Statistics, 2007) Index as having a high socio-economic status, while others are considered disadvantaged, but irrespective of the socioeconomic status

there is a high proportion of people from culturally diverse backgrounds living across the region (Boyages, 2006; Australian Bureau of Statistics, 2007). All statistics presented in this literature review relate to SWAHS (2005) unless otherwise specified.

Population demographics

The geographical area defined by SWAHS is one of the major areas of population growth in the Sydney basin. This is driven primarily by the release of cheaper land (Boyages, 2006). The AHS varies significantly in socio-economic advantage, with certain localities identified as having a high level of disadvantage. The LGA's of Auburn, Lithgow, Blacktown and to a lesser extent Penrith and Holroyd have a large number of residents who are tradesmen or labourers. These LGA's exhibit a lower educational and income level than the average LGA in NSW (Australian Bureau of Statistics, 2001).

Sydney West has the second largest number of child residents (under 18 years of age) in NSW, second only to South West Sydney, and has a projected increase in number of children by the year 2016 (Boyages, 2006). The LGA's where it is projected the population of children will increase are Baulkham Hills and Holroyd, due to new land developments. The population of SWAHS is also aging, with people aged 65 and over living longer in all areas of the region (Australian Bureau of Statistics, 2001).

Aboriginal population

Western Sydney is the traditional land of three main Aboriginal tribal groups: the Darug, Gundungarra and Wiradjuri people. In total, the area has around 14,500 Aboriginal residents who represent approximately 1.5% of the area's total population. The largest numbers of Aboriginal people live in Blacktown and Penrith LGA. However Lithgow has the greatest proportion and Baulkham Hills the lowest number of Aboriginal residents per head of population (Boyages, 2006).

The proportion of people aged between 0 – 24 is much higher in the Aboriginal population of SWAHS than in the non-Aboriginal population (59% versus 37%).

Aboriginal residents have a higher mortality rate than non-Aboriginal residents, and, as a result, the number of Aboriginal people in the older age group is less than that of the non-Aboriginal population (2.4% versus 9%) (Australian Bureau of Statistics, 2001). In SWAHS, Aboriginal residents are less likely to have completed Year 12 of high school or to have post-secondary qualifications. They are more likely to live in larger households than non-Aboriginal people and are less likely to own their home. Aboriginal people are about three times more likely than non-Aboriginal people to be unemployed, and this is reflected in their lower than average family income (Australian Bureau of Statistics, 2001).

Cultural diversity in Western Sydney

Since the end of the Second World War immigration and new settlement has dramatically changed the population of Australia, and more than 5.5 million people from as many as 170 countries have immigrated during this time (Kolar and Soriano, 2000). This is particularly evident in Western Sydney where many new migrants settle. Cultural diversity has long been the norm in the region, with large numbers of new settlers from a range of countries relocating to the area primarily because of low cost housing and culturally appropriate health and community services.

In the 2001 Census, almost 300,000 Western Sydney residents reported being born overseas (Australian Bureau of Statistics, 2001). These residents account for around 36% of the total Western Sydney population, compared to 24% of overseas born residents in NSW as a whole. The most common countries of birth listed in the 2001 Census were England, Philippines, New Zealand, China, Lebanon, India, Fiji, Malta, Sri Lanka, Italy, Vietnam, Korea and Hong Kong (Australian Bureau of Statistics, 2001). A larger proportion (36%) of these residents speak a language other than English at home compared to NSW as a whole (20%). The LGA where the highest proportion of residents spoke a language other than English was Auburn (72%), with a large number of Arabic speaking residents.

Although the only Pacific Island residents featuring in the top ten countries of birth of overseas-born residents are from Fiji and New Zealand, it is known that many residents of Polynesian ancestry were born in New Zealand (Va'a, 2003). At the time of the 1996 Census Pacific Island born residents accounted for 3.3% of the population of Western Sydney. Most of these residents were born in New Zealand, Fiji, Western Samoa and Tonga, with the majority living in Blacktown LGA (Epidemiology Indicators Research and Evaluation Unit, 2002).

Services for CALD families in Western Sydney

As Western Sydney has always been an area highly favoured for migrant settlement, the importance of providing infant health information to parents, in a range of languages, was identified early (Chesher and Moess, 1984). The Early Parenting Education Program was developed by the Bilingual Community Education Unit in Western Sydney in 1980, and continues in Western Sydney and other AHS's to this day. The program is delivered to families by specially trained Bilingual Community Educators (BCE's).

South Western Sydney Area Health Service developed the Ethnic Obstetric Liaison Program in the early 1990's, and was also implemented by SWAHS. The program was developed to improve accessibility and acceptability of maternity and early childhood services to women from CALD backgrounds. The function of the Ethnic Obstetric Liaison Officers has been to increase the knowledge of CALD women in all aspects of pregnancy, childbirth and child care and to improve access for women to health services, particularly maternity services. Although the Program operated successfully, and attempted to bridge the gaps in service access for women from a CALD background, many women were hesitant to use the services for reasons of confidentiality and the program was wound down in the early 2000's and no longer exists in its original form. To a large degree, the Universal Health Home Visiting Program has addressed many of the problems women from a CALD background experience, accessing early childhood health care. Interpreters accompany Child and Family Health Nurses on home visits to enable new mothers who do not speak English to have a service comparable to that for English-speaking mothers.

Epidemiology

Fertility rates

Data from the 2001 Census shows that the highest age specific fertility rate in NSW was in women aged between 30 – 34 years (84.5 per 1000). In contrast, the highest age specific fertility rate in WSAHS was in the 25 – 29 year old age group (129.7 per 1000). Adolescent (under 20 years) fertility rates have been declining across NSW as a whole for some years, and in the 2001 Census the rate had fallen in all LGA's in WSAHS. Blacktown had the highest adolescent fertility rate at 29.4 per 1000 (Wilson et. al, 2003). Since the introduction of the Australian Government's 'Baby Bonus Scheme' in 2004 there has been a noticeable increase in the Australian birthrate. This increase is evident in SWAHS where the annual birthrate has increased by around 10%. Aboriginal and Pacific Island communities in Western Sydney are known to have a higher birth rate than that of Anglo-Celtic communities (Wilson et. al, 2003).

Births to Aboriginal mothers in SWAHS

The Midwives Data Collection (MDC) indicates that births to Aboriginal mothers in SWAHS make up around 1.3% of all births in the area (MDC - HOIST, 2007). Of these births almost 10% were less than 2500 grams compared to 6.5% of non-Aboriginal births, although this proportion was not significantly different between the groups (OR = 1.5 95% CI 0.86 – 2.8) (Wilson, 2003). Figures from the MDC over a period of 5 years 2001 – 2005 indicate that approximately 40% of Aboriginal women in SWAHS do not present for antenatal care until after 20 weeks of pregnancy (MDC-HOIST, 2007).

Births in SWAHS to Pacific Island born mothers

Although residents from the Pacific Islands account for 3.3% of the SWAHS population, in 2002 births to Pacific Island mothers in SWAHS made up 7% of all births. In the five years from 1998 – 2002, 33% of Pacific Island women did not present for antenatal care until 24 weeks of pregnancy, with 20% presenting at 30 weeks or later (MDC - HOIST, 2007). Between 1998 and 2002, 6% of babies born to Pacific Island born mothers

weighed less than 2500 grams at births compared to 3.8% of the non-Pacific Island population (Figure 2). Of these, 1.8% of Pacific Island births were < 1500 grams compared to 0.6% of all births in Western Sydney and NSW as a whole (MDC-HOIST, 2007).

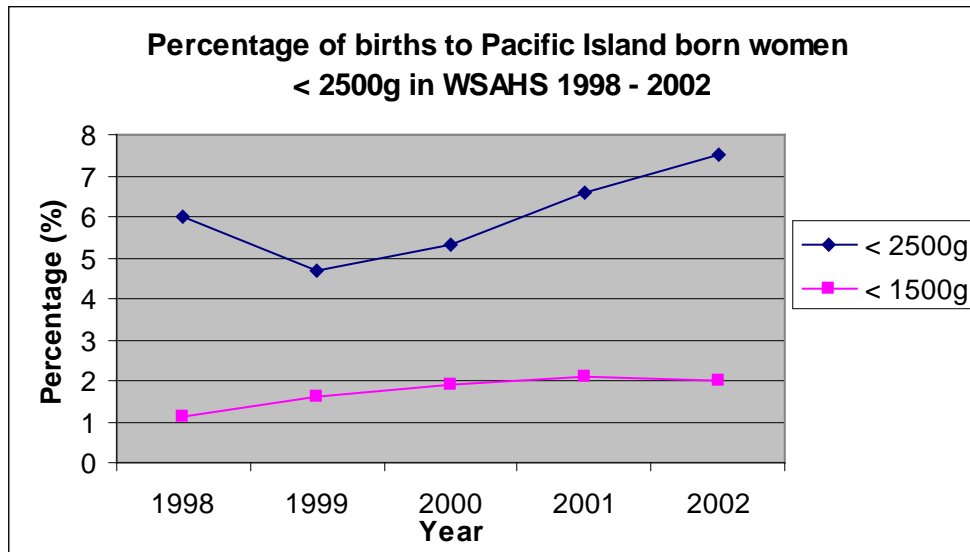


FIGURE 2: Percentage of births to Pacific Island born mothers < 2500 grams in WSAHS 1998 – 2002

Births to Asian mothers in SWAHS

Births to Asian mothers in SWAHS have remained steady since 2001, accounting for around 9.8% of births in the five years between 2001 and 2005. The majority of these births are to mothers born in the Philippines (32%), followed by mothers born in China (24%) and Vietnam (11%).

Births to mothers from a Middle Eastern background in SWAHS

Births to mothers from a Middle Eastern background living in SWAHS have remained consistently around 6% of all births since 2001. The majority of births in this group are to women born in Lebanon (50%), Turkey (18%) and Iraq (18%).

Infant mortality

The infant mortality rate is the measure of the yearly rate of deaths in infants less than one year of age, and is said to reflect the overall health and wellbeing of a given population (Last, 2001). The figures used are usually calculated by expressing the number of deaths in a given year as a proportion of live births in the same year (Last, 2001). The infant mortality rate can be used to identify problems in specific populations, problems with service delivery to mothers and babies, and provision of neonatal health care (Wilson et. al, 2003). Total numbers of infant deaths in NSW in a given year are available through the NSW Register of Deaths. These data can be extracted from the NSW Deaths dataset using NSW Health 'Health Outcomes & Statistical Toolkit' (HOIST). Statistics detailing the yearly number of perinatal deaths are collected through the Midwives Data Collection (NSW Health, 2004).

Infant mortality in NSW has been declining since the introduction of the infant welfare movement in the early 1900's (Lewis, 1976; NSW Health, 2006). Overall infant deaths have been declining in Western Sydney, falling from 9.2 per live births in 1992 to 4.7 per live births in 2000. The reason for this dramatic fall is due primarily to the reduction in deaths in infants dying suddenly and unexpectedly (attributed to SIDS), following the introduction of the 'Reduce the Risks' Health Promotion Campaign in 1994 (NSW Health, 2001b). There was a slight increase in the infant mortality rate in Western Sydney in 1999, however these results were comparable to the rate for NSW. Since 1993 the rate of infant mortality in NSW has declined dramatically, and figures for Western Sydney are comparable to the state average (Wilson et. al, 2003) (Figure 3).

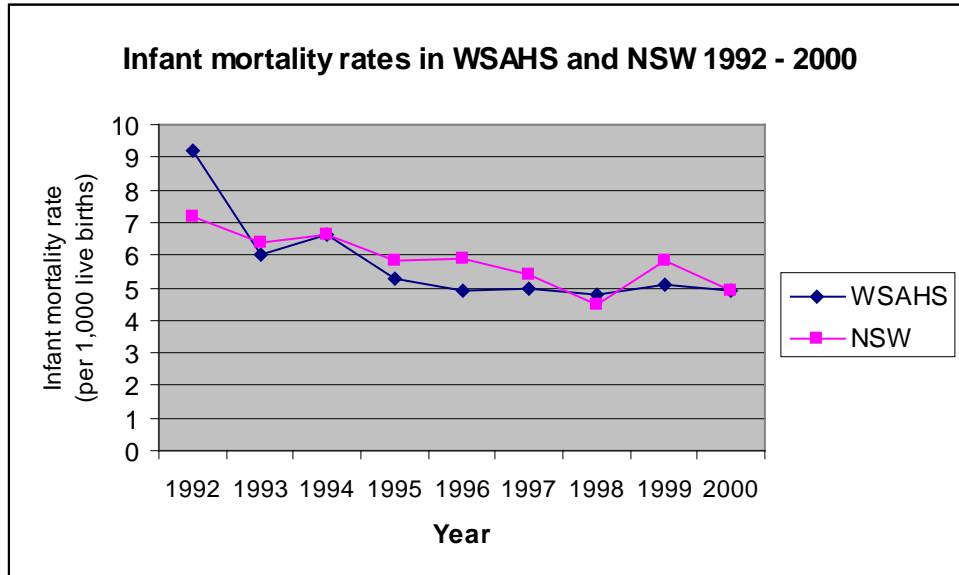


FIGURE 3: Infant mortality rates in Western Sydney (per 1,000 live births) 1992 – 2000.

Infant mortality related to SIDS

In 2000, SIDS (ICD10 R95) was the most common cause of death in infants in Western Sydney, accounting for 11 infant deaths. Between 1992 and 2000 inclusive the infant mortality rates as a result of SIDS were higher in Western Sydney than for NSW as a whole (Wilson et. al, 2003) (Figure 4).

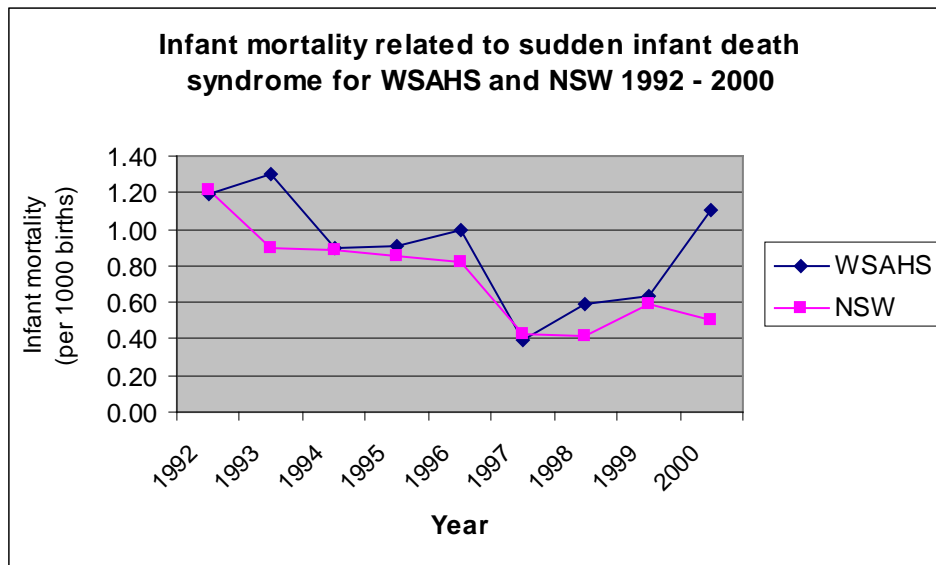


FIGURE 4: Infant mortality related to SIDS for Western Sydney and NSW 1992 – 2000

SIDS rates have fluctuated in Western Sydney with a distinct increase in the number of infant deaths as a result of SIDS in 2000. Examination of data from 1995 to 2004 indicates that although SIDS rates have declined in Blacktown, the LGA has the highest rate of SIDS mortality (Figure 5) in SWAHS, with many of the deaths occurring in particular suburbs (Wilson et. al, 2003).

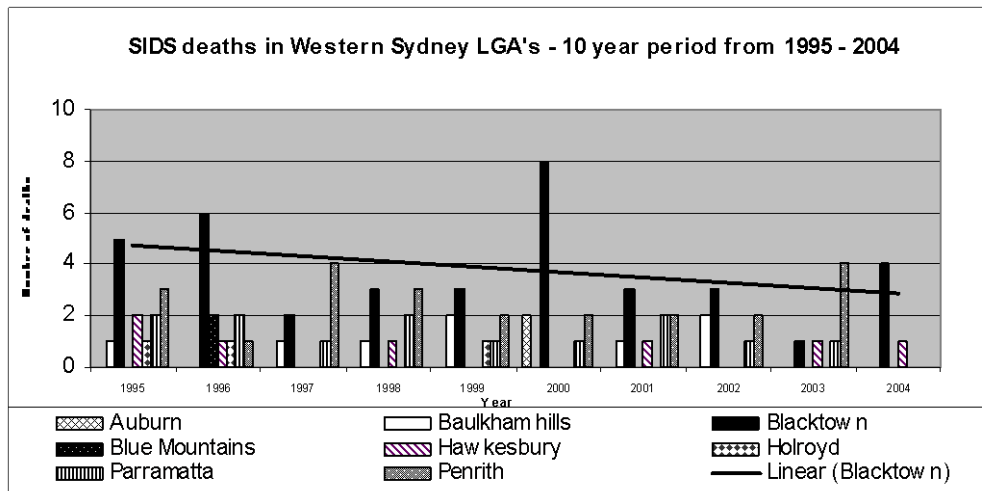


FIGURE 5: Total number of SIDS deaths in Western Sydney by Local Government Area 1995 – 2004 (showing trend line for Blacktown LGA)

These suburbs are known to have a high number of Indigenous and Pacific Island residents. Blacktown LGA had the highest rate of SIDS mortality in the year 2000 at 1.7 per 1000 whilst Auburn, experiencing a similar birth rate, did not experience any SIDS deaths in most of the years under review. The rate of SIDS in Parramatta has remained consistently below 1 per 1000 live births since 1992 (Wilson et. al, 2003).

SIDS in Aboriginal infants

Aboriginal infants are known to experience a higher rate of SIDS deaths than non-Aboriginal infants. Between 2001 and 2005, around 18% of all SIDS deaths in NSW were in Aboriginal infants. Four Aboriginal infants have died from SIDS in SWAHS between 2001 and 2005. All these infants were residents of Blacktown or Penrith LGA’s.

A brief overview of infant health services in Western Sydney

Following the introduction of the Baby Health Service in the City of Sydney in 1904, clinics for mothers and infants were established in the west of the city. The earliest Baby Health Clinics in Western Sydney were established in: Parramatta (1926); Windsor (1934); Blackheath (1935); Auburn (1944) and Blacktown (1947). More followed in newly developing areas with clinics built in Baulkham Hills (1957); Mt Drutt (1963); and Doonside (1969) (O'Connor, 1989).

The inception of the Health Commission of NSW in 1973 meant delivery of maternal and infant health services in Western Sydney changed dramatically. The new service model followed the 'Community Health' approach. In this innovative model, health services were co-located within the community to provide comprehensive health care for families. One of the first centres was the Mount Drutt Polyclinic that included a Baby Health Clinic, Dental Clinic, Women's Health Clinic, and many other ancillary services.

By 1978, the population of Western Metropolitan Health Region (similar in geographical boundary to SWAHS) was 1,166,500, with approximately 18,000 births per annum. At this time there were 64 Baby Health sisters employed across the region with a ratio of 0.5 Baby Health Sisters to each Baby Health Clinic, meaning clinics were often closed and staff were overloaded when sickness or annual leave occurred (Corn, 1980).

Following the review of services conducted by Corn in 1980, a number of recommendations for changes to service delivery in Western Sydney were made. These included: amalgamating centres, improving in-service education for all clinic staff and reviewing the number of clinic visits per family (thereby reducing dependence on the clinic sister) (Corn, 1980). In line with other health areas, Baby Health Clinics in Western Sydney were sold and services were amalgamated to provide clinics with at least two staff on duty. Home visiting to new mothers was always a major part of service delivery in Western Sydney. Using a 'generalist-nursing' model, vulnerable families received visits at home following the birth of a baby. When NSW Health introduced the Universal Health Home Visiting (UHHV) Program in 2002, there was a refocus of the

service to visit all families in the area, maintaining the focus on those women and families who were considered vulnerable. The generalist-nursing model was abandoned, and Child and Family Health Nurses were specifically employed to deliver services to women and families with a newborn infant (Witherspoon, 2007).

2.3 THE SUDDEN AND UNEXPECTED DEATH OF INFANTS AND SUDDEN INFANT DEATH SYNDROME

The sudden and unexpected death of apparently well infants has been recorded in literature since the days of the Bible. As a means of explaining this unusual phenomenon, the death was often blamed on ‘overlaying’ (Kings 3: 19 - King James Version). Until recent times people interpreted the manifestations in social terms rather than a syndrome with a medical basis and held parents culpable for either intentionally smothering their infants or overlaying (accidentally smothering) them whilst in bed (Savitt, 1979).

The sudden and unexpected death of infants who were apparently well was first recognized and called ‘cot death’ in the early 1960’s, although many authors had published articles on unexplained death in infants as early as the 1940’s (Abramson, 1944; Wooley, 1945). In 1979, the World Health Organisation recognized and named the phenomenon ‘Sudden Infant Death Syndrome’ (SIDS) and allocated the syndrome an International Classification of Diseases (ICD) Code (Vance et al., 1998).

Since that time SIDS has had a number of definitions, each attempting to clarify the nature of the infant death. The first definition was developed by researchers in the 1970’s and defined SIDS as: “the sudden death of any infant or young child, which is unexplained by history, and in which a thorough postmortem examination fails to demonstrate an adequate cause for death” (Bergman et al., 1970; Beckwith, 1973). Although not stated, the age range referred to in this definition is usually considered to be between the ages of 2 weeks and 2 years. In his article, ‘SIDS – A Syndrome in Search of a Cause’, Malloy comments that the development of the original definition was driven in part by parents of infants whose deaths were unexplained (Malloy, 2004). In 1989, an expert panel was convened to review scientific knowledge gathered about SIDS over the previous 20 years, and to determine whether current criteria for the diagnosis of SIDS should be revised. The result of this work group was an amendment to the definition to read ‘ the sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy,

examination of the death scene, and a review of the clinical history' (Willinger et al., 1991). This second definition restricts sudden unexplained death in infants, due to SIDS, to those children aged less than one year. This definition remains the one used internationally by clinicians and health professionals to identify SIDS cases, however cases of SIDS are identified in children over the age of one year, and generally less than two years (Vance et al., 1998).

There has been a great deal of discussion regarding the classification of deaths in infants who die unexpectedly (Byard, 2001; Tomashek et. al, 2004). In 2004 in the USA, the Centre for Disease Control began a national initiative to address the inconsistencies in classification of SIDS and to improve the accuracy of case reporting. The Centre for Disease Control convened a working group to develop and implement a comprehensive SUDI Reporting Form, which ensures meaningful data is collected on all SUDI cases and death scenes are thoroughly investigated (Centres for Disease Control, 2005, 2008).

In 1992, the *NSW Public Health Bulletin* reported that a formal protocol for the autopsy of all infants who die suddenly and unexpectedly would be implemented and used at the two main centres used for the autopsy of infants: The Institute of Forensic Medicine at Glebe and The Institute of Clinical Pathology and Medical Research at Westmead. Since then any infant who dies suddenly and unexpectedly in NSW is taken to one of these centres for autopsy. In spite of the formal protocol, police were not always routinely called to the scene of a SIDS death, with parents usually calling an ambulance or driving to the nearest hospital. Because SIDS deaths are infrequent, it is not possible for police to become experienced in the process of retrieval of evidence from the death scene, and this has led to inconsistency of practice (Frommer and Murphy, 1992). Due to the emotional circumstances surrounding the death of an infant, attending police or medical staff often dealt with SIDS deaths on a case-by-case basis, taking into account the shock and grief of the parents. Although all police involved in investigation of sudden unexpected infant deaths complete documentation including a NSW Police Report of Death (Form P79A) and a Sudden Infant Death - Death Scene Investigation Checklist (Form P534), these forms do not ensure consistency of investigation in all SIDS cases. (McCarthy, 2003; Arbuckle, 2005; Mowll, 2005). With the definition of SIDS one of exclusion, and

inconsistencies in death scene data, many infant deaths were incorrectly classified as SIDS. This was highlighted in local and overseas cases of multiple SIDS deaths in families, subsequently found to be homicide. As a result of this, the Child Death Review Team (under the Children (Care and Protection) Act 1987) initiated the Child Death Register in 1996. The purpose of the register is to classify deaths with a view to understanding the cause of death and preventing fatalities where possible (Child Death Review Team, 2001).

To address the inconsistencies in reporting of SIDS cases, a SIDS pathology workshop attended by State Coroners and pathologists from all over Australia was held in Canberra in 2004. At this meeting a new definition for SIDS, to be used in the Australian context, was determined by consensus (Byard, SIDS and Kids, 2004). This definition defines SIDS as ‘The sudden and unexpected death of an infant under one year of age, with onset of a lethal episode apparently occurring during sleep that remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and clinical history’ (Krous, 2004). This definition was based on the premise that ‘pathology has advanced to the point where the cause of death in a baby over one year of age is likely to be detectable, therefore a diagnosis of SIDS would not be appropriate’ (Public Health Association of Australia, 2005). The definition of SIDS however, remains one of exclusion, and, regardless of the age of the child, all other possible causes of death must be excluded before a definitive diagnosis of SIDS as a cause of death can be made.

Epidemiology of SIDS

Infants who die suddenly and unexpectedly as a result of SIDS account for the largest percentage (4.5%) of all deaths in infants aged less than one year in NSW (Malins, et al.2005) Prior to the introduction of the Reduce the Risks campaign in 1991, the rate of SIDS in Australia was approximately 1.87 per 1,000 live births. This was followed by a rapid reduction in the rate of SIDS, to 0.78 per 1,000 live births in 1995 and 0.51 per 1,000 live births in 2000. Evidence suggests the most common age of death from SIDS is

between 2 and 5 months, with a peak incidence at around 3 to 4 months (Hoffman and Hillman, 1995).

The rate of SIDS varies by country, region and ethnic group (Byard and Kohle, 1994). The reasons for these differences remain unclear. However it has been documented that SIDS occurs more commonly in areas with a temperate climate (Williams et al., and The National Cot Death Study Group, 1996). Male babies, babies aged between 2 and 5 months, and babies born with either low or very low birthweight are at increased risk of experiencing a SIDS death (Sullivan and Barlow, 2001). A number of additional factors are considered to contribute to an increased risk of SIDS, although the extent to which these factors increase SIDS risk remains unclear. Known major risk factors include: 1) prone sleeping position; 2) parental (particularly maternal) smoking; 3) low socio-economic status of parents; 4) young maternal age; 5) poor educational level in parents, particularly the mother; 6) overheating or overcooling of an infant; 7) loose bed-clothing in the baby's cot and 8) co-sleeping with parents or siblings – in particular where parents have been drinking alcohol or using other drugs (Sullivan and Barlow, 2001). Although all these risk factors have been identified as playing a contributing role in SIDS, none has been specifically identified as the sole cause. No consistent findings have yet been found in all SIDS cases (Hoffman and Hillman, 1995; Sullivan and Barlow, 2001). Other factors possibly having a role in the reduction of SIDS are breastfeeding and the use of pacifiers, however evidence to support these factors is limited (Mitchell et al., 1993; Sullivan and Barlow, 2001).

SIDS is more common in some racial groups such as Native Americans, Maori, Aboriginal and Torres Strait Islanders, and Pacific Islands (Everard et al., 1998; Vance et al., 1998; Fa'alau et al., 2003; Finau et al., 2003). The reasons for increased incidence in these groups is unknown, but it is likely that there is more than one factor associated with the increased incidence of SIDS such as socio-economic status, cultural practices, hereditary factors or educational level (Henderson-Smart et al., 1998).

SIDS is an important public health issue and has been identified as the most common cause of death in the first year of life in developed countries (Sullivan and Barlow, 2001).

Since 1990 SIDS has been declining around the globe due primarily to the introduction of the Reduce the Risks Campaign designed to alert parents to the dangers of placing babies to sleep prone (face down). In Australia, the rate of SIDS in male babies has decreased from 168.1 per 100,000 live births in 1991 to 63.2 per 100,000 live births in 2002 (AIHW, 2002). New South Wales has shown a similar reduction with the total number of SIDS cases in NSW falling from 131 in 1991 to 18 in 2004 (NSW Health, 2006). Although the rates of SIDS have dropped significantly there are still some areas of NSW where SIDS rates remain high. The reasons for this remain unclear but may be due to an interaction of factors including lower socio-economic status, high smoking rates, high numbers of young parents and lower educational status.

In a review of literature to assess population trends in SIDS, Ponsonby and colleagues concluded that the trends in SIDS decline since the Reduce the Risks campaign are striking, showing a decline in SIDS incidence of around 50% in communities where non prone, particularly supine sleeping has been actively promoted (Ponsonby et. al, 2002).

History of SIDS

In the nineteenth and very early twentieth century, infants who died suddenly and unexpectedly were thought to die of 'miasma' or 'be taken by an act of God', but in view of the prevalence of infectious disease and poor living conditions it is impossible to hypothesise how many of these deaths could have been due to SIDS (Gandevia, 1978). In the early 1950's sudden and unexpected death in infants was thought to be due to suffocation by bedclothes, overlaying (accidental smothering by someone else in the bed) or aspiration of vomit (Barrett, 1954). As medical techniques improved, researchers thought the phenomenon to be the result of some type of virulent infection or the result of an anaphylactic reaction to milk (Parish et al., 1960). In the early 1960's an increased focus on paediatrics stimulated the interest of medical professionals in the unexplained nature of 'cot death'. Increasingly, post mortem investigations were conducted to investigate the pathological features of cot death, with particular interest in the identification of a single causative agent such as a bacteria or virus (Coe, 1960; Cooke and Welch, 1964). In Cooke and Welch's retrospective 1960 study, sex of the deceased

infants, social and family background, season of death, feeding habits and sleeping position were all explored as possible contributors to the child's death. This landmark study identified a relationship between sudden unexpected deaths in infants and seasonality, social class of parents, birth weight of the child and size of the family. Although not concluding that sleeping position was a possible causative effect, Cooke described the range of sleeping habits of infants prior to death, including: sleeping in a parents' bed, in an armchair, on a settee, in drawers and in a carry cot (Cooke and Welch, 1964).

In the 1950's and 1960's, following the rapid arrival of new medical technologies, medical specialists developed equipment to assist babies who had complicated or early deliveries. Thus was born the Neonatal Intensive Care Unit, and the specialized nursing that went with the newly developed technology (Bredemeyer, 2005). One of the techniques discovered in neonatal intensive care was that small babies with respiratory complications survived better if nursed in the prone position. The basis for this practice was that infants have more regular breathing, and less oesophageal reflux. Studies conducted in the period from the 1950's to the 1970's showed that babies placed prone had better oxygenation, less apnoea and more sleep (Brackhill et al., 1973). Brackhill's findings also highlighted the reduction in crying the prone position afforded infants, and hypothesized that less crying reduced energy expenditure in hospitalized infants and was also 'easier on the nurses'. As a result of this evidence a new medical dictum emerged, that the prone position was beneficial to babies, and thus the practice was extrapolated to healthy full term infants (Brackhill et al., 1973; Hogberg and Bergstrom, 2000; Bredemeyer, 2005). Recommendations to sleep babies prone were published in books widely read by parents. **However the advice was based on untested theory.** A systematic review of the literature around preventable risk factors for SIDS available between 1940 and 1980 would have led to earlier recognition of the risks of sleeping prone, and may have saved thousands of lives (Gilbert et al., 2005).

In November 1966 an article referring to 'cot death' was published in the *Nursing Mirror and Midwives Journal* (Johnstone and Lawy, 1966). The article detailed the signs and symptoms of cot death and suggested ways nurses could prevent babies dying, however

there was no mention of sleeping position. Following the renaming of the condition in 1969, there were a number of articles published detailing possible hypotheses for the cause of SIDS, and mechanisms of action. These included such theories as ‘epidemic viral disease’ (Nelson et al., 1975), ‘airway occlusion, facilitated by a hypermobile mandible and an enlarged tongue’ (Tonkin, 1975), ‘changes in saliva’ (Campbell, 1975), ‘hypoglycaemia’ (Hirvonen et al., 1980) and ‘the inability of parents and practitioners to recognize illness in their children’ (McWeeny and Emery, 1975). As early as 1975 theories were published identifying dehydration as a possible cause of SIDS (Andrews, 1975) and in 1980 overheating was first hypothesized as having an association with unexpected infant deaths (Stanton et al., 1980).

Over the next six years research into the syndrome continued around the world, and in 1986 Beal compared the epidemiological characteristics of SIDS in Sweden and in Adelaide (Beal, 1986). The findings identified the absence of a winter peak in SIDS deaths in Sweden compared to Adelaide (probably due to household heating in Sweden), and a lower incidence of SIDS deaths in communities that use the supine sleeping position. Beal’s conclusion was that abandoning the prone sleeping position for infants in Adelaide should reduce the risk of SIDS. The identification of modifiable risk factors for SIDS was the beginning of a worldwide campaign to reduce the incidence of SIDS.

Reducing the Risks – Modifiable risk factors

Based on the latest evidence at the time, the Reduce the Risks campaign was initiated in Australia in 1991. This campaign conveyed four health education messages: 1) put your baby to sleep on the side or the back, 2) do not let your baby become overheated, 3) keep your baby in a smoke free environment and 4) breast feed your baby (National SIDS Council (Australia), 1991).

In 1992, after reviewing all of the available evidence, the American Academy of Paediatrics recommended that to reduce the risk of dying from SIDS, healthy babies should be placed on their back or side to sleep. In 1996, the recommendation was revised, clarifying that putting babies to sleep on their backs provides the lowest risk. The US

National Institute of Child Health and Human Development launched the 'Back to Sleep' Campaign in 1994 to promote the message that children should be placed on their back to sleep (Consensus Statement, 1991). This campaign was also run in the United Kingdom where the supine sleeping position was strongly promoted (Hiley and Morley, 1994).

Since 1991, new evidence has accumulated in relation to sleep position and other important risk factors for SIDS, and in 1997 the National SIDS Council of Australia convened a multidisciplinary forum to review and revise the guidelines where appropriate. The topics under review at this forum were sleeping position, safe bedding, smoking, breast-feeding, bed-sharing, temperature, and drug abuse (Henderson-Smart et al., 1998).

Based on strong evidence, the forum developed three main recommendations, in addition to providing information on other areas often discussed as possible risk factors, but for which evidence is not as strong. These recommendations are:

- 1) Put babies on their back to sleep
- 2) Make sure babies heads are uncovered during sleep
- 3) Keep babies smoke free before birth and after

Other factors raised as possibly having an association with SIDS were discussed and included:

- Bed sharing and co-sleeping
- Babies getting too hot or too cold
- Breastfeeding
- Immunisation

There are other possible contributing factors implicated in the occurrence of SIDS, although the evidence for these factors is not conclusive. These include the use of pacifiers (dummies), air quality, and 'malignant hyperthermia' (Fleming, 1999; Corbyn, 1999; Denborough, 1998).

The modification of parental behaviour patterns to encourage the use of the supine sleeping position, reduce smoking and limit loose bed-clothing has contributed to a significant reduction in the rate of baby deaths over the past 17 years (Ponsonby et al., 2002).

Sleeping position

The earliest research identifying a relationship between sleeping position and infants who die suddenly and unexpectedly was conducted in 1944 (Abramson, 1944). Abramson recommended that babies not be placed in the prone position, suggesting that infants had a higher risk of mechanical suffocation. The first studies presenting data, which showed an association between sleeping position and sudden death, were published in 1966 (Steele and Langworth, 1966). However it was not until the 1980's that data from studies in Australia and New Zealand highlighted the need for the introduction of public health campaigns addressing the importance of supine sleeping position (Beal, 1986, 1991; Tonkin, 1986). There is clear evidence that the risk of SIDS is higher when infants sleep prone (Beal and Finch, 1991; Dwyer and Ponsonby, 1996). Recent evidence suggests that there is a smaller, but significantly increased risk of SIDS when infants are placed on their sides to sleep, rather than on their back and this was one of the main reasons for a review of the Australian recommendations (Mitchell et al., 1992). The change in recommendations has contributed to a 62% reduction in SIDS cases in Australia between 1991 and 2000 (Al-Yaman et al., 2002). The main justification for recommending babies sleep supine and not on the side is the tendency infants have to roll over into the prone position while sleeping on the side, thereby placing them at increased risk of SIDS. To date, the results of intervention studies have thrown little light on the statistical difference in SIDS rate between placing babies on their side, compared to on their backs.

There is, however, evidence to support the safety of sleeping infants in a supine position. In a series of studies Jeffery and colleagues from the University of Sydney identified a mechanism by which the prone sleeping position could confer an increased risk of SIDS (Jeffery et al., 1999). Aspiration of regurgitated stomach contents was the major concern of practitioners about placing babies to sleep on their backs. This, however, has not been the experience in Asian countries, where babies are traditionally put to sleep on their

backs and physiological studies of spontaneous reflux suggest that healthy infants can protect their airways, and do so when they are placed supine (Beal and Finch, 1991; Page and Jeffery, 1996). Infants are not at increased risk of choking, providing that their swallowing and arousal reflexes are intact (Page and Jeffery, 1996) (Figure 6).

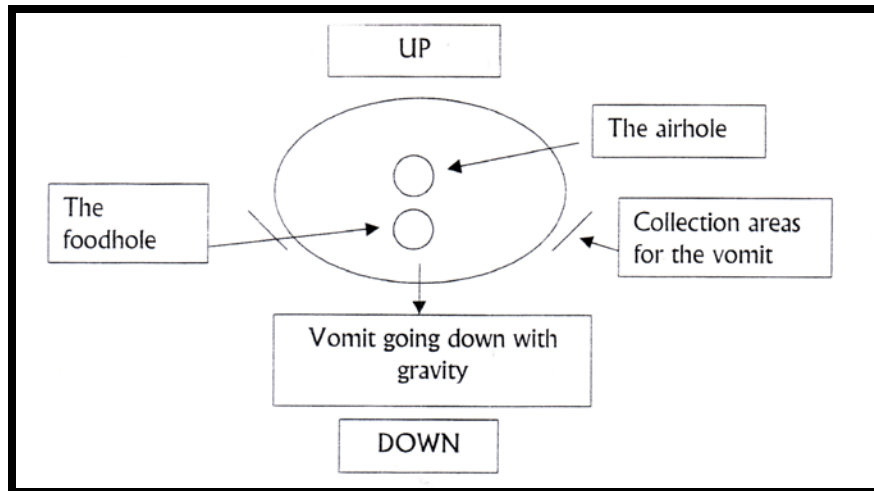


FIGURE 6: Simple anatomical diagram detailing the benefits of placing an infant on the back to sleep. (Jeffery, 2002)

Recent studies suggest that *consistency* of sleeping position is one of the most important risk reduction factors for SIDS (Mitchell, 1999). In a study supported by the National Institute of Child Health and Human Development, researchers showed that infants placed on their sides to sleep were twice as likely to die of SIDS as those placed on their backs. This is possibly due to the propensity for infants to roll onto their stomachs from the side position. However when researchers looked specifically at the position in which the infant was last placed to sleep compared to their normal sleeping position, infants who usually slept on their backs and were subsequently placed in the side position were at seven to eight times higher risk of dying from SIDS.

In a comprehensive review of physiological studies investigating prone versus sleeping position, Galland and colleagues concluded that when infants sleep prone there is reduced vasomotor tone, less flexibility in heart-rate variability, reduced arousal and waking ability and poorer ventilatory and airway protective responses. All these factors

contribute to respiratory stress, and while not the sole cause of SIDS could contribute to the increased risk of SIDS in infants (Galland et al., 2002).

Keeping babies heads uncovered during sleep

Evidence suggests that if a baby's head becomes covered during sleep, the risk of SIDS is increased (Beal and Byard, 1995; Wilson et al., 1994). This is particularly the case where the baby's head becomes covered with loose bedding, or pillows and quilts. Several case series have reported a proportion of SIDS infants are found with bed clothing over their heads, or their faces obstructed by bedding. It is recommended that soft surfaces and gas-trapping objects such as cot bumpers, sheepskins and soft toys be avoided in infants' cots and bassinets (Kattwinkel et al., 1994).

Blankets and other bedclothes used in cots have been individually studied to determine whether they have any relationship to the risk of SIDS. The majority of studies have investigated the use of duvets or quilts in infant beds and each have been found to be associated with an increased risk of SIDS due to their propensity to cover the whole cot (Fleming et al., 1996; Ponsonby et al., 1998). Ponsonby and colleagues established that infants sleeping supine or on their side had an increased risk of SIDS (Odds Ratio 3.81, 95% CI 1.68, 8.65), but that this did not enhance the already increased risk of sleeping prone (Odds Ratio for prone with no quilt 9.19 vs. 9.53 for prone with quilt). The authors of this study suggested that the adverse effect of a quilt could be due to the obstruction of the face by some infants, with older infants capable of pulling bedding over their faces while sleeping. Fleming's study did not analyse the data for the interaction between the use of a duvet and sleeping position.

In a study conducted by Skadberg and Markestad in 1997, 33 infants were monitored with computerized polysomnography recording breathing and physical signs during sleep. Results indicated that infants who were unable to remove bedding from around their face and head, there was a significant increase in CO₂ accumulation around the face and head. Infants placed in the supine position were more likely to be able to remove covers from around their face than those in the prone position (Skadberg and Markestad, 1997).

There has been little scientific investigation of the practice of swaddling infants and SIDS, although Beal has noted that Chinese infants who sleep supine and are tied into swaddling, which prevents them moving under the bedclothes or into the prone position, are at decreased risk of SIDS (Beal and Finch, 1991).

Parental smoking and SIDS.

The first study to investigate the relationship of maternal smoking to SIDS was conducted in Canada in 1966 (Steele and Langworth, 1966). Since that time a multitude of studies have been conducted to investigate maternal smoking during pregnancy, and in almost every epidemiological study maternal smoking has emerged as a major risk factor for SIDS (MacDorman, et al., 1997; Schoendorf, 1992; Sullivan and Barlow, 2001). Smoke in the environment after birth (passive smoking) is also associated with an increase in SIDS deaths, but analyzing the effect on SIDS rate between passive and maternal smoking before birth is difficult (Mitchell et al., 1992; Mitchell et al., 1993). An association with SIDS and exposure to smoke has been a consistent finding, and many studies have reported a dose – response relationship (Blair et al., 1996). The Reduce the Risks programs in most countries carried an additional message of not smoking near babies, however smoking behaviour has not declined as dramatically as the SIDS rate, so it is difficult to determine the contribution of smoking cessation to a reduction in SIDS cases. There are nevertheless some researchers who consider that after the effectiveness of public health campaigns to address the issue of prone sleeping, reduction of parental smoking has become the most significant avoidable SIDS risk factor in many countries (Sullivan and Barlow, 2001).

Air quality

There has been much research into the contribution of air quality to the rates of sudden and unexpected deaths in infants. The bulk of this research has investigated the contribution of parental and passive smoking to SIDS, although studies have also been undertaken to investigating the relationship of air quality and air pollution to SIDS

(Skadberg and Markestad, 1997; Colditz et al., 2002; Corbyn, 1993; Tong and Colditz, 2004).

Between 1992 and 2000, Andrew Corbyn, a mining engineer from the Department of Biological and Environmental Science at Murdoch University in Western Australia, published research investigating the effects of air movement and air quality on sudden infant death syndrome. Corbyn became interested in the effects of air quality on infants, following his experiences with poor air quality in mining ventilation shafts, and hypothesized that air exhaled by an infant can accumulate near the face in certain circumstances, becoming saturated by carbon dioxide, and deficient in oxygen. In his PhD thesis published in 1999, Corbyn writes “explanation for a proportion of SIDS deaths can be made in terms of the accumulation of exhaled air with excess carbon dioxide at the face during sleep. Exhaled air from other persons or animals sleeping close to the face of the infant may also contribute” (Corbyn, 1999) (Figure 6). As an engineer, Corbyn spent many hours conducting detailed experiments designed to measure air quality around the face of an infant, eventually designing a breathing environment simulator (Matthews, 2005). As a mining engineer, Corbyn’s work was not embraced by the medical mainstream at the time; however his work does provide a possible explanation for some of the inconsistencies of sudden and unexpected infant death.

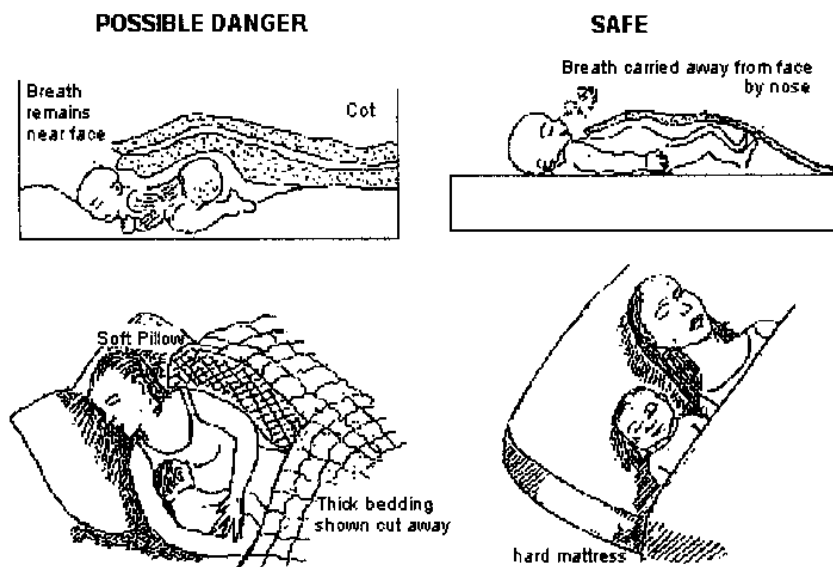


FIGURE 7: Mechanism for CO₂ buildup at face of sleeping infant. Corbyn, 1999

In 2002, Colditz and colleagues from the Perinatal Research Centre at the University of Queensland conducted further studies in the area of air quality, rebreathing and SIDS (Colditz et al., 2002). In their initial study of 56 healthy term infants, Colditz and his team sought to investigate the carbon dioxide dispersion and retention properties of some of the bed-coverings and mattresses commercially available for infants in Australia. The results of this study showed that some mattresses and bed-coverings trapped expired carbon dioxide and allowed high concentrations of the gas to accumulate around the face of an infant, and that some mattresses allowed more diffusion of carbon dioxide than others (Colditz et al., 2002). These findings supported those made by Corbyn ten years earlier and concluded that the findings may have implications for vulnerable infants who are already considered at risk of SIDS.

Medical studies have shown that infants are more at risk of SIDS if they are used to sleeping in one position and are then changed to another. Corbyn's research explains this by suggesting that a child who is used to sleeping prone or with heavy blankets and bedding becomes acclimatized to a hypercarbic (excess carbon dioxide containing) atmosphere. Upon subsequent exposure to a normal atmosphere (such as a change in sleeping position) the child may suffer from a reduced lung ventilation rate and stop breathing (Corbyn, 1999). One of the principle findings of Corbyn's research was that air that infants inhale should not mix with exhaled air, and that infants should sleep in a well ventilated area at all times (Corbyn, 2000).

In a detailed review of nine studies investigating air quality and SIDS, Tong and Colditz concluded that there was inadequate evidence to support any definitive relationship between air pollution and SIDS (Tong and Colditz, 2004). Although a direct relationship was not clear, they suggested that the body of evidence reviewed is suggestive of air pollution playing a role in the occurrence of SIDS, particularly in relation to the presence of fine particulate matter and gaseous pollutants (Tong and Colditz, 2004). Review of data in the manner performed by Tong and Colditz does have limitations, including exposure measure measurement bias, case classification bias and confounding by

inconsistency of aggregated socio-economic data. In view of this, and the complex nature and limited understanding of the SIDS process, Tong and Colditz recommend future studies should focus on research design, the role of indoor air quality and the effect of fine particulate matter on the mechanism of SIDS.

Bedding

It is known that the type of mattress on which the infant sleeps and the blankets used on top for coverings may have an effect on infant temperature and breathing, and as a result impact on the risk of SIDS (Sullivan and Barlow, 2001; Williams et al., 1996). In 1993 Bolton and colleagues proposed that using soft bedding which has poor weight resistance and a tendency to form pockets and indentations when an infant is sleeping, may predispose the infant to rebreathing carbon dioxide which collects around their face when they sleep in the prone position. This could lead to asphyxia from hypercapnia and hypoxia resulting in death (Bolton et al., 1993). This theory was first raised by Wooley in 1945 in a study looking at mechanical suffocation during infancy, and was again studied by Corbyn in 1992 and Guneroth in 1996 (Wooley, 1945; Corbyn, 1992; Guneroth and Spiers, 1996).

Polystyrene bead filled pillows were among the first soft sleep surfaces identified as contributing to deaths of infants, and as a result were removed from the market in the US (Kemp and Thach, 1991). In a study conducted in 1993, Ponsonby and colleagues reported that the adverse effect of sleeping prone was increased by the use of soft natural fibre mattresses. Ponsonby defined a natural fibre mattress as one filled with flakes of ti-tree bark or kapok. Natural fibre mattresses were shown to increase the risk of SIDS in infants sleeping prone, however they were not a risk factor for infants sleeping supine (Ponsonby et al., 1993). Natural fibre mattresses are described by manufacturers as 'allowing free passage of air', 'soft and fluffy', and 'shaped for comfort', whereas the propensity of these type of mattresses to indent and form pockets suggests that rebreathing of air by infants is a strong possibility. Kemp and colleagues investigated this further and found that bedding filled with ti-tree bark had a more limited capacity for carbon dioxide dispersal than conventional firm bedding (Kemp et al., 1994). It has been

suggested that the preference for firm mattresses in the USA, and for soft mattresses in Australia and New Zealand could explain why sleeping prone is a more important risk factor in the latter two countries compared to the USA (Sullivan, 2001). In a later study, Guneroth suggested that it would be unlikely for an infant to proceed to the point of asphyxiation from rebreathing as a result of soft bedding, as even moderate levels of hypercapnia cause arousal (Guneroth and Spiers, 1996).

It has been suggested that sleeping on bedding previously used by others may play a part in SIDS (Tappin et al., and the Scottish Cot Death Trust, 2002). This study highlighted an increased incidence of SIDS if a child slept on a mattress that had previously been used by another child, however the risk increased significantly if the mattress was from another home. There remained however, insufficient evidence to establish a cause and effect relationship (Tappin et al., 2002).

Co-sleeping and bed-sharing

It has since early times been known that accidental overlaying of an infant by a sleeping mother is a cause of infant death, and that the Greek physician Soranus recommended supine sleeping and discouraged co-sleeping for this reason (Alm, 2007). The introduction of less rigid feeding schedules and recommendations to improve mother to baby skin contact, and therefore increase bonding, saw the popularity of bed sharing and co-sleeping emerge in the 1960's. There is much debate in the literature about the practice and definition of bedsharing and co-sleeping, and for this reason the current Information sheet for parents around 'Sleeping with a Baby' produced by SIDS and Kids NSW uses the terminology 'sharing the same sleep surface' when referring to the practices of bed-sharing and co-sleeping (SIDS and Kids, 2007).

There have been several studies that showed infants who sleep in close proximity to their mothers have better outcomes related to breastfeeding (McKenna, 1997; Ball, 2004). However, there is also strong evidence to suggest that co-sleeping or sharing a surface for sleep purposes will increase the likelihood of SIDS (Mitchell et al., 1992). Hospital based studies which investigated cribs that attach to the mothers bed or are close to the bed have

shown these practices are effective in promoting breastfeeding, while preserving infant safety (Ball, 2004).

Information from pathological case-series suggests that certain co-sleeping situations may be particularly dangerous and increase the risk of SIDS in the infant. In these cases it is often difficult to determine the cause of death as SIDS, or accidental death (Scragg et al., 1993). Adverse sleeping conditions that may occur when co-sleeping include; being smothered by bedclothes, being trapped face downwards in a space between the parent and the bed, the wall or the back of a couch, and being face down in an indentation pocket of an adult waterbed (Mitchell, 1992). Co-sleeping is particularly dangerous when the parent is in an unnaturally depressed state of consciousness, such as from alcohol or drugs (Scragg et al., 1993). Recent evidence has shown there is a significant risk of SIDS from bed sharing with mothers or parents who smoke (Blair et al, 1996). There is also evidence to suggest that room sharing (i.e. an infant in the room, but not in the bed) with one or more adults decreases the risk of SIDS (Scragg et al., 1996). In a three-year population based case-control study undertaken in England from 1993 to 1995, Blair and colleagues investigated the factors contributing to an unsafe sleeping environment, and the risk of SIDS (Blair et al., 1999). Results of this study showed that co-sleeping with an infant on a sofa was associated with a particularly high risk of sudden infant death syndrome. There was no increased risk of SIDS associated with bed sharing when the infant was placed back in his or her cot, and the risk of SIDS associated with bed sharing in young infants seems to be associated with recent parental consumption of alcohol, overcrowded housing conditions, extreme parental tiredness and the infant being under a quilt or duvet (Blair et al., 1999). Bed sharing and co-sleeping is particularly common in Aboriginal families, and families from other cultures including the Pacific Islands (Stanton, 1984; Guneroth and Spiers, 1995; Eades et al., 1999).

Temperature

In the early 1980's Stanton identified a link between babies who become either too hot or too cold and SIDS (Stanton, 1980; Stanton, 1984). There have also been numerous studies showing that the risk of SIDS is associated with the amount of clothing or

blankets on an infant, the room temperature, and the season of the year (Ponsonby et al., 1992; Ponsonby et al., 1998; Sullivan and Barlow, 2001, Wilson et al., 1994). The increased risk of overheating is particularly evident when the infant sleeps in the prone position, but is less clear when the infant sleeps supine (Ponsonby, et al., 1993; Williams et al., 1996). The SIDS statistics have always shown a distinct seasonality, with higher rates recorded during winter months (Beal, 1991; Williams et al., 1996). This may be as a result of overuse of blankets, quilts, room heaters and clothing in the colder months, or a reflection of the increase in infections, more common in colder weather (Beal, 1991; Gilman, 1995).

Socio-economic status

Early studies on SIDS highlight the role low socio-economic status has on families who experience loss of a child to SIDS (Guneroth and Spiers, 1995). One of the constant difficulties with this observation is the extent to which low socio economic status is a marker for other SIDS risk factors. Risk factors such as smoking, young maternal age, high parity, co-sleeping and poor education are highly associated with low socio-economic status in addition to SIDS (Sullivan and Barlow, 2001).

Breastfeeding

Although several retrospective studies have demonstrated a protective effect of breastfeeding on SIDS (Ford, 1993) other prospective cohort studies failed to find such an effect after adjustment for confounding variables (Kraus et al., 1989; Ponsonby et al., 1995). At the present time there is no conclusive evidence to suggest that breastfeeding is protective against SIDS; however recommendations are that women breastfeed wherever possible.

Immunisation

The peak age at which children die from SIDS coincides with the time most babies have their first immunization. Clinicians reviewing evidence on immunization have found that despite isolated case reports, there is no increased risk of SIDS associated with

immunization (Beal, 1990; Byard, 1991). Beal reported that in South Australia, the age of infants experiencing SIDS had not changed when the age for first immunization was altered from three to two months. In a study conducted in the UK between 1993 and 1996, Fleming and colleagues investigated any association between an accelerated immunisation program in infants and SIDS. After adjusting for confounding variables, the investigators concluded that immunisation does not lead to sudden infant death, and may in fact be protective (Fleming, 2001).

Non-modifiable factors

Evidence indicates that there are other non-modifiable risk factors predisposing infants to SIDS. Although these factors cannot be altered, raising awareness of the nature of the risk can assist in an overall reduction of SIDS cases.

Male gender

The vast majority of epidemiological data on SIDS highlights a higher proportion of male cases (60%) than female cases (40%), yet there are a greater number of males represented in all causes of infant mortality (Guneroth and Spiers, 1995; Mage and Donner, 1994; Tong and Colditz, 2004). In a report prepared in 1992, Guevarra and Taylor identified a higher proportion of male infants (69.4%) than female infants (30.6%) who died from SIDS in NSW that year, giving a male to female ratio of 2.3 :1 (Guevarra and Taylor, 1992).

Preterm birth and low birthweight

Some studies indicate that infants who are born before term or who are low birthweight are at increased risk of SIDS, and risk increases with decreasing gestational age and birthweight (Hoffman, 1995; Malloy and Hoffman, 1995). The increased risk cannot be explained by a greater likelihood of apnea of prematurity among preterm SIDS victims while they are in the hospital after birth (Hoffman, 1995). It is not known whether the complications of prematurity can explain a significant amount of the increased risk of

SIDS associated with prematurity. In a study conducted by Grether and Schulman of 2962 cases of SIDS derived from linked birth and death records, no association could be found between birthweight and SIDS incidence (Grether and Schulmann, 1989). In a study conducted in 1991 Li and Daling showed that SIDS was more prevalent in low birthweight babies in the five racial groups under study (Li and Daling, 1991). It should also be remembered that factors contributing to low birthweight, such as maternal smoking, alcohol consumption and low socio economic status are all independently associated with an increased risk of SIDS.

Infants who are preterm or born with low birthweight should still have the same risk reduction strategies applied to them as for full term infants. This is particularly the case where infants have been nursed in the prone position in an Intensive Care Unit (ICU) setting due to their prematurity.

Young maternal age

Young maternal age and being a single mother are risk factors for SIDS, and may be related to a tendency to use the prone position (Gray and Rogers, 1994). Studies in Canada, Australia and the USA have shown an association between maternal ages less than 20 years and the likelihood of using the prone position (Dwyer and Ponsonby, 1995; Guneroth and Spiers, 1995; Leach et al., 1999; Steele and Langworth, 1966). A study in the USA showed that teenage mothers were 10 times more likely to place their infants in a prone position to sleep, even if they had been given sleep position advice, than mothers who were aged 20 years or older (Lesko et al., 1998). Among those unaware of sleep position advice, unmarried mothers were 14 times more likely to place their infants in the prone position than were married mothers (Brennar et al., 1998). It is thought that the contribution of young maternal age to the risk factors for SIDS is based on a lack of experience and awareness of the parenting process, rather than a result of the maternal age 'per se' (Lesko, et al., 1998). It is also possible that young mothers are aware of the improvement in baby's sleep and reduction in crying when on their tummies and use this position to enable both mother and baby to sleep better.

Parity

Mothers who have larger families are at greater risk of having an infant die as a result of SIDS. The firstborn in these families has the highest risk, with the risk subsequently declining, relative to the firstborn (Sullivan and Barlow, 2001). In an English study undertaken by Leach and colleagues in 1999, the two most significant maternal risk factors were maternal age less than 20 years and high parity (Leach et al., 1999).

Cultural background

Ethnic background has not been proven to be a predictor of SIDS. However ethnic disparity in rates of death attributable to SIDS has been observed for many years. Despite decreased SIDS death rates following the 'Back to Sleep' campaign in 1994, the disparity in death rates has increased (Unger et al., 2003). Research has shown that African American, Maori, Australian Aboriginal and Torres Strait Islander, and Pacific Island populations have an increased risk of SIDS (Eades et al., 1999; Fa'alau et al., 2003; Finau et al., 2003; Guneroth and Spiers, 1995; Sullivan and Barlow, 2001). It remains unclear whether these population groups have an increased genetic risk of SIDS, or whether environmental and cultural practices play a major part in an increased risk (Sullivan, 2001). In a study of Pacific Island communities living in New Zealand (Aotearoa), Finau and colleagues concluded that Pacific Island infants' vulnerability to SIDS was increased by environmental factors in the womb, the sleeping environment of the baby and the family situation (Finau et al., 2003). Research in the Pacific Island population in New Zealand has shown that despite nationwide SIDS prevention campaigns, the implementation of the SIDS awareness program does not appear to be reaching the Pacific Island population Paterson et al., 2002a, 2002b; Tipene-Leach et al., 2000). It was raised whether a monocultural approach should be used in relation to SIDS prevention in this context (Everard, 1997) and following this a specific SIDS prevention program was instituted for the Pacific Island population (Finau et al., 2003).

The New Zealand SIDS Infant Mortality Register collects cultural demographics on any child that dies as a result of SIDS in New Zealand (Everard et al., 1998). This ensures

that accurate statistics are available on SIDS deaths in particular cultural groups, and culturally specific education programs can be implemented.

Although the bulk of research has shown that SIDS deaths are more prevalent in Aboriginal and Pacific Island communities, many other cultural groups exhibit practices known to be risk factors for SIDS. It is known that many Asian families practise over-wrapping and over-clothing of infants, particularly when the infant is very young, although in general rates of SIDS are lowest in Asian populations (Guneroth and Spiers, 1995). Co-sleeping and bedsharing is commonplace in cultures where the extended family is involved in caring for the newborn infant. This is particularly the case in Pacific Island, Maori, Japanese, Vietnamese and Chinese families (McKenna et al., 2000).

Grether and Schulman in a 1989 study suggest there is little evidence to support genetic factors playing a part in SIDS rates in differing cultures, rather differences in SIDS rates in immigrants merge toward the predominant culture, reflecting an adoption of local infant care practices (Grether and Schulman, 1989). This however is not the experience of the local Indigenous people of Australia and New Zealand, where rates of SIDS are known to be higher than in the migrant population (Eades et al., 1999; Tipene-Leach et al., 2000).

At the present time, there are no cultural demographics recorded for infants that die of SIDS in NSW (Calvert, 2004). Although the number of SIDS deaths in NSW has decreased dramatically and numbers are small, collecting data on cultural background in SIDS deaths would allow information to be provided to specific communities should the New Zealand experience be repeated in NSW. In the years 2005 – 2006 the infant death rate has increased in NSW, although no clear-cut reason for this has been identified, and there is no data to determine the racial background of children who have died (Child Death Review Team, 2006).

Factors protective against SIDS

There are some behavioural practices thought to have a protective effect against SIDS. In addition to the evidence suggesting that room sharing (i.e. an infant in the room, but not in the bed) with one or more adults decreases the relative risk of SIDS (McKenna et al., 1994). Recent studies have reported substantially lower SIDS incidence among infants who used pacifiers (dummies) (Arnestad et al., 1997). While the association in these studies has been strong and consistent, it does not prove that the use of pacifiers prevents SIDS. At the present time there is insufficient evidence to recommend the use of pacifiers in relation to SIDS, particularly as pacifiers are known to have other adverse effects on health outcomes, such as jaw and tooth misalignment (Sullivan, 2001).

Other causes of infant death

Several other causes of infant death can be mistaken for SIDS. Studies evaluating SIDS in siblings have found having a sibling who has died from SIDS is a significant risk factor for SIDS in the other siblings (Beal, 1989). Other studies however, have been unable to replicate these findings. In most SIDS cases, there is no evidence of parental psychiatric disease or neglect of the infant, but more recent findings have shown that in families where there are multiple cases of SIDS, or where other children have died, further investigation should be undertaken. A thorough investigation of the medical history and the death scene is crucial in every case, as it improves the chances for an accurate diagnosis (Byard, 2004).

Other causes of death such as cardiac and respiratory abnormalities, metabolic disorders, and neurological disturbances can be misclassified as SIDS deaths (Byard, 2001). This reinforces the importance of the SIDS definition, as a 'diagnosis of exclusion' as all of these potential causes of death should be eliminated before an infant death is classified as SIDS. To this end, the protocol developed by Byard and colleagues assists in ensuring a consistent method of SIDS death investigation is undertaken (Byard, 2004).

2.4 INFLUENCES ON INFANT CARE PRACTICE

The history of infant and maternal health services in NSW

The focus on infant health in NSW can be traced back to 1898, when Dr William George Armstrong was appointed as Medical Officer of Health for Sydney and suburbs (Lewis, 1976). With a passion for infant health, Armstrong was particularly interested in reducing infant mortality following his experiences studying public health in Cambridge (Armstrong, 1939). In 1904, Armstrong set out to adopt specific measures to address infant mortality. Believing that education of mothers, ‘particularly young mothers’, in mothercraft was the best way to improve infant health Armstrong obtained permission from the City Council of Sydney to employ ‘a trained health visitor to personally visit and instruct the mothers of all newborn babies, who were not receiving medical care’ (Armstrong, 1939). In Armstrong’s 1939 article he outlines the aim of his ‘home visiting strategy’:

“To visit every mother of a newborn child in the city...within a day or two of registration of birth...so the health visitor could talk to her confidentially on the management of the child and advise the methods she ought to follow. The great importance of breast-feeding and its superiority over other forms of feeding are stressed. The conditions as to the cleanliness of the dwelling are noted and in cases of poverty, families are referred to appropriate charitable institutions for supplies of milk food and blankets” (Armstrong, 1939, p 643).

The dramatic results in reduction of infant mortality obtained by health home visiting in Sydney led to an increase in the number of home visitors to undertake similar work in the populated industrial suburbs immediately surrounding the city (O’Connor, 1989). The introduction of a ‘Baby Bonus’ payment by the Commonwealth Government in 1912 greatly increased the early registration of births, particularly those of lower socioeconomic families who needed the money to pay for food and the expenses associated with raising an infant (Lewis, 1976). As Lewis writes:

“The mothers reached were working-class residents of the inner city area who were unlikely to be influenced by private practitioners and whose infants were more at risk, given their environment, from the threat of diarrhoeal mortality” (Lewis 1976, p 285)

In 1914, the then Minister for Health laid down policy that there should be established ‘clinics where expectant mothers might keep in touch right up to the time of crisis...and after birth the mother and infant would be visited in their home by a clinic nurse’ (Armstrong, 1939). The role of the clinics was: to weigh babies to ensure they were ‘thriving’, to encourage breast feeding and refer them to medical practitioners should there be any illness present. Two nurses staffed clinics; one remained on the premises, and one undertook ‘home visiting’ (Armstrong, 1939).

The clinics instructed new mothers in health care hygiene and infant nutrition with such good results that the service spread, leading to the necessity for additional qualifications in the ‘mothercraft’ or ‘baby health nurses’ who staffed the Baby Health Clinics (Corn, 1980). Specialist, unpaid, training was undertaken by nurses over a period of months, conducted in the nurse’s free time as they continued to work in the centres. On completion of training the nurses were equipped to provide prescriptive information to mothers on sanitation, food handling, vermin control, and child management including feeding discipline and establishment of routines (NSW Nurses Registration Board, 1982). By 1975, there were over 500 Baby Health Centres across the state (McLachlan, 1975).

As the focus on infant and maternal health increased, other organisations concerned with infant welfare emerged. In 1907, Truby King introduced his model at his home in Karitane, New Zealand, providing nursing care for babies with feeding problems. Truby King’s experience as a practitioner in the mental health area made him realize that many problems could be eliminated by education of mothers in preparation for motherhood and management of the child (Mein Smith, 1997; O’Connor, 1989). In 1923, The Australian Mothercraft society was established in Australia, following the model developed and implemented in New Zealand by Sir Truby King.

In 1918, the Royal Society for the Welfare of Mothers and Babies (now Tresillian) was formed, with the aim of coordinating the efforts of the different associations and bodies occupied or interested in furthering the welfare of mothers and babies (Armstrong, 1939). Dr Margaret Harper, a paediatrician from the Royal Alexandra Hospital for Children, was commissioned to visit The Karitane Hospital in Dunedin and to report on its value as a training school. Dr Harper commented on her return:

“the problem which confronts NSW is much more difficult of solution than in New Zealand, there are however certain New Zealand methods which could be applied successfully here”
(Armstrong, 1939, p 646).

As a result, the first ‘Tresillian Mothercraft Training Home’ was established in Petersham in 1921. The Tresillian homes proved so successful that two others were established, in Willoughby in 1927 and Vacluse in 1937. Training of Baby Health Nurses was transferred to these centres, and in the early part of the twentieth century, all Baby Health Nurses were trained through these centres (Armstrong, 1939; Cohen, 1971). Between 1944 and 1964, the Baby Health Centres were inundated with work, due primarily to the post-war ‘baby boom’, and many more Baby Health Centres were built. Due to the increase in number of births, home visiting was scaled back and prioritized to infants who were premature infants, multiple births, having feeding difficulties, had a disability or mothers who needed ‘guidance and supervision’ (O'Connor, 1989).

The Baby Health Clinics continued to provide both clinic-based services and home visiting to new mothers until the mid 1960’s. For women who were socially isolated in rapidly developing areas with poor transport and little access to other mothers, the Baby Health Centre provided a place to meet others and learn about all aspects of infant care (O'Connor, 1989). Around 1965, services were reviewed when the whole of NSW was divided into health districts. The Division of Maternal and Baby Welfare was amalgamated with the School Medical Service to form the ‘Bureau of Maternal and Child Health’, with the aim of providing continuing, complete preventive services to mothers and children from conception to school leaving age (O'Connor, 1989). Following the

establishment of 'the Bureau', the health needs of all children were recognized, including the importance of metabolic screening, visual and audiometry screening and immunisation. As a result of the declining birthrate, the service was reviewed and only priority home visiting was recommended so that other services could be provided (Department of Public Health, 1968).

“To home visit 81,000 families, even once, is a mammoth task, particularly in terms of the nursing staff available. Even if the staff were available, much time can be wasted by visiting homes of capable and knowledgeable mothers. Further, many Australians resent the continued intrusion into their privacy although most accept one visit and more if there are problems. Priority visiting is the most efficient and effective answer.”

(Department of Public Health Annual Report, 1968, p 70)

The baby health centres continued to provide services, which were both clinic based and involved some home visiting until the 1970's. Around this time the community health model was introduced, encouraging other child health services to co-locate with baby health centres, or increasingly, work closely in specifically designed community health centres (O'Connor, 1989). By this time women attending the baby health centres were declining due to a number of factors. Women were more confident in their own ability as parents, and many were emotionally unable to handle the rigid, prescriptive advice of the baby health sisters (O'Connor, 1989).

In 1973, the Department of Public Health was again restructured, leading to the formation of the Health Commission of NSW. Under this new administrative change, the state was divided into 14 geographically defined 'regions'. From this point maternal and child health became the responsibility of the Regional Director of Health in each region. The baby health centres were incorporated into the larger service called 'Community Health' (Health Commission of NSW, 1979).

The early 1970's saw the introduction and expansion of antenatal education, provided through the baby health centres. The decline in infant mortality, which had been arrested earlier in the century, was shown by research to still be an issue in post neonatal infants (from one month to 12 months). Around 68% of these deaths occurred between 4 and 20 weeks of life, many as a result of 'cot death' (O'Connor, 1989). Demographics of the urban population changed significantly in the 1970's. Increasingly there were more young mothers, single parents and families with both parents working. Women delayed getting married, and as a result began their families later in life. There was more access to other sources of information on child rearing, including books, pamphlets and television. In a report prepared around this time, Deirdre Degeling makes a comment about the increasing difficulty new mothers experienced obtaining advice that was accurate and meaningful:

“Advice today on how to bring up one's baby comes from many different sources – book and television, doctors and baby health nurses, neighbours and grandparents. This is often very confusing to new mothers, as people have very different opinions on just about everything to do with babies. Even the experts disagree”

(Degeling 1979, pp 21 – 22)

In 1979, to evaluate the service changes implemented by four 'regions', the Health Commission of New South Wales, led by Juliet Corn conducted a review of the changes to service delivery in baby health centres since the inception of the Health Commission of NSW. In addition to evaluation of changes, the review intended to make recommendations for future service development (Corn, 1980).

Corn's 1980 review of Baby Health Services highlighted the changes that had occurred in the provision of services to mothers and infants over time. Many of the baby health sisters interviewed in the review commented on the change in focus from 'the mother and infant' to the 'family context'. The difficulty of providing services from a clinic staffed by one baby health nurse was also raised. As part of the review, recommendations were made to amalgamate clinics where one clinic sister worked alone, enabling the provision

of a more diverse range of services to families. Recommendations included: providing more social mothers groups, group education, linking with other child health services, increased in-service training for staff and a more stream lined way of identifying the mothers who should attend the centres (Corn, 1980). Corn's report identified significant changes that had impacted on the baby health service since regionalisation. These included; a lack of management for the baby health nurses, and little reassessment of the ways services were provided, in spite of a change in clinic sisters' role from that of procedural work, to a focus on counselling (Corn, 1980). In a survey of baby health sisters following Corn's review one nurse commented:

“People did not have the overwhelming debt they have now. They weren't as stressed about money, even though they were quite hard up. They didn't have the overdraft or the big house and two cars...most grandmothers are out at work now, too, so they don't have their support”

(Baby Health Activity Survey, May – June 1984 p 25)

Following the Baby Health Activity Survey, policy guidelines were introduced and endorsed by the Policy Review Committee of the (now) NSW Department of Health, in July 1987. The policy guidelines on 'Early Childhood Services' recommended a change of terminology to reflect the focus of the new service. Centres were now to be called 'Early Childhood Health Centres' and nurses 'Early Childhood Health Nurses' (Department of Health, 1986). Increasingly, evidence highlighted the importance of caring for children not as sole beings, but within the context of the family. Social research has provided detailed knowledge about what is best for the family and infant, leading to evidence-based informed practice in all child health disciplines. The 'new' service delivery model in maternal and infant care aimed to provide a wholistic and evidence based approach to child health care, and led to an increase in local and overseas research on the best ways to provide services to children and families (Australian Government, 2004; Olds, 1986; Vimpani, 2001).

Throughout the 1990's health promotion activities focused on the health of children and families. Campaigns were aimed at reduction of SIDS (through the Reduce the Risks

Campaign) improving children's dental health (through the Save our Kids Smiles campaign) and immunisation (SIDS and Kids, 1999; NSW Health, 2000).

In 2002, the NSW government announced the formation of a 'cross government strategy' known as 'Families First' (now known as Families NSW). The strategy was implemented to provide a cohesive, consistent, evidence based approach to child and family health and reduce duplication of services between agencies.

Made up of five key government departments (Health, Community Services, Education, Disability and Home Care and Housing), Families NSW set out to improve the health of children and families across NSW. One of the first strategies implemented through Families NSW with funding from NSW Health was the reintroduction of a universal home visiting service to new mothers and their infants, based on evidence highlighting the benefits of 'investment in the early years'. In addition to this strategy, Families NSW initiated a model of service delivery based on the 'Family Partnership' model developed by Hilton Davis (Bidmead, Davis and Day, 2002). Under this model Early Childhood Health Nurses work in partnership with families to increase their effectiveness as parents, thereby empowering parents to identify and respond appropriately to concerns about infants (Keating, et al., 2007).

The Universal Health Home Visiting Strategy is based on evidence from Olds and colleagues in the USA, whose research showed a reduction in neglect and harm to infants who were visited by nurses in their homes soon after birth. Olds' research showed that this was particularly the case in families where women were 'at risk', experiencing postnatal depression, were disadvantaged, had poor support networks or had little sense of control over their lives (Olds et al., 1986, 1997). Across NSW, this strategy was implemented in each Area Health Service, incrementally rolled out as funding became available and requiring a re-orientation of the way Child and Family Health Services were provided. Under this strategy, all families are visited once in their home following the birth of an infant (where possible within the first two weeks following birth), and multiple times where indicators of risk are present (NSW Health, 2002, 2008).

One of the major benefits of the Universal Health Home Visiting strategy is the ability of the child and family health nurse assess new mothers and infants in their own homes. In the home setting a quality interaction between nurse and mother (or both parents) can occur, and detailed information can be provided to the family on infant health, and management of family issues as they occur (Scott, 1997; Driesma, 1998). Early referral to appropriate services can be made by the nurse when assessments for postnatal depression and psychosocial issues are conducted early in the home (NSW Health, 2002, 2008). Currently child and family health nurses offer a combination of services including home visiting and clinic-based services to over 85,000 families each year. Since the introduction of a 'Baby Bonus' Payment in 2004, numbers of births are increasing in all areas of NSW (NSW Health, 2006). At the present time, there is still no streamlined way for child and family health nurses to access all women who give birth in NSW. Although public health facilities refer all new mothers to Child and Family Health Centres on discharge, many mothers elect not to take advantage of the home visiting service, preferring to use clinic based services. Women who give birth in private hospitals are often not referred to Child and Family Health Centres due to poor communication links with the local services and staff workload.

The role of 'the expert'

Prior to the establishment of the infant and maternal health services in New South Wales, new mothers relied heavily on the expertise and advice of midwives, nurses and other women with children to assist them in caring for their new infant. These women were the first 'experts' in infant care (NSW Midwives Association, 1984). The health home visitors, followed by the Baby Health Sisters (both in clinics and home visiting), became the 'trained experts' in infant and maternal health care (O'Connor, 1989). Specialists in paediatrics including Dr Margaret Harper and Dr Charles Clubbe from the Royal Alexandra Hospital for Children were experts in maternal and infant care in the 1930's and were well respected following their development and support of the Tresillian Mothercraft Homes (Cohen, 1971). The Baby Health Clinics were important to all new mothers, assisting them with day to day problems of infant care, stressing the importance of hygiene, breastfeeding and proper nutrition (O'Connor, 1989). The dramatic results in

the reduction of infant mortality due to diarrhoeal disease, infections and ‘failure to thrive’ gave the infant and maternal health service credibility as the ‘experts’ in infant care (Armstrong, 1939). The approach of the baby health sisters to mothers with newborn infants was prescriptive and authoritarian, and this approach was reflected in many of the publications produced by the service (NSW Department of Public Health, 1942). Many of the edicts of the baby health nurses, and guidebooks made mothers feel incompetent and insecure about the way they cared for their infants. An example from the ‘Our Babies’ handbook for mothers in 1942 states:

“If mothers could only realize that ARTIFICIALLY-FED BABIES ARE SEVERELY HANDICAPPED and that no infant can be deprived of his natural food without detriment, they would not neglect these simple precautions”.

(Our Babies, 1942 p39)

Following the Second World War, there was an increased focus on the development of medical specialties. Psychology and paediatrics developed as health specialties in the 1950’s and as a result, new infant care experts emerged and new methods of information delivery were used. In Sydney, Dr Clair Isbister, a paediatrician from the Royal North Shore Hospital, was the first woman to discuss infant care and parenting on the radio in 1957 (Isbister, 2005). In the USA, Dr Spock began a revolution in infant and childcare practice. Publications by these experts were readily available for new mothers to purchase enabling women to gain expert advice from a range of sources (Spock, 1946; Isbister, 1958, 1963, 1965; Spock and Gessell, 1961). As Fowler and Lee reported in 2007, *‘Many healthy human experiences and practices have become medicalised and professionalised within health during the last century’* (Fowler and Lee, 2007, p 181). The medicalisation of normal practice led families to seek advice and information from those medical personnel who were considered ‘expert’.

For many women, the person they consider most expert in infant and child-care is their mother, someone they can trust to explain the methods of child-care that work. However this does not mean that the advice given is always correct. In an article written in 1964, but that still holds true today, Rendle-Short commented:

“In Western countries, the prime responsibility for looking after the younger child rests on the mother, with what help she can muster from father, grandparents, neighbours and paid or unpaid babysitters. Very likely none of these persons have ever received any instruction in childcare or have even read anything (current) on the subject apart from the occasional article in a women’s magazine. The lore and myths of previous generations are handed down from mother to daughter”

(Rendle-Short 1964)

Confusion about the best methods of infant care has escalated since the introduction of the Internet as an information resource. Little is known as to what motivates women to use the internet in the first place, however as Pandey and colleagues highlight; “volumes of information on any conceivable topic are only a few ‘mouse-clicks’ away” (Pandey et al., 2003). Many people (particularly those from a low socioeconomic background) are caught in the ‘digital divide’ and there are gross inequities associated with those who have access to computer technology and those who do not (Pandey et al., 2003).

With the role of the baby health centre /early childhood centre so pivotal for mothers with new infants, and because early childhood nurses are so highly and specifically trained, the nurse has always held credibility as an ‘expert’ in caring for infants and children. The recent changes to service delivery including working under the ‘Family Partnership model’ is a difficult and sometimes confronting experience for many child and family health nurses, and for parents. Under this model the *parent* is seen as ‘the expert’ on their child, and is asked to provide solutions they might be able to use to address problems. This process should not however be unidirectional, but an "active and engaging method of knowledge transfer between knowledge providers and the families who are consumers of that knowledge "(Fowler and Lee, 2007).

The role of literature

Armstrong produced the first official publication for new mothers in Sydney in 1903, in the form of a brief pamphlet titled “Advice to Mothers” (Armstrong, 1939). A range of

publications aimed at new mothers followed, spurred on by an increase in 'medicalisation' of infant care, the high infant mortality rate and rise in consumerism (Keane, 2001). Baby care experts gave advice to mothers on reducing infections and diarrhoea, and improving chances of survival, as well as how to dress a baby and keep them 'on schedule' (for feeding and sleeping) in order to instill good habits (Chapin, 1902; Harper, 1940; Health Department of NSW, 1942). In Australia, publications about infant care were aimed primarily at women who could read and wanted to refer to expert advice on caring for a new baby (Mein Smith, 1997). To encourage women with little money to read literature on parenting methods, health authorities and companies who made baby products produced free publications addressing methods of infant care. These were distributed through baby health centres, hospitals and pharmacies (Nestle Anglo Swiss Milk Company, 1938; Department of Public Health, 1942; O'Connor, 1989). In a Guild Pharmacy Promotion in 1959, copies of "The Parents Book" by Dr Margaret Harper from the Royal Alexandra Children's Hospital were distributed to all mothers of new babies who attended the pharmacy to purchase baby products (Hoskin, 2004). The NSW Health Department infant care booklet 'Our Babies' was first introduced in the early 1930's and remained in use (in a much changed and updated format) until the mid 1990's.

There has been a long debate in sociology and in social and women's history as to whether books, guidelines and manuals detailing how mothers ought to raise their infants corresponded with or influence mother's actual behaviour (Mein Smith, 1997). Mechling drew on anthropological theory to raise objections to the use of manuals in educating women in childcare. He stated that exposure to books depended on the mother's socio economic status and that childrearing behaviour was learned from one's own parents (Mechling, 1975). In a study of infant feeding in the United States, Apple found that broadly speaking with regard to childcare, women read the information given and act on the advice provided (Apple, 1987).

Socio-economic status

Social class was noted to have an effect on infant health outcomes in Sydney as early as 1903 when Armstrong introduced the health visitor program aimed at women who did not

attend private medical care due to poverty and poor education (Armstrong, 1939). Social class is known to impact on the way parents care for their infants, and research shows that educational level of the mother has a strong correlation on parenting ability and subsequent infant health outcomes. Where mothers are poorly educated they may be less inclined to listen to expert advice, instead relying on advice from family and friends who may provide misinformation. Interviews conducted by Mein Smith in Wonthaggi, Victoria, in 1995 indicated that women from poorer social backgrounds had less access to information than those from wealthier backgrounds, and as a result relied more on family and friends for information on childrearing (Mein Smith, 1997). A study undertaken in suburban Sydney in the early 1980's by Wearing on 'The Ideology of Motherhood', highlights the difficulties mothers from poorer socio-economic areas, such as Mt Druitt, have accessing luxury items such as books and magazines, and their reliance on family and friends for support (Wearing, 1984).

Social support systems

There is speculation as to whether women gain knowledge from insights passed down from generation to generation (Mechling, 1975). To further examine where women obtain their infant care knowledge it is essential to review research involving women who are mothers (Mein Smith, 1997; Wearing, 1984). In her 1997 study Philippa Mein Smith interviewed women who were mothers during the 1950's. These women highlighted the challenges they faced as 'new mothers' in the post-war years. Women commented on the difficulties of balancing advice from Baby Health Sisters, local General Practitioners, and their own mothers and friends, finally raising their baby with a little advice from all, mixed with their own discretion (Mein Smith, 1997).

As part of the Baby Health Activity Survey in 1984, the nurses who were interviewed highlighted the changes in society between the 1950's and the 1980's, and commented on the effect this change had on parents (NSW Department of Health - Health Services Unit, 1984). Since 1984, significant social changes have continued to occur. The past 20 years have seen the introduction of computers into the workplace, the introduction of the internet, an increase in working parents, single parent families and older parents, a

decline in the birthrate, reduction in family size and an increased number of children in out of home care (AIHW, 2002).

Cultural background

Culture can be defined as a shared set of values, norms, perceptions, assumptions and social conventions which enable a community of people to function cohesively as a group (Schott and Henley, 1996). Culture is not something which is genetically inherited, rather it is a set of values acquired during childhood, influenced by family, friends and the society in which we live (Hofstede, 1991). The traditions and values that are learned differ markedly between cultures. Nowhere is this more obvious than in relation to infant care and childrearing. What is acceptable to one cultural group may be abhorrent or shocking to another, even though each culture see perfect sense in their own traditions (Schott and Henley, 1996).

Initial Australian studies on motherhood were mainly conducted with women from middle class, Anglo – Celtic backgrounds (Brown et al., 1994; Brown et al., 1997; Everingham, 1994; Wearing, 1984). It is only relatively recently, that the implications of motherhood in a country other than a native homeland have been studied (Liamputtong and Naksook, 2003; Rice and Naksook, 1998; Small et al., 1999).

There has been much research undertaken in relation to cultural beliefs and practices surrounding childbirth, particularly in Asian and Indian women (Manderson, 1981; Manderson and Matthews, 1981; Rice, 1994, Rice and Naksook, 1998; Small et al., 1999). There are some small-scale Australian studies investigating the culturally specific childbirth practices of women born in the Pacific Islands (Gray et al., 2002). Studies investigating infant care practices in this group are more likely to have been conducted in New Zealand (Finau et al., 2003; Gray et al., 2002, Tipene-Leach et al., 1999).

Health care beliefs about what causes illness and where assistance should be sought are as much influenced by our culture as our views on family patterns, acceptable dress and what constitutes normal behaviour (Grant et al., 2005). Complex health systems such as those found in Western countries are often taken for granted by those who have grown up

with this system. It can be a surprise to learn that many cultures have completely different systems for providing care surrounding pregnancy and infant care. Western medicine and traditional cultural practices show tremendous variation in both practice and attitude (Schott and Henley, 1996).

Culture and the individual's experience of the health care system influence the way people relate to health professionals and what they expect of them (Schott and Henley, 1996). Culture is known to influence what people regard as healthy, and when they should present to hospital for further care. For example, many Pacific Island women associate hospitals with those who are 'sick' or who are going to die, and therefore avoid attending the hospital for antenatal care because pregnancy is a normal, natural, 'well' state in their community (Wilson et al., 2007). This simple belief can sometimes place the woman and her baby in jeopardy, particularly where high-risk pregnancies require early antenatal intervention. In an interview with the senior Pacific Island Health Worker in Western Sydney, the approach Pacific Island women take to their health was outlined. "Traditionally Pacific Island born women like their health care to be very prescriptive and hierarchical, in the same way as their village practices were. They like to be told step by step, and trust elders, doctors and teachers to know best. They are not stupid, they just don't like the responsibility of making decisions in this regard" (Peacock, 2003).

For women from CALD backgrounds, negotiating the 'Western' health system can be very difficult and disturbing (South East Health, 2002). Women who do not speak English, or who have differing expectations of the health system, are at increased disadvantage when accessing maternity or infant care facilities (South East Health, 2002). Studies investigating the experiences of immigrant women show that the local practices and beliefs are at odds with that of their homeland, and this can have implications for professionals promoting local practices such as rooming in, early mobility and exercise following birth (Small et al., 1999).

Many women who give birth in a new country do not speak the local language, and this can have serious implications for both the woman and the health care professionals involved in her care (Small et al., 1999; South East Health, 2002). Situations including

misunderstanding medical processes, terminology and instructions, have all been reported in women who have limited English skills, often resulting in adverse health outcomes for either the mother or her infant (South East Health, 2002). Although much information is now available in other languages, full understanding of this information is reliant on the woman being literate in her native language (Boules, 2007; Gray et al., 2002; Small et al., 1999). Poor language skills, lack of family support and subsequent isolation can lead to an increase in postnatal depression in many immigrant women. The separation from loved ones at a time when the woman would traditionally be provided with support, encouragement and advice adds to the sense of isolation and loneliness (Liamputtong and Naksook, 2003; Small et al., 1999).

Although Australia had long been the destination for migrants from a range of non-English speaking countries, the cultural background of women attending baby health centres had never been assessed or documented in a systematic way (O'Connor, 1989). Some migrant health programs were implemented in communities where there was a concentration of migrants from a specific country such as Italian and Greek migrants in metropolitan areas. Bilingual Community Educators generally ran these programs in the native language of the various ethnic groups (O'Connor, 1989). The change in cultural demographics was highlighted in the Baby Health Activity Survey conducted in 1984 (NSW Department of Health - Health Services Division, 1984). More overseas born mothers were found to be accessing baby health services and increasingly, language barriers were an issue. Around the same time, the NSW government initiated a 'Ministerial Taskforce on Obstetric Services in NSW', and in 1989 released its findings and recommendations in the Shearman Report (NSW Department of Health, 1989). One of the major recommendations of the Shearman Report was around providing services specifically for women from diverse cultural backgrounds.

2.5 INFANT CARE PRACTICE AND RELATIONSHIP TO SIDS

Cultural practices and the relationship to SIDS

Many cultural practices have the potential to impact on the rate of SIDS in infants (Tipene-Leach et al., 2000; Tipene-Leach and Haretuku, 2002; Tirosh et al., 2000). The most common practices which have a cultural basis and are also risk factors for SIDS are: maternal smoking; bed sharing, bed clothes and covers, co-sleeping and inconsistent sleep position and young maternal age (Sullivan, 2001; Abel et al., 2001; Finau et al., 2003). There have been studies undertaken in cultural groups known to exhibit a higher risk of SIDS. These studies are outlined below.

Infants born to Aboriginal mothers

Aboriginal infants are known to have poorer health outcomes than non-Aboriginal infants, including higher rates of SIDS (Alessandri et al., 1994). In a case control study undertaken in Western Australia in 1996, Alessandri and colleagues investigated the antenatal and perinatal risk factors for SIDS in the Aboriginal population of WA through the analysis of routinely collected data (Alessandri et al., 1996). Alessandri found that SIDS in Aboriginal infants in Western Australia was strongly related to maternal age, high parity and with infants being small for gestational age. The study highlighted the need for further research into infant care practices in the Aboriginal community (Alessandri et al., 1996). Following this, Eades and colleagues collected data on infant care practices of Aboriginal mothers, in conjunction with the Bibbulung Gnarneep ('Solid Kid') Project being conducted in Western Australia (Eades et al., 1999). This study of Aboriginal mothers living in metropolitan Perth indicated that 11% of Aboriginal infants slept prone, 96% shared a room and 68% shared a bed. Of those interviewed, 65% of mothers smoked during pregnancy and 80% of the infants were regularly exposed to tobacco smoke. While the rates for prone position and bed sharing are similar to that of the overall WA population the results of exposure to cigarette smoke in these infants was significantly higher than for non-Aboriginal infants (Eades et al., 1999). One of the

limitations of this study was the under-representation of young mothers, known to be at increased risk of having an infant die from SIDS (Eades, et al., 1999).

Infants born to Maori and Pacific Island mothers

High rates of maternal smoking and bedsharing largely explained the high rate of SIDS deaths in Maori infants in New Zealand (Tipene-Leach and Haretuku, 2002). Bedsharing is commonplace in Maori families, and indeed in all Pacific Island cultures. In this setting infants rarely sleep prone, but sleep between the parents in the supine position. Although co-sleeping is considered a risk factor for SIDS, researchers in New Zealand found that maternal smoking and co-sleeping had a confounding relationship and while maternal smoking and bedsharing together increased the risk of SIDS significantly, bedsharing alone did not (Tipene-Leach and Haretuku, 2000). Pacific Island families traditionally 'overclothe' their children, particularly when they have a fever. Culture says that children must be protected from 'the chill'. As a result babies are often heavily swaddled and wrapped in blankets to sleep in the Australian climate which is considered 'cold' (compared to the Pacific climate) (Peacock, 2003). Pacific Island born mothers do not react quickly to illnesses in children, tending to 'play them down'. As a result many children do not present to hospital until seriously ill (Peacock, 2003).

In a 2003 paper on SIDS in Pacific Island countries, Fa'alau and colleagues comment that 'SIDS is rare in the Pacific countries where bedsharing has been predominant as the infant sleeping arrangement (Fa'alau et al., 2003). One of the clear indicators of the New Zealand Cot Death Study was that 'cultural traditions need to be considered when providing information to families regarding SIDS prevention' (Davidson-Rada et al., 1995; Everard, 1997). Everard, in her paper 'Managing the New Zealand Cot Death Study: Lessons from between the rock and a hard place' commented that in cultural groups "the whole approach to SIDS needs to be removed from the narrow medical framework and be repositioned in the context of well childcare" (Everard, 1997). Similarly Fa'alau and colleagues comment that regular health programs within each ethnic community providing health information in each Pacific language and context could make a difference to the various Pacific groups (Fa'alau et al., 2003). Pacific Island

families learn best from pictures and doing, they are an 'oral' culture and revel in oratory and storytelling. This makes tailoring educational programs especially important (Peacock, 2003).

In 1998, Tipene-Leach and colleagues conducted a study investigating the infant care practices of caregivers of infants under 12 months of age from Maori, Tongan, Samoan, Cook Islands, Niuean and Pakeha (white) communities in the Auckland region of New Zealand (Tipene-Leach et al., 1999; Abel et al., 2001). This qualitative study used a combination of interviews and focus groups to elicit information from the participants about their childbirth experiences and their methods of infant care. Results from this study highlight the reliance of women from a Pacific Island background on traditional methods of pregnancy and infant care. Many Pacific Island women attended a 'fofo' (traditional healer) during their pregnancy, and practiced the avoidance of certain foods during this time. Pacific Island women commented on the importance of family support, and women who were not closely connected to family described the experience of childbirth and infant care 'difficult and overwhelming' (Tipene-Leach et al., 1999). Women who were raised in New Zealand of Pacific parents and who favoured Western practices experienced conflict with their families over a departure from the traditional ways, in some cases leading to a reduction in support from their families (Abel, et al., 2001; Tipene-Leach et al., 1999). In a study investigating the parenting practices of Samoan parents in New Zealand, McCallin and colleagues highlight the difficulties experienced by parents living 'between' cultures, commenting that 'striving for the best of both worlds often creates conflict' (McCallin et al., 2001).

Infants born to Middle Eastern mothers

Some small-scale studies have been conducted on other practices (such as overheating and overdressing of infants) thought to contribute to an increased risk of SIDS (Tirosh et al., 2000). In a study of Arab and Jewish mothers in Israel, overdressing of infants was not found to be associated with an increased risk of SIDS in Arab infants compared to Jewish infants. Compliance with recommended (supine) sleep positioning was still lower

than expected in both groups (Jewish infants 65%, Arabic infants 73%) (Tirosh et al., 2000).

Infants born to mothers from other CALD groups

In a study conducted in Victoria, Australia, Potter and colleagues investigated the home environments of four groups of women from differing cultural backgrounds and investigated the risk of SIDS in infants by studying differences in sleeping position, smoking, breastfeeding and bed sharing (Potter et al., 1996). In this study, fewer than 10% of mothers used the prone position to sleep their infants, and although more than 50% of infants in the high risk group regularly slept with their parents, so too did one quarter of infants in the Asian group (considered low risk for SIDS). The researchers concluded that these risk factors did not clarify the reasons for the differences in SIDS in Victoria (Potter et al., 1996).

The Chicago Infant Mortality Study was conducted in the late 1990's and aimed to determine the contribution of prone sleeping position and other potential risk factors in a high-risk urban African American population living in the United States. Rates of SIDS are known to be over twice as high in African Americans compared to Caucasian Americans (Hauck et al., 2002). The major findings from the Chicago Infant Mortality study indicate that prone sleeping was a significant risk factor for SIDS in the population under study, with around one third of SIDS deaths being attributed to prone sleeping position. Only half of the African American mothers were advised about sleep position in hospital after delivery, and more black mothers were advised to use the prone position (Hauck et al., 2002). Although the participants in this study gave birth in the early years of the Back to Sleep Campaign, this study highlights the importance of providing a consistent message to all mothers.

Changing fashions in infant care and the implications for SIDS

There have been demonstrable changes in the provision of maternity care, paediatric medicine, and infant care practices over the last 100 years (Gaisford, 1964; Keane, 2001; Isbister, 2005) Publications used by mothers in the 1940's and 1950's include; 'The Parent's Book'; 'The Lactogen Book'; 'Our Babies'; and 'The Commonsense Book of Baby and Child Care' (Harper, 1940; Nestle Anglo Swiss Milk Company, 1938; Department of Public Health 1942 - 1990; Spock, 1946). In Karen O'Connor's 1989 publication "Our Babies – the States Best Asset", she details the changing advice to mothers given in Australia and NSW between 1910 and 1990. As many of the original documents giving advice to mothers were discarded, or deteriorated due to age and fragility of the papers used, O'Connor's publication is the most detailed, comprehensive account of advice to mothers in the setting of New South Wales (O'Connor, 1989).

Changes to advice on sleeping position

In Australia, recommendations on the method of putting a baby to sleep were documented as early as the 1930's. The NSW Department of Public Health booklet 'Our Babies' dated 1942 advised mothers to:

'Place baby in a cane bassinet to sleep allowing plenty of ventilation and air movement' (NSW Department of Public Health, 1942).

The Nestle publication 'The Lactogen Mother Book' dated 1938, similarly advised mothers to:

'lie a baby on their back as flat as possible' and 'ensure appropriate bedding and fresh air.....baby should sleep alone in a well ventilated, airy room, protected from draughts, and should be trained to sleep in the open air as soon as possible', (Nestle Anglo Swiss Milk Company, 1938).

The Parent's Book clearly stated an infant should be put to sleep in:

'a darkened well ventilated room', as 'sleeplessness can be caused from a lack of fresh air around the face'

(Harper, 1940).

Examination of 'Our Babies' (1942) indicates that all illustrations and pictures show infants lying supine, however the front cover of 'The Lactogen Mother Book' has an illustration of a baby lying on its side (Department of Public Health, 1942; Nestle Anglo Swiss Milk Company, 1938) (Figure 8 and 9).

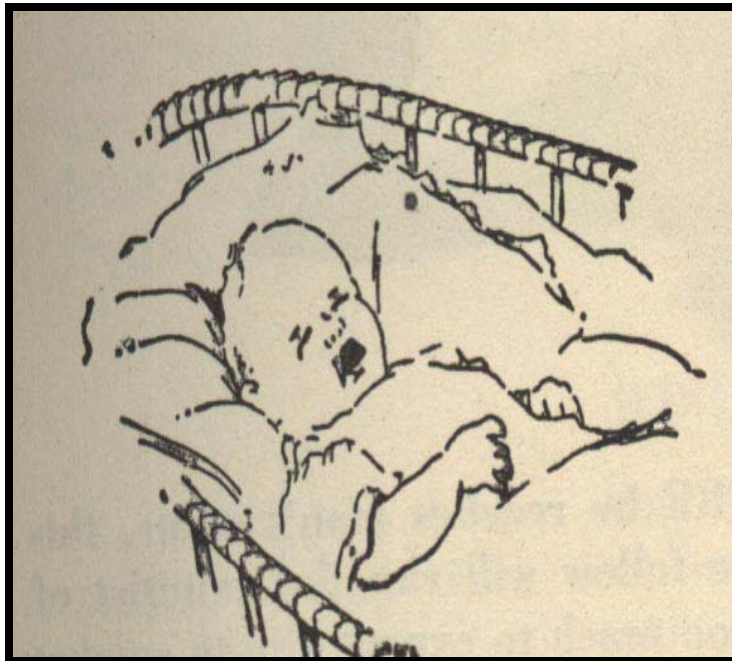


FIGURE 8: Photos and illustrations of babies lying supine in 'Our Babies' NSW Health 1942 (pages 4, 12 and 43).

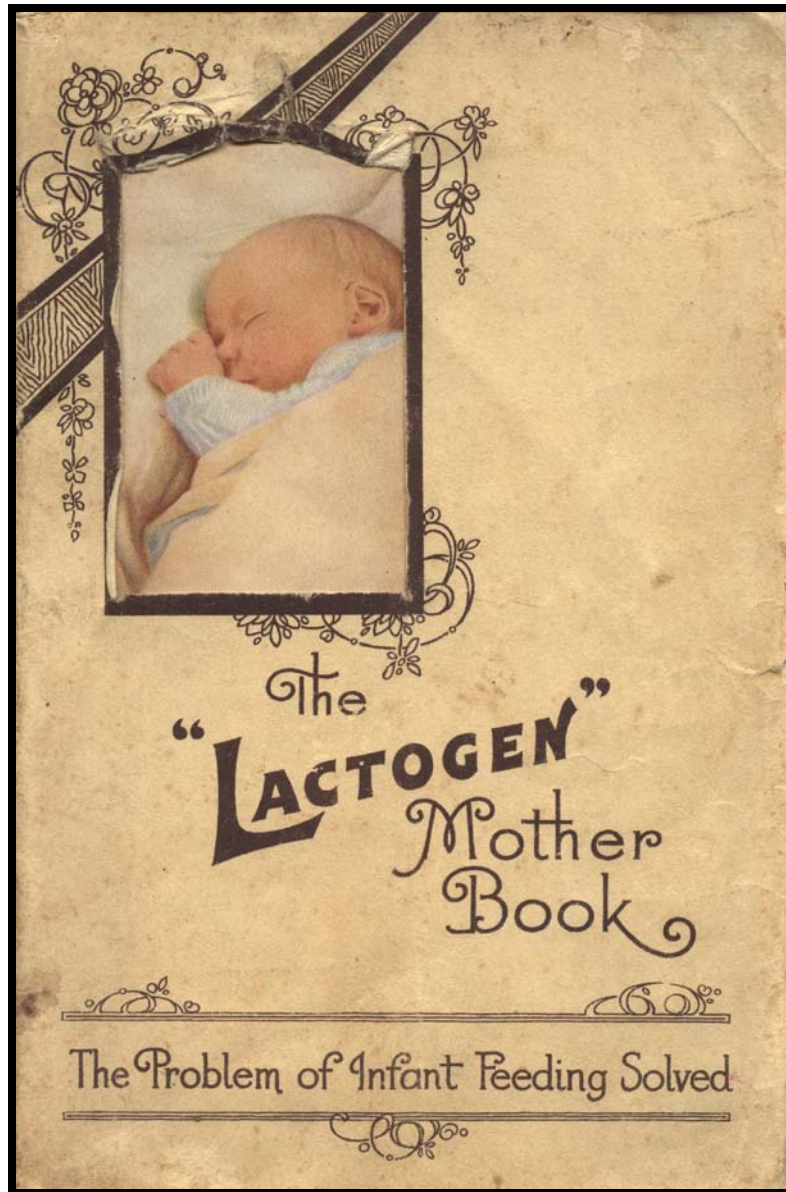


FIGURE 9: Illustration from front jacket cover of 'The Lactogen Mother Book' 1938 showing infant sleeping on side.

In their article written in 2000, Hogberg and Bergstrom, outline in detail the historical aspects of supine and prone sleeping positioning in Sweden (Hogberg and Bergstrom, 2000). In this definitive article, Hogberg and Bergstrom highlight the changes to practise around the world from supine to prone sleeping position in the 1950's, suggesting that one precursor to this practice was the good results in survival following prone transportation of critically wounded soldiers during WWII and the Korean War (Hogberg and Bergstrom, 2000). In the 1960's it was believed that most American mothers used the prone sleeping position for their infants, whereas European parents put their infants to sleep either on their backs or on their side. However, by the 1960's lying prone was considered optimal for an infant and in the 1957 edition of his baby and childcare book, Spock highlights:

'a majority of babies seem from the beginning to be a little more comfortable going to sleep on their stomachs. This is particularly true of the baby who develops colic: the pressure on the abdomen seems to partly relieve the gas pains. Others either do not care at first, or prefer to sleep on their backs. If they vomit, they are more likely to be choked by the vomits' (Spock 1957).

The major source of evidence on which sleeping prone was based was physiological research conducted on pre-term infants during the 1960's which indicated that in this group there was less risk of gastroesophageal reflux, better psychomotor development, relief of colic and increased oxygenation (Engelberts and de Jonge, 1990; McKee et al., 1966). Researchers also reported finding that children slept better in the prone position and experienced less screaming and fatigue (Brackhill et al., 1973).

The practice of putting babies to sleep prone was informally disseminated among doctors, who passed the information to Baby Health Clinic Sisters and new mothers. However, advice on which position was actually *best* was never clear-cut (Hogberg and Bergstrom, 2000).

Bedsharing and Bedding

From the earliest times bedsharing with an infant has been common and widely practiced, particularly in certain cultures (Boules, 2007; Hogberg and Bergstrom, 2000; Rice and Naksook, 1998; Schott and Henley, 1996). There is also no doubt that bedsharing or co-sleeping with an infant is now a hotly debated topic in the literature (Mesich, 2005). In the first half of the 1900's in Australia many mothercraft books and child-care experts were very clear about the dangers of co-sleeping and bedsharing. Some publications warned against the dangers of bedsharing with an infant, providing instructions such as:

“ A young baby should never be allowed to sleep in the same bed with an older child or an adult”

(Nestle Anglo Swiss Milk Company, 1938)

and

“He (the baby) must SLEEP ALONE”

(NSW Department of Public Health, 1942)

In Australia, early infant care literature clearly specified the type of mattresses mothers should use for newborn babies.

“A hair mattress should form a firm foundation, on top of this place a chaff mattress. The chaff mattress is soft and warm, it makes a nest for the baby to sink into”

(Harper, 1940)

“The mattress should be firm and made of horse hair or good quality kapok. Over this should be placed a small loose mattress made of soft chaff, the pillow being of the same material”

(NSW Department of Public Health, 1942)

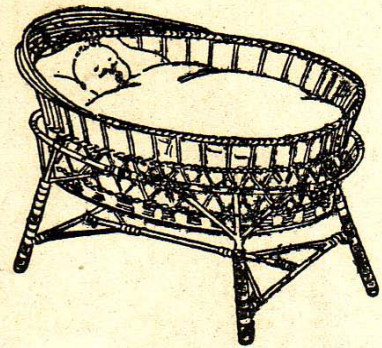
Although these type of mattresses have now been associated with increased SIDS risk, when pictured, babies using chaff, kapok or ti-tree mattresses were always pictured sleeping supine (NSW Department of Health, 1942) (Figure 10).

BABY'S LAYETTE

The best and most hygienic crib for a baby is the simplest and least expensive on the market, i.e., split cane (not pith, as borers destroy it) open basket with a stand of similar material into which the basket fits.

The cot should be about 37 inches long, 20 inches broad, and 14 inches deep, with three loops of cane over the top end for support of the mosquito net. The stand should be 27 inches high.

These cots are very light to carry about the house or into the garden, and do not get spoiled by sun and air. It is a serious mistake, for many reasons, to train a baby to go to sleep only in a darkened room. The garden or yard—or, failing these, near a wide open window—is far the best sleeping place.



Baby is comfortable in a suitably made cot.

FIGURE 10: Excerpt from 'Our Babies' (1942) page 21.

Plagiocephaly - the flattened head

There is an increase in the number of parents reporting children with 'flattened heads' (plagiocephaly) since the introduction of back sleeping position in infants in the early 1990's (Biggs, 2004). Posterior skull deformation can occur when an infant is left in the one position on the back for long periods of time, with a resultant flattening of the soft bones of the skull. There are few reports of head flattening prior to the introduction of the Reduce the Risks Campaign, even though infants slept primarily on their back prior to the 1940s and 1950s, when tummy sleeping was introduced. Many cultures view particular head shapes as indicative of high social standing, or particular ethnic background (Biggs, 2004). This practice has implications for the use of back sleeping position, as Pacific Island cultures see flattened heads as detrimental in their culture, and are more likely to use other sleeping positions such as side and prone positions which do not impact on the shape of the head (Peacock, 2003).

2.6 KNOWLEDGE OF SIDS REDUCTION STRATEGIES

As early as 1944, Abramson highlighted the need for a public health education campaign around the ways of preventing accidental mechanical smothering of infants using the prone position for sleep (Abramson, 1944). It was not until the rapid rise in SIDS deaths and subsequent 'Back to Sleep' and 'Reduce the Risks' Campaigns of the 1990's that public health education around SIDS prevention was instituted widely.

The Sudden Infant Death Association of NSW (SIDA) (now called SIDS and Kids) was established in Australia in the 1980's to assist families grieving the loss of a child. In 1992 The Sudden Infant Death Association joined with NSW Health in the promotion of messages aimed at reducing the incidence of SIDS (Murphy and Adelston, 1994). This non-government organisation has grown substantially since the early 1990's and is now partly (around 8%) funded by NSW Health, but exists primarily on donations raised through the annual major fundraiser 'Red Nose Day'. SIDS and Kids produces brochures, posters, door hangers and a range of other promotional material designed to spread the message of SIDS reduction. Initially, aimed at reducing SIDS, the messages now promoted are around 'Safe Sleeping' and include a range of strategies to ensure babies are safe while they sleep. SIDS and Kids brochures are provided free to anyone who requests them, however costs associated with postage are charged to the user. The nature of SIDS and Kids in NSW as a non-government organization means that staffing levels are minimal, and although an educator is employed to provide in-service education to a range of groups, this service is limited by the capacity of the worker (SIDS and Kids NSW, 2007).

In Australia in 1991, all states except Victoria used the brochure 'Help Reduce the Risks of Cot Death', produced by SIDS and Kids Australia. Victoria used a slightly different version titled 'Reducing the Risks of Cot Death' (Ford and SIDS and Kids, 2004). These campaign brochures have been updated regularly since they were first introduced, and form part of the annual 'Red Nose Campaign' designed to promote awareness of SIDS reduction strategies in all communities throughout the country (Ford and SIDS and Kids,

2004). Although SIDS and Kids have the Safe Sleeping brochures in a range of languages on the SIDS and Kids Website, this is a medium often unable to be accessed by CALD families due to low socio-economic circumstances or inadequate English skills to locate the website in the first place.

General Practitioners knowledge of SIDS reduction strategies

Few studies have been undertaken to assess general practitioners knowledge of SIDS reduction strategies. Many GPs are the first point of contact for parents of a new infant. In a study conducted by Moon and colleagues 3,717 physicians from the North Carolina and Washington regions were surveyed to assess their knowledge of SIDS reduction strategies and 23% responded. Most of the respondents were aware of sleeping position and smoking as the main risk factors for SIDS, however of those surveyed only 56% of family GPs discussed SIDS routinely with their patients and only one third of paediatricians provided written information for new parents regarding SIDS (Moon et al., 2002).

In Australia, SIDS and Kids provide online information for GPs to access regarding SIDS reduction strategies (SIDS and Kids, 2007). Until the commencement of this research study in 2004, there have been no studies in Australia to investigate Australian GP's knowledge of SIDS reduction strategies (SIDS and Kids NSW., 2007).

Nurses knowledge of SIDS reduction strategies

Evidence suggests that nurses caring for infants in hospital settings put infants to sleep on their side to prevent aspiration (Hein and Pettit, 2001; Jeffery, 2003; Young and O'Rourke, 2003; Bullock, 2004). As well as putting infants at risk, this practise models incorrect behaviour, sometimes adopted by parents (Fleming and Blair, 2002; Young and O'Rourke, 2003). Studies have also highlighted the fear nurses have of infants aspirating stomach contents when lying in the supine position (Stasny, et al., 2004; Bullock, 2004). This fear is the single most persuasive factor in nurses using the side position for infants (Stasny, et al., 2004). In a survey of Nursing Unit Managers in maternity and children's

hospitals throughout NSW in 2002, Jeffery and colleagues identified around one third of nurses still placed infants to sleep using the side position (or in positions other than supine) (Jeffery, 2003). The nurses interviewed justified this practice saying that infants who are 'vomity' or appeared to have reflux problems may choke. In a similar study conducted in nurses and midwives in Queensland, Young and O'Rourke identified several inconsistencies between known SIDS risk factors and participant attitudinal responses in relation to sleeping position and Reduce the Risk messages (Young and O'Rourke, 2003).

Parents knowledge of SIDS reduction strategies

Although education campaigns have been conducted around the world addressing the use of prone sleeping position, and advocating for the use of the supine position, studies have shown that many parents have not taken up this message and still put their infants to sleep in the prone position (Kemp et al., 2006; Schluter and Young, 2002; Waseem et al., 2004; Willinger, 2002). This phenomenon has been evidenced more frequently in caregivers from a CALD background (Hauck et al., 2002; Kemp et al., 2006; Paterson et al., 2002).

Between 1994 and 1998, Willinger and colleagues conducted annual representative telephone surveys in 48 states of the United States, to examine the characteristics of parents and their motivation to adhere to the safe sleeping messages promoted through the 'Back to Sleep' Campaign (Willinger, 2000). In the 48 states surveyed between 1994 and 1998, prone placement declined in white infants from 44% to 17 %, and in black infants from 53% to 31%. Where prone placement was used for infants, the main reason given was for infant comfort (Willinger, 2000). Although recommendations for supine placement had been made through well baby clinics, doctors' surgeries, hospital staff and media advertisements, parents still believed in the use of the prone position (Willinger, 2000).

Paterson and colleagues surveyed Pacific Island parents living in New Zealand to assess their awareness of the risk factors for SIDS (Paterson et al., 2002). Pacific Island mothers who had babies aged six weeks were recruited and questioned on their knowledge of

SIDS reduction strategies. Of those surveyed, almost 39% could not name any risk factor for SIDS. Prone sleeping position was identified by 53% and smoking by 31.5%.

Paterson highlighted the difficulty of providing up to date information around SIDS reduction to women who do not attend antenatal classes or access postnatal groups, and concluded that novel ways of providing health information, such as ethnic radio should be considered (Paterson et al., 2002). Similar results were found in a study in predominantly Hispanic and African American women, undertaken by Waseem and colleagues in New York (Waseem et al., 2004). In this study Waseem found that around half of the women interviewed did not know the term 'SIDS'. Forty six percent of those interviewed did not know that prone sleeping was a risk factor for SIDS and around 75% did not know smoking was also a risk factor. Waseem found that 40% of the women surveyed were placing their babies in the prone position to sleep (Waseem et al., 2004).

In a recent Australian study, Kemp and colleagues investigated the knowledge of SIDS reduction strategies in a socio-economically disadvantaged population in the south-western area of Sydney (Kemp et al., 2006). The women enrolled in this study were interviewed by a midwife at the booking in stage of their pregnancy and asked to complete a screening tool to identify any vulnerability. Vulnerability in this context included young maternal age (< 19 years), first presentation for antenatal care at > 20 weeks, poor support networks, mental illness or significant risk of depression or low self esteem, experience of child abuse or domestic violence, substance abuse or misuse or experience of a major stressor in the past 12 months. Just over half the women (n=116) interviewed were born overseas. Women enrolled in the study were asked whether they could name two SIDS reduction strategies. Results of this study indicate that of those interviewed (n=233) 75% could name at least one SIDS reduction strategy. Of the remaining 25% who could not name any SIDS reduction strategy, almost 75% were born overseas. This study also highlighted the misinformation some women have about infant care practice potentially having a negative impact on infant health outcomes. Comments received in the study included 'keep the baby warm,' 'cover with blankets' and 'put them on their stomach to sleep' (Kemp et al., 2006).

Childcare workers, relatives or friends who are not aware of the current recommended SIDS reduction guidelines for safe sleeping, are also at risk of putting infants to sleep in an unsafe position (Cote et al., 2000; Evers, 2004; Gershon and Moon, 1997; Moon et al., 2000).

2.7 SUMMARY AND STUDY CONTEXT

In summary, the literature and statistics reviewed suggest that some localities in Sydney West Area Health Service have poorer infant health outcomes, including deaths from SIDS, than others (Wilson et al., 2003). The localities where SIDS rates are high are home to large numbers of Aboriginal and Pacific Island residents (Australian Bureau of Statistics, 2001). It is known that the Aboriginal community in Australia have a higher rate of SIDS than their Caucasian counterparts and based on research in New Zealand, it is possible that the Pacific Island community in Australia also have a high rate of SIDS (Tipene-Leach et al., 1999). Due to the relatively small number of SIDS deaths, data on ancestry of a baby who dies from SIDS (other than those of Aboriginal or Torres Strait Island ancestry) is not currently collected in Australia (Lawrence, 2003; Calvert, 2004; Murphy, 2008). It is possible that residents living in areas where SIDS rates are high have different infant care practices to those in other areas, as a result of their cultural background, educational level or experiences with health care providers. The level of knowledge regarding SIDS reduction strategies has never been studied in the NSW GP population (SIDS and Kids, 2002).

CHAPTER 3 - METHODS

“Perplexity is the beginning of knowledge”

Kahlil Gilbran - A Tear and a Smile (1950)

3.1 FOCUS OF THESIS

This thesis focuses on the knowledge of health professionals and parents around ways of preventing sudden and unexpected death in infants. The main objectives of this thesis are to present data collected over a four-year period which:

- 1) details current knowledge of ways to minimise sudden and unexpected death in infants, in three key groups of infant care providers,
- 2) identifies the main influences on infant care practice in the multicultural community of Western Sydney
- 3) reports any new infant care practices which have the potential to impact adversely on infant health and wellbeing and
- 4) makes recommendations for future strategies in health care delivery aimed at minimising the number of infants who die suddenly and unexpectedly in NSW.

Using primarily qualitative methods, this research study collected detailed and informative data relating to knowledge of the ways to reduce sudden and unexpected death in infants. An ethnographic phenomenological approach enabled the researcher to gain an in-depth understanding of the opinions and perspectives of health professionals and parents on infant care practices.

Focusing on three groups of people who care for infants aged 12 months or less enabled the researcher to explore different perspectives on infant care. This provided a broad

insight into the major influences on parents who care for an infant, particularly around knowledge relating to the prevention of sudden and unexpected death.

3.2 STUDY AIMS

The main aim of this study was to assess the level of knowledge of health professionals and parents on ways of preventing sudden and unexpected death in infants, in the area geographically defined by Sydney West Area Health Service.

A secondary aim of the study was to identify the major factors influencing levels of knowledge in health professionals and parents and make recommendations for changes to health care delivery based on the findings of the study.

3.3 RESEARCH QUESTIONS

This study attempted to answer the following research questions:

1. Is there variation in knowledge between health professionals and parents concerning ways of preventing sudden and unexpected death in infants?
2. What factors influence the way health professionals and parents care for infants?
3. Is there inconsistency between knowledge and practice of ways to safely care for infants?

3.4 STUDY CONDUCT

This study was conducted between 2004 and 2007, and data collection was supported by a grant from Kid's Health Promotion, at The Children's Hospital at Westmead. The grant covered the costs associated with questionnaire production, postage, advertising and participant recruitment. Total funds received for this study were \$5,000. Data collection was conducted in four distinct phases between June 2005 and December 2007.

3.5 STUDY DESIGN

This cross-sectional study investigated the knowledge of SIDS reduction strategies in GPs, nurses, and parents involved in caring for infants in SWAHS over a four year period. The study used a combination of qualitative and quantitative methods, with the main focus on qualitative research methods. Quantitative methods enable the researcher to collect inferential and empirical data while qualitative methods enable the exploration of the dynamic and first hand experience of study participants (Silverman, 2005).

There were three groups of study participants included in the study. These were:

- General Practitioners currently practicing medicine in SWAHS.
- Nurses from all disciplines who were currently caring, or had ever cared, for infants in a professional capacity in SWAHS.
- Parents, including those who had responsibility for caring for an infant aged 12 months or less and who lived in SWAHS.

The qualitative methods used in this study were: self-completed questionnaire, telephone administered semi-structured interviews, and focus groups. Telephone interviewing was used for all of the nurses and parents who participated in the study. Telephone interviewing has been shown to be a valuable data collection strategy enabling data collection from participants who are widely dispersed across a geographical area, for women who are housebound with infants and in cases where traveling to a face to face interview would be difficult for the participant (Sweet, 2002). As many of the participants in the study were in these categories, telephone interviewing was employed in this study.

Focus groups have been shown to be an effective data collection strategy, providing a rich source of information. Focus groups enable researchers to gain detailed information from a group of people in a more comfortable and natural setting than that of a one-to-

one interview. Focus groups are particularly useful in collecting opinion and data from multicultural groups, where issues of specific relevance to a particular culture can be explored (Halcomb, et al., 2007). Focus groups have many advantages, in that they are relatively easy to conduct, provide a rich source of detailed information and increase the sample size of a group of participants by talking with many people at once (Marshall and Rossman, 1999). Another advantage of focus groups is that the researcher can observe the participants in the group during the course of the consultation, collecting data on body language and non-verbal cues in relation to particular prompt questions. Focus group participants should be, where possible, a representative sub-group of the population under study and should be similar in characteristics (Marshall and Rossman, 1999, McLafferty, 2004). In line with research by McLafferty in 2004, focus groups in this study were kept to a manageable size and were composed of people who did not know each other, but had similar characteristics where possible to maximize homogeneity and encourage open and honest discussion (McLafferty, 2004).

Interviews and focus groups were held with nurses and parents from a variety of cultural backgrounds, to obtain information on the cultural aspects of infant care, which could impact on adverse infant health outcomes, such as SIDS.

Although a range of cultural groups was included in this study, Australian Aboriginal families were not included as a specific group under study. The reasons for this included: known disparity in rates of SIDS between Aboriginal and non-Aboriginal families, known data relating to the incidence of Aboriginal infants who die as a result of SIDS in Western Sydney and the time cost / benefit ratio of obtaining Ethics Committee approval through the Aboriginal Health and Medical Research Council (AH&MRC) for a small scale study which would be reporting existing Aboriginal data. It is acknowledged however, that the comments of Aboriginal parents with regard to parenting practice is an area worthy of future study.

3.6 RECRUITMENT AND SAMPLE SIZE

General Practitioners

Around 60% of general practitioners in SWAHS work in large practices, and 40% are sole practitioners. Many of the GPs in the area belong to the Australian General Practitioner Alliance, and many belong to local Divisions of General Practice where these exist. The researcher aimed to recruit fifty GPs who worked in SWAHS, and who treated and provided information to mothers of infants aged 12 months or less. The sample size was based on other qualitative studies and known data on GP response rates. Due to their workload, GP response rates to surveys and questionnaires are low and known to range from 5% - 20%. Fifteen hundred (1,500) GPs working in SWAHS, were identified through Divisional GP databases, telephone directories and Internet based databases. These GPs were entered into a purpose built database and allocated a randomly generated number. Seven hundred GPs were randomly selected to receive an invitation to participate in the study through the completion of an anonymous questionnaire, with a target of 50 completed questionnaires. The first 350 surveys were mailed to the randomly selected GPs between 1st March and 30th April 2005. By 30th July 2005, GPs had completed and returned 60 questionnaires to the researcher.

It was anticipated that it would be difficult to elicit responses to a questionnaire from GPs working in SWAHS. The main reasons for this were the known poor GP response rate to questionnaires, known heavy caseload, and a perceived reluctance to respond to a questionnaire where GPs may be required to admit not knowing current recommended SIDS reduction messages. The study was funded by a grant from 'Kids Health Promotion' at The Children's Hospital at Westmead. This was noted on the introductory letter and all completed questionnaires were returned by mail to this address.

Each GP selected was sent a letter outlining the purpose of the study, clearly stating that participation was voluntary, and inviting them to participate in the study (Appendix 2). As Practice Managers often open mail for the GP to filter advertising material and locate test results etc, a cover sheet asking the Practice Manager to pass the information on to

the GP was included in the package (Appendix 3). General Practitioners were asked to return the questionnaires in a reply paid envelope. These were collected until the required number (50) had been returned. Once the target had been met, no further questionnaires were sent out.

The rapid responses of the GPs to the questionnaire, and the short time required to reach the target number of responses was probably due to a combination of the strategies used and the high profile nature of the funding body. In retrospect, it would have been an advantage to collect information on the suburbs in which GP practices were located, as lack of SIDS knowledge in GPs may have correlated with the higher rate of SIDS deaths in some suburbs. However, providing their suburb or postcode may have discouraged some GPs from accurately answering the questions around SIDS reduction knowledge.

Nurses

Nurses are a key group of health professionals closely involved with pregnant women and those who have infants aged less than 12 months of age. For this reason nurses from a range of disciplines were invited to participate in this study. The researcher aimed to recruit 50 nurses, (including early childhood health nurses, midwives, neonatal and paediatric nurses). The decision to recruit 50 nurses was based on the premise that it would match the sample size of doctors, and combined there would be a health professional sample of around 100 participants.

Between January and September 2006 advertisements inviting participation from nurses, midwives, early childhood nurses, paediatric and neonatal nurses in the study were placed in local newspapers, nursing journals and association newsletters (The Lamp, Neonatal, Paediatric and Child Health Nursing Journal) (Appendix 4). Recruitment flyers were sent to local Early Childhood Health Centres, parenting centres, hospitals and other organizations where nurses provided services for infants in SWAHS (Appendix 5).

Fifty two nurses responded to advertisements and interviews were conducted between June 2005 and May 2006. The sample consisted of 21 midwives, 20 child and family health nurses, 6 paediatric nurses, 4 neonatal nurses and 1 registered nurse working in the maternity section of a general hospital. All nurses either lived or worked (or had ever worked) in the area covered by SWAHS, and were therefore deemed eligible to participate in the study. All advertisements asked for volunteers to participate in the study. A consent form was not provided for the nurses who responded to the advertisement, as response implied consent, however all nurses were read a copy of the Study Information Sheet prior to being asked for verbal consent to participate in a telephone interview (Appendix 1). Identification was by first name only, and no details of place of work or residence were recorded in order to ensure accuracy of responses. The nurses and midwives were keen to answer questions using telephone interviews. This process ensured they could also speak freely, and be 'semi-anonymous', only providing their first name and telephone number. Although all the nurses currently worked or had ever worked in 'Western Sydney', not all of these were currently involved in the provision of infant care.

Parents

Parents and other infant carers were integral to this study, and were recruited from a range of cultural and socio-economic backgrounds. For the purposes of this study 'parents' were defined as relatives caring for infants on a regular basis, or people who were caring for infants on a professional basis. Due to the variability in infant care practices in parents and the broad range of cultural diversity in Western Sydney, more parents were recruited (150) than health professionals (100). Parents were invited to participate in a semi-structured interview using a telephone administered questionnaire and were recruited using a combination of methods. Between June 2005 and December 2006, advertisements were placed in local newspapers and Sydney's Child Magazine (Appendix 7), and Flyers were sent to Early Childhood Health Centres, Migrant Resource Centres, Hospitals, Playgroups and Child Care Centres (Appendix 8).

One hundred and four people responded to the advertisements and flyers inviting parents of infants to participate in study interviews. Telephone interviews were conducted between June 2005 and December 2007. All of the people who responded to the advertisement were eligible for the study, and agreed to participate. A Study Information Sheet was read to all interview participants and a convenient time for an interview was scheduled. Many participants rescheduled their interview time due to changes in their personal circumstances or inability to speak on the telephone as they were attending to their infant.

Recruitment of participants to participate in focus groups conducted in the community was conducted using advertisements in local newspapers, flyers in Community and Early Childhood Health Centres and through the researcher's own networks. Newspaper advertisements were printed in English and flyers were printed in English, Chinese, Vietnamese and Arabic. Participants needed to be the parent, or carer, of an infant aged 12 months or less, and live in one of the following Local Government Areas (LGA's): Auburn, Baulkham Hills, Blacktown, Hawkesbury, Holroyd, Parramatta, Penrith or the Blue Mountains.

In order to obtain representation of parents from a CALD background, and to elicit specific detail about the issues of parenting in a new country, focus groups comprised of parents from specific backgrounds were conducted with parents from a Filipino, Lebanese (Arabic-speaking), Chinese, Samoan/Tongan and English-speaking background. Existing community based parenting groups attended by parents from a CALD background, were approached by the researcher to recruit participants and given information about the study. Any parents interested in participating in a focus group were given a Participant Information Sheet and a Consent Form. These documents were translated by the community group leader into the appropriate language, and read aloud to study participants. Any parents interested in participating in a focus group were then enrolled in the study. Focus groups were held in non-threatening environments including community centres and church halls in SWAHS, where women felt comfortable. Most

participants of the groups knew at least one other person in the focus group. Each participant was paid \$20 to cover costs of travel and other incidental expenses.

Fifty four people parents responded to the advertisements inviting parents of infants to participate in focus groups. Focus groups were conducted between June 2005 and December 2007. All of the people who responded to the invitations were eligible for the study, and agreed to participate.

As with the GP questionnaire, it was anticipated it would be difficult to recruit parents to participate in the study, however with the well-supported advertising campaign sponsored by Kid's Health at The Children's Hospital at Westmead, the study target of 150 parents was easily achieved. There were some logistical challenges when interviewing parents of infants by telephone. Most notably these were due to parents being unable to commit to specific interview times, based on their children's sleeping schedules or feeding habits. Where difficulties occurred, the researcher continued to make calls until an appropriate time could be arranged. This often occurred late at night when both parents were at home, with one parent participating in the interview and the other caring for the infant. There were some challenges associated with recruiting parents from CALD groups to participate in focus groups. Where possible, pre-existing groups (such as playgroups or mothers groups) were approached, and women were asked whether they were interested in participating in a focus group. This approach worked well, as sometimes only one or two women agreed, but they brought a friend or family member who also had an infant aged less than 12 months along with them to the focus group. Interpreters were used for the Arabic speaking and Vietnamese groups, but most of the women in the groups spoke a little English and so the groups tended to be a mixture of English and the native language. This was at times, difficult to follow, and made transcription of the tapes quite a challenge, however notes taken by an independent observer (who was also a health professional) clarified many of the difficulties in analysis of the transcripts.

All participants were remarkably frank in their responses to the questionnaires, interviews and focus group questions. The participants, particularly those from a CALD background

seemed keen to be able to express their views on parenthood. It is an assumption that participants provided accurate responses, however based on the findings, it is reasonable to assume that the results are indeed accurate.

3.7 DATA COLLECTION

Data were collected from health professionals and parents using a number of methods including; self-completed questionnaires, telephone interviews and focus groups. By utilizing a range of strategies, a rich and detailed pool of information could be obtained from all study participants, thereby maximizing the likelihood of obtaining comprehensive and accurate data. Demographic data were collected to describe participant characteristics.

Questionnaires

A specifically designed questionnaire was developed for each of the three categories of study participants. Questionnaires were piloted prior to use on members of the three groups to assess reliability and validity. All questionnaires were printed on brightly coloured paper to enable the researcher to distinguish between respondent groups easily when entering data.

General Practitioner Questionnaire

A two page self-completed anonymous questionnaire and reply paid envelope were included with an invitation to participate in the study mailed to selected GPs in 2005 (Appendix 9). Due to the high workload of GPs and the known low response rate of GPs to surveys, the questionnaire was kept to two pages with a total of seventeen questions. To maximize response rates, three strategies were used. These included: addressing a letter outlining the importance of the questionnaire to the practice manager; making the questionnaire totally anonymous, and including a reply paid envelope.

Living or working in Western Sydney was an eligibility criterion for this study. As questionnaires were sent to GPs known to be working in the area, it was assumed that all respondents met the eligibility criteria, however asking the GPs whether they lived in the local area provided additional information as to whether the GP lived *and* worked in the area of their practice. By establishing the length of time GPs have practised in the area, an insight can be gained into how familiar the GP is with the needs of the local community.

The questionnaire was specifically designed to capture a range of demographic information from the GPs including: the year GP training commenced, place of GP training, gender, place of birth, area of current residence and length of time practicing in Western Sydney. Consultation with child health experts at The Children's Hospital at Westmead, and the Western Sydney Division of General Practice determined the main reasons parents of infants visit a GP. Providing a list of options as to why parents come to the GP enabled respondents to clearly list the main reasons mothers presented to their particular practice with infants.

The questions used in the GP questionnaire were designed to investigate any association between year of GP medical training (specifically prior to the introduction of the Reduce the Risks campaign in 1994) and level of knowledge of safe sleeping messages. Most University medical training now incorporates information on safe sleeping in infants, and ways to prevent SIDS. Identifying the year and place of GP medical training assisted the researcher to make linkages between these factors and GP knowledge of safe sleeping messages. Due to the emotive nature of any sudden and unexpected death in an infant, and the increased number of women working in General Practice, it was essential to determine the gender of GP respondents. Determining the ratio of male to female GPs in the workforce and then comparing this to the male to female ratio of respondents enabled the researcher to establish whether more female GPs than anticipated responded to this survey. Female GPs (particularly if they are mothers) may be more aware of the latest SIDS prevention guidelines, and thus more likely to respond to a questionnaire of this type.

The key research question to be investigated by this study is whether there is variation in knowledge of safe sleeping and SIDS reduction messages between health professionals and parents. To address this question the GP questionnaire asked a series of questions including: GPs personal knowledge of safe sleeping, whether GPs had ever had training in SIDS reduction, whether safe sleeping information was easily available in medical practices and whether parents asked for information about safe sleeping and SIDS reduction. Since the introduction of the Reduce the Risks campaign, the number of sudden and unexpected deaths attributed to SIDS in SWAHS has dropped dramatically, from 44 deaths per year in 1988 to 5 per year in 2004. The reduction in deaths means many younger doctors may never care for an infant who later dies from SIDS, or experience interaction with a family who has lost a baby to SIDS. The questionnaire sought to identify whether any respondents had ever cared for an infant who later died from SIDS and if so to investigate the referral pathway used by the GP following this event.

It is known that Western Sydney has a culturally diverse population. What remains unclear is from where parents with a CALD background receive most of their parenting information, including information on SIDS. Asking GPs to provide an estimate of the number of women from a CALD background with infants aged less than 12 months, who regularly attend their practice, provides an insight into the numbers of CALD women who attend the GP for routine care. This information can then be compared to information provided by nurses and midwives about CALD women attending other health care services. In view of the increasing numbers of CALD families in SWAHS, the questionnaire asked GP respondents to outline who or what they personally believed had the most influence on 'new' parents. This information is valuable in the context of this study, and assists in the development of future strategies addressing infant health care.

Nurses & Parents Questionnaire

Similar questionnaires were developed for both the nurse and parent questionnaires (Appendix 10). Each questionnaire asked questions to establish eligibility for inclusion in the study and collect demographic data on all participants. Questions used in the parent questionnaire were based on those developed for the Pregnancy Risk Assessment Monitoring System Questionnaire originally developed in 1987 by the Centre for Disease Control, and more recently updated in the PRAMS Model Surveillance Protocol (Centres for Disease Control, 1999).

Questionnaires for both nurses and parents included questions on knowledge of safe sleeping and SIDS reduction strategies, where that knowledge was obtained and the current practices recommended and/or used. Nurses were also asked about their experiences as parents, and particularly about how practices have changed in infant care and nursing care of infants over time. Parents and caregivers were asked to outline the changes to infant care practice over time, particularly since their mother's day, and to discuss this in relation to their own practice. Both the nurses and parents questionnaires were administered over the telephone using a semi-structured interview technique.

Interviews

Nurses or parents who responded to advertisements left a message on an answering machine dedicated to the study. Each potential participant was asked to leave their first name only and a telephone number for a return call. All calls were returned within 24 hours and potential participants were thanked for their response to the advertisement.

The Study Information Sheet was read in full to each participant and they were asked to consider whether they would like to be involved in the study. A hard copy of the Study Information Sheet was sent to the potential participants. If the person agreed to be involved in the study, a mutually convenient time for a detailed interview was made. This enabled all those interested to further consider their participation, and for parents to discuss this with a partner. Arranging a dedicated time for an interview also ensured the

parents had adequate time available to answer a semi-structured questionnaire over the telephone. This was a particularly important consideration, in the knowledge that parents were caring for infant children and many nurses were working full time or on shift work.

In order to maintain anonymity a Consent Form was not used for interview participants. Verbal consent (after reading the Study Information Sheet) was considered consent to participate. Addresses of participants were not sought as this would break anonymity, and potentially reduce the accuracy of the response to the questionnaire.

Although the interview took an average of twenty minutes to complete, initial piloting with nurses and parents indicated that some interviews took much longer than this, depending on the length of the answers. For this reason, nurses and parents were advised to leave up to forty five minutes to complete the interview. Most nurses answered the survey 'after hours' when they were able to dedicate time to answering the questions in detail. Parents who responded generally asked to be interviewed at a time when their baby was normally asleep, or after hours when a partner would be home to attend to the baby while they were on the phone. Flexibility by the researcher was essential in order to meet these requirements. At the predetermined time, the researcher telephoned the participants and asked if they were still interested in being involved in the study. Those who agreed were asked questions using a semi-structured questionnaire (Appendix 10).

Nurse interviews

Nurses were asked to describe themselves by type of practitioner (e.g. as a midwife or Early Childhood Nurse), when they trained, and whether they lived or worked in Western Sydney. Any person who responded but was not a nurse, or who did not live or work in Western Sydney, was excluded from the study. Eligible nurses were then asked a series of demographic questions, covering their current work status, history about their training – including the year they trained, where they trained and their country of birth. These questions were asked to help elicit information about the knowledge and practices the nurses use with regard to infant care.

Nurses were then asked about their work experience regarding infant care including how they showed mothers to put infants to sleep. Nurse participants were asked where they obtained most of their mothercare training and to estimate the percentage of first time parents they saw in their work practice. The nurses were asked to detail their interactions with new parents around settling, feeding, sleep positioning and general infant care. All participants were asked whether they recommended any books or printed material for new parents, and if so what. The nurses were also asked in their opinion who or what they felt had the most influence on new parents, choosing from a list of options including: Child and Family Health Nurse, Midwife, GP, Obstetrician /Gynaecologist, family and friends, printed literature, the Internet, or other influences.

It is known that women from many cultures access the services provided by midwives and Child and Family Health Centers. Nurses were asked to estimate the percentage of their clients who were from a CALD background, whether these women took part in pre natal classes, and if not the reasons for this. Participants were asked whether as Health Professionals, they had ever experienced conflict or problems with parents regarding traditional (cultural) versus current Australian recommended methods of infant care, particularly with women from a CALD background. Where nurses responded that they had experienced conflict, respondents were asked to expand on this and describe the major sources of conflict or problems.

To gain additional information about changes to practice over time, nurses were asked about their own experience as a mother or a parent with their first and subsequent children. Where nurses did not have children, this was left blank. Nurses with children were asked how long ago their first baby was born, whether they attended pre natal classes, referred to any literature, or consulted anyone for advice during the child's first year. All participants were asked the sleeping position they used for the infant, the feeding routine they used, and the bedding they used when the child was newborn. Each participant was asked whether they had noticed any changes to practice in infant care over time. Nurses with children were asked their cultural background and whether this had ever caused any conflict with regard to parenting or infant care practice.

All participants, whether they had children or not, were asked questions around knowledge of SIDS reduction strategies. Nurses were asked whether SIDS brochures were routinely distributed to new parents at the centre where they worked and if SIDS posters were on display. In order to establish the nurses' knowledge of current SIDS reduction strategies, all respondents were asked to list these. Nurses were asked to comment on any changes to infant care practice they had observed over time.

Parent interviews

The parent questionnaire was similar in structure to that of the nurses' questionnaire and determined eligibility and demographics. Any potential participant who did not meet the eligibility criteria was excluded from the study. Eligible participants were then asked a series of demographic questions about themselves and the infant they cared for.

Participants were asked about their relationship to the infant, the age of the infant, where the infant was born, and if a grandparent or paid carer, the number of hours they care for the infant per week. All participants were asked in which country they were born.

Participants were also asked to describe how they put the infant to sleep, where they learned this technique, the type of bedding and blankets they use and whether they smoke at home.

Many infants are cared for by 'paid carers' when their mothers return to work. These initial demographic questions provided information about the participants who responded to the study advertisements, and helped to establish whether there are differences in practices between parents, grandparents and paid carers. All participants were asked about their first child. For some, this was the infant for which they were currently caring, while others had many children. Any participant who was not a parent but a grandparent or paid carer was asked to comment on their own experience with any natural children. Paid carers without children were not asked this section of the questionnaire.

Parents were asked where and when their first child was born, who delivered the infant and whether they attended pre-natal classes or read any books about infant care. Where

participants remembered literature they had referred to, this was recorded. Participants were asked whether they had ever accessed the Internet to find information, or had extended support available when their infant was young. The questionnaire covered issues including parent's use of support services such as Universal Health Home Visiting, Child and Family Health Centres and Playgroups, as well as issues around returning to work and feeding practices. Parents were asked in detail about how they position the infant for sleep, and where they learned this method. The type of bedding used was also discussed. All parents with more than one child were then asked the same series of questions in reference to their second or subsequent child.

All participants were asked to describe their cultural background. Participants or partners born in another country were asked a series of questions relating to cultural practices in infant care. Where parents and partners were born in Australia these questions were not asked. Parents born overseas were asked whether there were any traditional practices around pregnancy and childcare in their country of origin, and whether they still practiced these in Australia. Participants were asked whether there were any difficulties combining traditional (cultural) practices with current recommended Australian practices, and to describe any experiences they had in this area. Parents and carers from overseas were asked about their support networks and where they received the bulk of their information on infant care.

All participants were asked the section containing questions relating SIDS knowledge. This section of the questionnaire explored levels of knowledge around safe sleeping, the key strategies that can be used to minimize SIDS, and knowledge of, and access to, posters, brochures and information on SIDS. The last section of the questionnaire asked participants about changes to practice over time.

Focus groups

Focus groups were held with parents/caregivers in community settings in Western Sydney between June 2006 and December 2007. Each participant was provided with a

Study Information Sheet and a Consent Form. Where focus groups were held in another language the Study Information Sheet and Consent Form were read to the group in their native language prior to the commencement of the focus group. A standard and approved list of questions was asked of each focus group (Appendix 11).

Focus groups aimed to elicit information from new parents including how many parents had attended pre-natal classes, how many used the services of the Child and Family Health Centre and how many parents had received a Universal Health Home Visit from the Child and Family Health Nurse. The focus groups were also asked to discuss any cultural issues encountered in raising infants, and any conflicts arising as a result of differences in culture and current recommendations.

Participants were asked to outline their practice regarding sleeping of infants, and knowledge of safe sleeping and SIDS reduction strategies. All participants were also asked to nominate who or what they believed had the biggest influence on their infant care practice.

3.8 DATA ANALYSIS

Quantitative analysis

As this study is primarily a cross-sectional qualitative study, there were few quantitative statistical analyses to conduct. However quantitative statistical analyses relating to GP demographics such as average length of practice and years since training were calculated using statistical functions in Microsoft Excel and SPSS. Quantitative content analysis was used to collate the responses to factual /closed ended questions posed in the questionnaires and interviews.

Qualitative analysis

All qualitative data (open-ended questions and narrative) provided by study participants was entered into an excel spreadsheet and coded by category of participant and type of

response. All data collected in focus groups was taped, transcribed, coded and entered into an Excel spreadsheet for further analysis. Data was analysed for content, specific themes and underlying messages or feeling within the narrative.

Content Analysis

Content analysis has been used for several decades, and is often rejected for not being sufficiently qualitative, but more quantitative because the method uses discrete coded categories (Morgan, 1993). Content analysis enables a consistent set of codes to collate data into 'blocks' of similar responses. Typically in content analysis the frequency of responses in each coded section is counted to get a sense of the strength of the responses (Morgan, 1993). In this study codes were assigned to each 'influence' on infant care practice raised by the nurses and parent participants. The number of times these responses were raised, or key words were identified signaled the code to which the response was allocated. Codes included 'family influences', 'health professionals', 'cultural practice', 'societal change', etc.

Thematic Analysis

Thematic analysis is a poorly demarcated and rarely acknowledged yet widely used qualitative analytic method (Luborsky, 1994; Boyatsis, 1998; Roulston, 2001). Thematic analysis is used in qualitative methods including grounded theory and phenomenological research, and is a flexible method of qualitative analysis able to be used across a range of methodologies. Thematic analysis was used to analyse the responses to open-ended questions provided by both the nurses and parents in the interviews and focus groups. Data were transcribed from questionnaires and focus group recordings and entered into an Excel spreadsheet. Recurring words and key themes were identified and highlighted for more detailed analysis. The key words and themes were then studied in context and in relation to the setting in which the data was collected. The key themes identified have been presented in Chapter Four.

Discourse Analysis

Discourse analysis has been used for analysing social data since the 1960's, and is a method of analyzing the ranging levels of conversational discourse, including intonation, expression, gestures, rhetoric and veiled meanings (Taylor and Bogdan, 1998). In this study, discourse analysis was used to analyse the intensity of feeling or meaning expressed by the participants during the course of their conversation with the researcher. Investigating how and why parents care for their infants the way they do has the potential to raise emotional responses in those being questioned. The intensity of feeling expressed by participants in their narrative is highlighted using **bold type** to convey emotion and emphasis on particular words or phrases.

3.9 ETHICAL CONSIDERATIONS

Approval for the study to take place was given by the Human Research Ethics Committee of the University of Sydney, and separately by the Ethics Committee of The Children's Hospital at Westmead.

Participant responses were anonymous or identified to the researcher by first name only to encourage accurate and truthful responses to the questions. General Practitioner questionnaires were completely anonymous, without any identifying information to indicate the name of the general practitioner or in which area their practices were located. For this reason, GPs were not provided with a consent form to participate in the study, and a completed questionnaire was considered implied consent. This procedure was given approval by the Ethics committees of both institutions listed above. Similarly, nurses and parent participants who were interviewed by telephone only provided a first name and telephone number. A Study Information sheet was read to each participant prior to the telephone interview (Appendix 1).

Due to known constraints and difficulties associated with ethical approval to study the Australian indigenous community, indigenous families were not included in this study.

CHAPTER 4 –RESULTS

The whole is more than the sum of the parts

Aristotle (Metaphysica 10f-1045a)

The first section of this chapter details the demographic characteristics of participants in each category. The second section of the chapter addresses each of the research questions individually.

The participants in focus groups were asked a series of prompt questions, and allowed to openly discuss their feelings and opinions in response to the prompt question. The narrative responses are presented in *italic type*. Where emphasis or intense feeling was displayed, the words are highlighted in **bold type**.

4.1 DEMOGRAPHICS

General Practitioners

All general practitioners (n = 60) who completed the questionnaire worked in suburbs covered by the Sydney West Area Health Service boundary, and around two thirds of these (38) lived in the area as well. All had been practicing medicine in the area for at least 2 years, with the average length of practice 18 years and the longest 35 years. Over half (32) the respondents were female, a slight over representation compared to the percentage of women who complete medical training (40%).

Two thirds (40) of the GPs trained at Australian Universities, with around half of these (22) training at Sydney University. Fifteen of those who trained in Australian universities were born overseas, with more male respondents completing medical training in a non-

English speaking country than females. The majority of GPs participants commenced medical training after 1970. Of those who commenced prior to 1970, three commenced in the 1950's (1950, 1956 and 1958) and 17 commenced training in the 1960's. Only 5 of the medical practitioners who trained prior to 1970 were female.

The majority of GPs (42) estimated that mothers with infants aged less than 12 months made up less than 20% of the total practice caseload. The remaining one third (18) said between 20 – 70% of the practice caseload was made up of this group.

Around two thirds (37) of the GPs ranked immunization as the most common reason women attend GP practices with infants. Others listed the most common reasons for presentation as infections (12), general check ups (4) and feeding problems (2). Three GPs ticked all categories as reasons for presentation but did not rank them. Other reasons GPs listed as reasons for coming to the surgery were: unsettled babies, sleep problems, rashes, colds, crying babies and health of the mother.

General practitioners were asked whether mothers of infants ever asked them about ways of preventing SIDS. One third of GPs (20) commented that mothers did ask this question, just under two thirds (37) of the GPs said mothers never asked them this question and three GPs said they had rarely been asked this by mothers. Although posters and brochures about SIDS are readily available, just under half (26) of the GPs who responded to the questionnaire did not have SIDS brochures or posters in their medical practice. Thirty four GPs had either a poster for parents to look at or brochures available to take away.

It is known that women from CALD backgrounds access GP surgeries for the majority of their health care needs. In particular, women with poor English skills prefer a medical practitioner who speaks their native language, ensuring an accurate understanding of the health condition under review. The GPs in this study estimated that on average 35% of the clients they saw were women with infants who came from a CALD background. This

ranged from 2% - 70% in some practices. Due to the anonymous nature of the questionnaire, it is impossible to determine where these practices are located.

Nurses

All nurses who were enrolled in the study (n = 52) were female, and the majority (39) were Australian born. Thirteen were born overseas and came from the UK (5), Europe (4), New Zealand (3), Cyprus (1), China (1) and the Philippines (1). Thirty five nurses were employed on a part time basis, 8 were employed full time and 9 were retired. The nurses were not asked their age, but indicated they undertook nursing training between 1955 and 1995, with the majority (43) training prior to 1984.

Nurses were generally familiar with current SIDS reduction messages, and all nurses said they were familiar with brochures and posters about ways of preventing sudden and unexpected death in infants. Most nurses interviewed (42/52) said they always put babies to sleep on their back with 10 nurses admitting to use a range of sleeping positions either in their professional capacity as a nurse or at home as a (current) mother or grandmother. Older nurses commented that prior to the Reduce the Risks campaign they had always used the prone sleeping position as it helped the infant to sleep more soundly.

Paediatric nurses working in The Children's Hospital at Westmead commented on the hospital policy which ensures all cots in the hospital are made up in accordance with SIDS and Kids guidelines for making up a cot.

Nurses working in the Neonatal Intensive Care Unit commented that they did on occasion nurse premature infants in the prone position, but always explained to the mothers that this practice was for use only while the infants were in the Intensive Care Unit.

Parents who participated in interviews

One hundred and four people responded to advertisements and flyers asking for participants to take part in an interview about infant care practices. The majority of respondents were mothers of infants aged 12 months or less (88), and 4 were fathers. Twelve people described themselves as ‘carers’ of infants, and were either grandparents (9) or professional carers (3). One of the professional carers described herself as a ‘nanny’. Because of the small numbers of carers these are referred to as ‘parents’ from here on for simplicity. Thirty seven of the interview participants were born in an overseas country and 34 parents who responded to the advertisements were from a CALD background. All spoke conversational English (although the majority (28) spoke a language other than English at home), all were women, 2 were grandmothers of the child they cared for and 32 were mothers.

All of the parents lived in SWAHS, and all were caring for an infant aged 12 months or less. The average age of parent respondents was 31 years (range 20 – 38). Around one third (32) of the respondents were caring for a first born child. A higher number of infants than anticipated were born in hospitals outside the SWAHS, however the reasons for this are not clear. Thirty two mothers were from a CALD background.

The average age of grandparent carers was 62 years (range 56 – 70 years), and of professional carers 28 years (range 23 – 33 years). Grandparent carers reported caring for their infant grandchildren on average three times per week, with two of the grandparent carers born overseas in a non-English speaking country.

The three professional carers were born in Australia and cared for infants between three and five days per week. All professional carers commented that the infants they cared for were from families where both parents had ‘high powered’ careers. Two women cared for other children as well as the infant in a day care situation. One carer described herself as a ‘nanny’ and lived with the family and the infant in her care. Both professional and grandparent carers commented that their caring responsibilities were on a regular basis to enable the child’s parents to go to work. None of the grandparent carers had undertaken

any professional infant care training and had not cared for infants since their own children were young. Two of the professional carers had undertaken childcare training through TAFE and were licensed child care providers. The third professional carer had no formal childcare qualifications, however said she had cared for many children and was ‘quite experienced’.

	Australia	Europe	Asia	South America	UK	Total
Number of interviews	61	24	5	5	3	104

TABLE 1: Country of birth of 'parent' participants interviewed by telephone.

Parents participating in focus groups

A total of eight focus groups were conducted with parents who were all female. Each focus group was culture specific. Two focus groups were conducted with Arabic speaking and Australian women (4) and one focus group was conducted with Vietnamese, Chinese, Filipino and Pacific Island born women (4). Interpreters were used for Arabic and Vietnamese speaking women. Women born in China, the Philippines, Pacific Islands and Australia spoke English well (Table 3).

	English speaking	Arabic speaking	Vietnamese speaking	Chinese speaking	Filipino (spoke English)	Pacific Islands (spoke English)	Total
Number of focus groups	2	2	1	1	1	1	8
No participants	15	12	5	6	10	6	54

TABLE 2: Demographics of participants in focus groups

Women participants ranged in age from 22 to 43, with an average age of 32 years. All participants were currently caring for an infant aged 12 months or less and all were mothers of the infant. All participants were asked the same ten focus group questions, however focus groups varied in length from 40 minutes to 75 minutes depending on the

amount of discussion generated by the group and the time taken to translate the questions and answers through the interpreter. The discussion within the group was tape recorded and facilitated by the researcher. An independent observer recorded detailed notes regarding the content of the discussions.

4.2 RESEARCH QUESTION 1

In your opinion is there variation in knowledge between GPs, nurses and parents on ways of preventing sudden and unexpected death in infants?

General Practitioners

Thirteen GPs out of the 60 participants reported that they were taught SIDS reduction strategies as part of their medical training, although on further examination 9 of these GPs trained prior to the introduction of the Reduce the Risks Campaign in 1991. A further 23 GPs had attended educational sessions covering SIDS reduction strategies as part of ongoing in-service training, however 24 GPs had never attended any educational session on SIDS reduction.

General practitioners were asked in the questionnaire whether they had ever cared for an infant who later died from SIDS, and considering SIDS numbers have reduced significantly, it was surprising to find that almost one third (19) of the respondents had done so. Further examination of these results indicated that only one GP had cared for a baby who had died since the 1991 'Reduce the Risks' campaign. Of the 19 GPs who knew a family whose baby died from SIDS, six provided counselling themselves for the family, eleven referred the family to private counselling, 'SIDS and Kids' or both, and three did not refer. One doctor commented there were no services for parents in those days (1950's). One of the GPs who responded noted that he and his wife had lost a baby to SIDS.

Almost half of the GPs surveyed were not familiar with current SIDS reduction strategies. When asked to list current safe sleeping messages as outlined in the SIDS reduction campaign promoted by SIDS and Kids NSW, just over one third (22) could not list *any* SIDS reduction message. Thirty GPs listed 'sleeping on the back', as a SIDS reduction message, with 25 listing this as the '*most important*' message. Eleven GPs listed 'sleep baby with face uncovered' and 30 listed 'cigarette smoke is bad for baby'

with 5 GPs listing the latter as the '*most important*' message for SIDS reduction. Only 4 GPs out of those who completed the questionnaire could list all four messages from the Safe Sleeping Campaign. One third of the GPs (20) could list three messages, eight could list two and seven could list three messages from the Safe Sleeping Campaign (Table 3).

Breastfeeding is recommended for all infants for optimum nutrition and general health, but there is currently no evidence to support its use as a SIDS reduction strategy, although six GPs did list breastfeeding as a SIDS reduction strategy. Twenty three GP participants listed strategies not endorsed by SIDS and Kids NSW and not supported by research evidence to suggest they would reduce the incidence of SIDS. These included 'wrapping a baby tightly', not wrapping a baby tightly, 'watching for signs of respiratory distress', 'wearing proper clothes' 'not using a dummy at night', 'using a dummy', 'watching a baby if breathless', and 'not using a bottle at night'. Six GPs listed incorrect sleeping positions as the *most important* SIDS reduction message stating; 'put the baby on the side' (4) and 'place baby on the tummy'(2).

Around one third of the GPs surveyed could not list any SIDS reduction messages. In view of this these GPs were investigated further to determine whether there was any commonality between them. There was no difference in the place of medical training in the group, with half (11) training in overseas universities and half (11) training in Australian universities. There were slightly more males (13) represented in the group who could not list any messages than females (9). Interestingly, all respondents in this group trained prior to 1986, well before the introduction of the Reduce the Risks Campaign. Significantly, almost 70% (15) of the GPs who could not list any SIDS reduction messages were born in a non-English speaking country.

Six GPs listed incorrect sleeping positions. There were no commonalities in when or where these GPs trained or their country of birth. Strategies including 'use a dummy at night', 'watch baby', 'watching a baby if breathless', 'not using a bottle at night', 'wearing proper clothes', 'wrapping a baby tightly' and 'not wrapping a baby tightly' were listed by GPs born both overseas and in Australia.

TABLE 3: General Practitioners' knowledge of SIDS reduction messages as outlined in the SIDS and Kids Safe Sleeping Campaign.

GP KNOWLEDGE OF SIDS REDUCTION MESSAGES	N/60
Number of GPs who listed 'put baby on the back to sleep' as a SIDS reduction message	30
Number of GPs who listed 'sleep baby with face uncovered' as a SIDS reduction message	11
Number of GPs who listed 'cigarette smoke is bad for baby' as a SIDS reduction message	30
Number of GPs who listed 'safe sleeping' as a SIDS reduction message (included in these responses were no blankets, bumpers or doonas, no co sleeping, safe mattress, feet to foot position)	21
Number of GPs who listed 'put baby to sleep on back' as the <i>most important</i> SIDS reduction message	25
Number of GPs who listed 'cigarette smoke is bad for baby' as the <i>most important</i> SIDS reduction message	5
Number of GPs who correctly listed 4 the SIDS reduction messages in any order	4
Number of GPs who correctly listed 3 SIDS reduction message in any order	20
Number of GPs who correctly listed 2 SIDS reduction message in any order	8
Number of GPs who correctly identified 1 SIDS reduction message	7
Number of GPs who recommended 'side/back' or tummy sleeping	6
Number of GPs who listed incorrect advice regarding SIDS reduction messages	23

Nurses

All nurses who participated in the study could name at least 3 SIDS reduction messages. Nurses who were currently employed as child and family health nurses could list all SIDS reduction messages. All nurses listed putting baby on the back to sleep as the most important SIDS reduction message, followed by ‘reduce exposure to cigarette smoke’. Thirty six nurses also listed removing bumpers, linings, toys and blankets from the cot and twenty one listed the ‘feet to foot position’ as a SIDS reduction strategy. Many also listed breastfeeding, and although encouraged, breastfeeding is not listed as a SIDS reduction message. All nurses were familiar with the SIDS brochures and posters, and all reported having these available for new parents in their clinics or workplace. Retired nurses also commented that they had seen the brochures (mostly through having their own grandchildren).

Nurses were asked a series of questions about the way they currently (or used to if they were retired) put babies to sleep. All the nurses currently working full time or part time (n = 43) knew that it was best to put babies on the back to sleep. Of these, 25 commented that they had previously put babies to sleep on their tummy, prior to the SIDS and Kids campaign. Twelve nurses who were currently working commented that they ‘sometimes put babies on their side’. When questioned further about this, ten said it was useful if the babies were ‘refluxy’ and two said it stopped the babies getting a ‘funny shaped head’. All of the nine nurses who were retired commented that they previously used a combination of positions for sleeping infants, including ‘side to side’, ‘on the tummy’ and ‘side and back’. The nurses were keen to comment on these changes and many wanted to discuss the benefits and disadvantages of different sleeping positions at length. Some of these comments included:

“You know things have changed a lot since I began training... we always used to put the babies on their tum and turn their head to the side, it just seemed good sense. They didn’t choke if they spat up and they slept really well.....but you can’t do that now.”

Part time nurse

“we used to be really worried about babies choking...we used to suck them out and put them on their tummies to help drainage. We also used to wrap them up tightly. I don’t think they suck babies out any more...”

Retired nurse

Many nurses commented on the settling techniques they used to put babies to sleep. These included wrapping them up tightly, patting and stroking them to sleep. Almost all nurses (45) commented on the settling benefits of wrapping a baby tightly to protect the Moro (startle) reflex and to simulate the close environment of the womb. Some nurses reflected on their experience trying to settle babies in a ward setting.

“We used to wrap them (the babies) in ‘the Karitane Wrap’ a technique where you put their hands down and folded the wrap around tightly so they couldn’t get their hands out, then we would put them in the portable cots and rock them two at a time over a bump to get them to sleep”

Part time nurse

“You had to try and settle them quickly as there were so many babies, so you would put them on their side and stand on the other side of the cot, so you didn’t have eye contact (you had to let them know it was not play time) and then you would pat them while looking away...”

Retired nurse

The nurses were asked why they previously put babies on their tummies and side to sleep. Forty nurses commented that babies sleep better this way, and of these thirty four said the babies settle more quickly. Twelve nurses said they thought the babies were less likely to choke, even though they now know there is little chance of this sleeping in the supine position. One nurse commented:

*“We were **always so mindful** that the babies shouldn’t choke.....it is just **ingrained** in me that it is safer on the side so they can spit up.....”*

Part time nurse

Many of the nurses commented that they were shown sleep positioning by more experienced nurses while they were training. These nurses spoke vividly about the ‘strictness and rigidity’ of the older nurses, and the fear they had about doing the wrong thing when looking after babies.

*“You just **had to do it that way**....there was **no** choice...they were the experienced ones and we were learning, so **we did as we were told**...”*

Retired nurse

The nurses were asked about their experiences with other safe sleeping messages and their experiences with promotion of safe cots, discussions around co sleeping, and talking to parents about the risks of smoking. There were many lengthy responses here, and the nurses were all keen to share the situations they had encountered and the changes they had witnessed. The majority (38) of the nurses working full and part time said they spoke to women about safe sleeping in either the hospital setting or as an early childhood nurse. The neonatal nurses all commented that they sometimes used side and tummy positioning for very premature babies, but that they always told the parents this positioning was ‘only for use in the hospital not at home’.

Many of the retired nurses commented on the previous use of ti-tree mattresses and small pillows for babies. All of these nurses said they did not focus on safety of cots or bedding prior to the introduction of the Reduce the Risks campaign. The early childhood nurses involved in home visiting (20) all commented that they assess the cots when they visit the mother’s homes, and discuss appropriate bedding, smoking reduction and safe sleeping. Three nurses commented that they often see babies sleeping in portable cots (not recommended for permanent sleeping), in cots and bassinets with frilly bumper linings and toys in cots. Fifteen of the nurses commented on the difficulty of discussing co-sleeping with women from a non-English speaking background, as co-sleeping is strongly

encouraged in many cultures. Some of the comments from nurses around these issues are as follows:

*“I have seen all sorts of sleeping arrangements, **believe me**.....I went to one family last year and the poor little darling **was sleeping in a suitcase !!** In this day and age....would you believe it? I had to talk to the parents about the importance of trying to get a suitable cot”*

Child and Family health nurse

*“Many of the Middle Eastern women **insist** on sleeping with their babies...(and they smoke a lot) some Asian and Indian families don’t even **have** a cot at first as they always sleep with the parents...this is a difficult one to talk about because you feel like you are intruding on their cultural customs..”*

Child and Family health nurse

*“You **still** see things that are not recommended, like sheepskins and heavy blankets to cover up the baby in the cot. Many parents still have this thing about ‘keeping a baby really warm’, even when it is hot”*

Child and Family health nurse

Of the 36 nurses who responded to this section of the questionnaire, 33 used either the side or the tummy position, or a combination of both to sleep their own babies. Three nurses whose babies were born since the Reduce the Risks campaign used the back sleeping position. All those who responded had initially placed their baby to sleep in a cane bassinet or a wooden cradle, moving the baby to a cot when they reached about six months of age. Most (28) had used cotton liners or bumpers, and almost all (33) remembered using a ti-tree mattress in the bassinet or cradle. Two nurses said they used a horsehair mattress and one could not remember. Thirty nurses used a small pillow for their infants, and all nurses interviewed said the blankets they used were made from either wool or cotton.

Over half mentioned the technique of ‘propping’ the baby. This procedure was used to stop a baby rolling onto its back and ‘possibly choking’. The technique involved rolling a cloth nappy or cotton ‘bunny rug’ into a roll and placing it along the baby’s back while they were lying in the side position. It was thought that protecting the baby from rolling onto the back would prevent possible aspiration of any stomach contents. Most nurses said they learned to do this as a student or when they were in hospital, others said they had seen it done in hospital and copied the technique when they went home.

Parents

Sixty eight parents were able to rate back sleeping as the most important SIDS reduction message (although only 66 of these used this position routinely). The majority of the remaining parents believed that a combination of back and side sleeping was protective from SIDS. Almost all parents knew that parental smoking was a risk factor for SIDS, and although only one third of respondents admitted to smoking, over half of these said they never smoked near the baby. Only one third of all parents interviewed mentioned the ‘feet to foot position’ as a reduction strategy for SIDS. Although over half of those interviewed knew that co-sleeping should be avoided where possible, most admitted to co-sleeping with their infants sometimes, particularly when the infant was distressed or would not settle.

The majority of parents knew that bumpers and liners are not recommended in babies’ cots, although some parents still used these for protective or aesthetic purposes. Many parents admitted putting favourite toys into the infants’ cots (usually to assist them to get to sleep), and most mentioned were soft toys such as teddies.

Parents were asked to describe the way they usually put their baby to sleep and who instructed them to use this method. The majority of parents (60) put infants to sleep in the supine position. Twenty two parents used a combination of side/back sleeping position, 4 parents used side sleeping position only and 2 parents put infants on the tummy to sleep. All parents who reported using the supine position had been shown this method by nurses

in hospital, or early childhood nurses. The parents using the combination and side sleeping position also remembered being shown to use this position by nurses, although interestingly, just over half (13) of these parents had older children, and had possibly been shown the combination with their first child years previously and continued this practice. Of the two parents who placed their infant on the tummy to sleep, one said she had been shown this by an early childhood nurse, and the other could not quite remember although she did remember discussing this with her mother and mother in law.

Many parents commented that they wrapped the babies tightly prior to putting them down to sleep, two said they used the 'Karitane wrap' and described this a particular method of tightly wrapping infants so the arms do not come out of the wrap while sleeping. Most parents said their infants slept in a cot, although around half of these were in the same room as the parents. Four parents said their infants slept in a portable cot, a practice not recommended by SIDS and Kids as a safe sleeping practice.

Around two thirds of those interviewed said they did not use bumpers or liners in the baby's cot, although many reported putting teddies and favourite toys into the cot with their infant. Eight women said they used a 'Snugglebed' inside the infant's cot. Snugglebeds are not recommended for safe sleeping by SIDS and Kids. Of those who did use liners and bumpers, the reasons included: protecting the baby from the bars of the cot, keeping them warmer, preventing draughts, and 'making the cot look nicer'.

Most of those interviewed said that sometimes they took the baby into their own bed and slept with the baby. The main reason parents reported doing this was: to get some sleep, to settle the baby and to (breast) feed the baby. Many women (60/104) said they had fallen asleep while breastfeeding the baby in their own bed. Some women reported putting the baby back in their own cot once they had fallen asleep, but on the whole most left the baby with them once the baby had settled.

*“I know I am not **supposed** to do it (sleep with the baby), but both my husband and I have to get up for work, so anything for a peaceful life and a little sleep I’m afraid”*

Working mother

One father commented that he had to learn all this ‘from scratch’ and was quite interested in the different ways of putting the baby to sleep. He commented on the amount of reading he had done, and said:

“It is probably helpful for fathers to be more involved. I was more prepared to question than my partner was. She felt more vulnerable I think, and I wanted to know every little detail. I know the reasons why my son should sleep on his own and on his back”

First time father

Ninety two parents were interviewed retrospectively as to whether they had ever used a blanket to cover the prams or strollers of their infants. Eighty (87%) of these said they had used a muslin wrap or blanket at some time to cover their infant's pram or stroller. One third of those who said they used covers over the pram said they used 'heavy blankets' or 'bunny rugs' to do this. Reasons given were 'to encourage sleep' (78%), 'to prevent others 'touching' the baby' (62%), 'to protect against sunlight' (10%), and 'protection from the wind and dust' (58%).

Parents participating in focus groups

Fifty four parents all of whom were female, participated in one of eight focus groups.

Focus Group Participants by COB	Language used in focus group consultation	Number of Participants (n = 54)
Australia	English	15
Lebanon	Arabic	12
Vietnam	Vietnamese	5
China	English	3
Hong Kong	English	3
Philippines	English	10
Samoa	English	2
Fiji	English	2
Tonga	English	1
New Zealand	English	1

TABLE 4: Parents participating in focus groups by language spoken and country of birth.

Australian born women

Fifteen Australian born, English-speaking women participated in one of two focus groups. The women ranged in age from 28 – 43 with the average age of these women 35 years. Eight women were first time mothers and seven had at least one other child in addition to their infant. The average age of infants in this group was 9 months.

The women in each group were shown the latest SIDS and Kids Safe Sleeping brochure and were asked if they had ever seen the brochure or received a copy. Five women in one group had seen the brochure; the other two said they had seen the advertisements, but not the brochure. Out of the second group of eight women, only three had ever seen the brochure about Safe Sleeping. The women who had seen the brochure in both groups commented that they had received a copy in their Personal Health Record (commonly referred to as ‘The Blue Book’) or been given a copy by the Child and Family Health Nurse. Some women had seen the brochure in hospital or in their General Practitioners’ surgery.

“I know I got one in my ‘Blue Book’, and the nurses were pretty good about showing me the right way to put her (the baby) to sleep”

Group 2 mother

This led to a discussion in both groups about the way mothers put their babies to sleep. Mothers in the first group appeared to be more conversant with Safe Sleeping messages. Many of these women said they investigated the ways to prevent SIDS when their babies were newborn. Only one woman said she sometimes used the side position for her infant, if he ‘was snuffly’. The other women were quick to tell this mother that she should always use the back sleeping position. Discussions around sleep position in the second group of Australian born women were quite different. In this group, two mothers were quite vocal about their choice of sleeping a baby on the tummy, explaining ‘**how much better**’ the baby slept when positioned this way. Others in the group commented that they used either the side or back sleeping position. When questioned about where they learned to sleep their babies on the tummy both mothers said they had learned this technique from a mutual friend, (a mother) when they were having difficulty settling their children.

*“I couldn’t for the life of me get her to sleep, and I had tried **everything**. I was at the **end of my tether** this day and I was on the phone to my friend. She said, put her over your knee and pat her back and then put her to sleep on her tummy, she will sleep better. I tried it and it worked, I have been doing it ever since. She is six months old now”.*

Group 2 mother

Arabic speaking women

Twelve women from an Arabic speaking background took part in one of two focus groups. All women were from Lebanon and were a mixture of Christian and Muslim women. The group was held with the assistance of an interpreter, although most women could understand and speak a little English. The majority of the women had been in

Australia at least two years. One woman had only been in Australia for just over one year. All of the women participants knew at least one other member of the group and some were related to one another.

The women were shown a SIDS and Kids brochure in English and in Arabic (printed from the website). Only three women had seen the Arabic version. Three had seen the English version, but none of the other mothers (6) had seen either version of the brochure. When asked whether the women knew how to prevent SIDS, most said 'watch the baby often', three mothers mentioned back or side sleeping position, two said 'no smoking', and four said 'breastfeeding'. The women in both groups did not seem to have an in-depth knowledge of SIDS or SIDS prevention.

Chinese born women

Six Chinese women participated in the focus group, and all spoke English reasonably well. The women were aged between 24 and 32 years with an average age of 26. The women were keen to participate in this group, and spoke among themselves at length prior to the commencement of the group. The average age of the babies in this group was 4 months. All but one of these women attended antenatal classes prior to the birth of their baby. Most attended classes in English, but one woman said she attended a class provided in Cantonese. All women felt comfortable about giving birth in SWAHS, and observations indicated that the women in the group were well educated. All women mentioned that educational material on childbirth and infant care was available in their language, much more so in Australia than in China or Hong Kong.

All the Chinese women said they placed their baby either on the side or back to sleep. All women knew about placing their babies on the back to sleep. However four women commented that 'babies get a 'flat head' when they regularly sleep supine'.

*"I always wrap my baby and put her on her back... but **I do** move her about from side to side, so she does not get a flat head"*

Group 5 mother

Vietnamese born women

Five women born in Vietnam participated in a focus group held in October 2006. The average age of the women was 31 years (range 25 – 40 years). All women had lived in Australia for at least three years. Some spoke a little English, however most were more comfortable answering question in Vietnamese language. The average age of babies in this group was 6 months. The women in the group knew at least one other member of the group.

When asked where their babies slept, all women said their babies had a ‘cot or cradle’. All babies slept in the same room as the parents, and most mothers commented that they sometimes take the baby into bed with them to feed the baby or to help the baby settle. The Vietnamese women commented that they wrap their babies tightly, and often carry them around close to the body. This helps keep the baby settled and assists with sleep. The women used a combination of back and side sleeping for their infants, three used the back position exclusively and two used both back and side sleeping. All mothers commented on the ‘flat head shape’ some babies get when slept solely on the back. Three of the Vietnamese women had seen the SIDS and Kids Safe Sleeping Brochure, two had not. When asked if they could name any other factors associated with SIDS and Safe Sleeping, only one woman mentioned no parental smoking.

Women born in the Philippines

Ten women who were born in the Philippines participated in a focus group held in SWAHS in June 2006. These women were aged between 26 and 42, with an average age of 34. They were all mothers to babies under the age of twelve months, with six women mothers to two or more children. The average age of the infants of the mothers was 10 months. All the women knew each other through a playgroup and had been meeting regularly since their babies were small. They were keen to participate in the focus group to provide their perspective about being a mother in a foreign country. All women spoke English well.

The women knew about putting their babies on the back to sleep, and most had seen the SIDS and Kids Safe Sleeping brochure. Four women admitted to still putting their babies on the side, because they were 'told in hospital' the side position was OK. (These women all had older children in addition to their infant). All women said there were times when they brought their babies into bed with them, primarily for feeding, or so the parents could get some sleep. Each woman said their baby had their own cots, but most were in the parents room, or in a room with siblings. Women commented that they used cotton and woolen blankets, and two women said they used a 'Snugglebed'.

When asked whether they could name any other SIDS reduction strategies, the women mentioned 'breastfeeding', 'watching the baby' and 'no parental smoking'. One woman thought sleeping with the baby was protective against SIDS.

Women born in the Pacific Islands

Six women who were born in various places in the Pacific Islands were willing to participate in one of the first focus groups held in December 2005. These women came from a number of different Pacific Island countries including Samoa, Niue, New Zealand and Tonga. The women were aged from 28 – 38 with an average age of 32. The average age of infants in this group was 10 months. All women had at least one child in addition to their infant and all had lived in Australia for at least five years. Many had migrated from New Zealand even though their country of origin was a Pacific Island other than New Zealand. Some of the women knew each other through their local church, however the women were not related, nor had they been part of an organized group prior to the focus group.

Not all women had a cot for their baby, some slept in a bassinet or a cradle. The women knew that infants were supposed to sleep alone, however most said the babies often slept with them or other siblings, as it made it easier for the baby to settle. One woman commented that she did not have enough money to buy fancy cots and equipment for her baby and most things she used were from her sister's children or from friends. Again, the

statement below highlights conflicting beliefs between health professionals and cultural groups, who have differences of opinion around reusing equipment, particularly infant mattresses and car seats.

“We share all the baby things...when my baby is too big, she needs it back for another baby of hers, so it goes round and round.....this is good that we can do that”

Group 8 mother

All women were asked whether they had seen the SIDS and Kids Safe Sleeping brochure. All women said they had seen the brochure, either at the Child and Family Health Centre or in the hospital. Not all women had read the brochure. When asked whether they knew of any ways to reduce the likelihood of SIDS, most women said ‘no smoking near the baby, only one said ‘sleeping position’. The majority of women said they place the baby on the side and back to sleep, using a combination of sleeping positions so the baby does not get a ‘misshapen head’. Two women thought breastfeeding was a SIDS reduction strategy, but only three of the women said they had breastfed for three months or more, most saying they stopped because they ‘ran out of milk’ or did not want to continue. One woman said for her, it was ‘much easier to bottle feed’.

Carers who were not parents

The carers who were not parents used a variety of sleeping positions for the infants in their care. All three professional carers placed babies to sleep on their back. Of the grandparent carers, 3 placed babies on their backs to sleep, 2 used the side position, 2 used a combination of side and back sleeping and 2 placed babies to sleep prone. Those who used the side, side/back and tummy positions were asked why they used these positions for the infants. All said this sleeping position was what the baby was used to, and was the position used by the child’s parents. One grandmother said in her experience babies slept better on their tummy and this is the way her grandson had always slept.

Carers' knowledge of SIDS reduction messages was less than ideal. All of the grandparent carers were familiar with the term SIDS and 'cot death'. Three said they knew someone who lost a baby to SIDS many years ago when their own children were young. Only seven of the nine grandparents were aware that sleeping position was associated with SIDS, and only three knew that back sleeping is the only recommended sleeping position for infants. Most thought that side sleeping was associated with a decreased risk of SIDS. The two grandparents who placed their grandchildren on the tummy to sleep were both born overseas, and commented that tummy sleeping was the position they used for their own infants. Neither of these grandparents had seen SIDS messages in their own language. Six of the carers mentioned the feet to foot position as the way they slept the baby, all these had either been trained this way, or been shown by their daughter or daughter in law. All carers knew smoking around a baby is not recommended, and none of the carers smoked near the babies for which they were caring.

4.3 RESEARCH QUESTION 2

What factors influence the way health professionals and parents care for infants?

The results from questionnaires, interviews and focus groups from all participants have been pooled for this section of the chapter. Findings are presented for each factor considered to have an influence on the way participants care for infants. The factors are: i) family and friends, ii) health professionals, iii) education, iv) literature and media, v) culture, vi) tradition, vii) previous experience & personal preference, viii) socio-economic status, and ix) society.

(i) Family and friends

Friends and family were considered the major influence on new parents by over half (34/60) of the GPs who responded to the questionnaire. Similarly, the majority of nurses (46/52) felt that family and friends were the biggest influence on new parents. Four early childhood nurses felt that family and friends were the biggest influence on women from CALD backgrounds (while health professionals were the main influence on parents from an English speaking background). Twelve nurses commented that ‘other mothers’, in either groups or friends with children were highly influential to new mothers, sharing their recently gained ‘experience’.

Four nurses believed the partner, mother and mother in law are the most influential people in a new mother’s life. One nurse commented on the importance of partner support for women to maintain breastfeeding. Another commented:

*“The most influence comes from who they are with everyday – lets face it if you are living with your mother or mother in law **they have influence !**”*

Full time nurse

Many parents commented that they had family close by and used them extensively for support, while for others this was not possible. Some of the overseas born women said their mothers had come to visit them following the birth of the baby to assist them to care

for the infant. The majority of Australian born women said they had attended ‘mothers groups’ or ‘playgroups’ since the birth of their baby. All commented that these groups assisted them to care for their infant, as they learnt new ideas and methods of feeding, were able to discuss their child’s milestones with others, and debrief with other mothers about the joys and challenges of raising a child. Some of the mothers commented that mothers groups could be a source of pressure and stress as there was a perceived competitiveness between some parents.

“I feel there is a lot of pressure on new mothers, and I have to be honest, I put a lot of pressure on myself. I sometimes feel that other mothers look at me and compare me to themselves, I am trying to work and study and be a supermum”

First time mother

Almost all of the parents interviewed said they relied heavily on friends for advice and support. Most could name at least two friends they could turn to if they needed advice or assistance. Women from a CALD background commented on the isolation they felt as mothers in a new country, however most of the CALD women interviewed said they had friends from their native country to help them, or members of extended family for support in an emergency. There were some women who made detailed comments about raising children in a new country:

“It is very hard being a mother in a different country. I miss my mother a lot, I can’t just visit and ask for her advice, help and support. I have found friends that speak Spanish, and that is good, because they have little children too”.

Spanish speaking mother

“I sometimes feel very alone...without my mother and my sisters. My husband is a great help but sometimes you need to talk to another woman to share the load. This is not possible for my mother is in Brazil”

First time mother

Most Arabic speaking women said they had gained their experience from friends and family, with many caring for younger siblings and other infants in an extended family situation. Many of the women (7/12) said their mother or mother in law had visited from Lebanon to help them care for the baby when it was very young. One woman said she felt comfortable asking her relatives for help:

*“If I need help I go to my family, **they know** the best ways and the things that can help me get my child better, they also know me and can **tell me** what to do”*

Group 4 mother

(ii) Health Professionals (GPs and Child and Family Health Nurses)

Fifteen of the GPs felt that doctors (of any specialty) were the most important influence on new parents. After family and friends, the majority of GPs surveyed listed the early childhood health nurse as the major source of advice for new parents (32).

The majority of nurses interviewed (30/52) placed the ‘baby clinic sister’ as the person they consulted most frequently about infant health and child-care issues when their babies were young, although many nurses referred to multiple sources for infant care advice and information. Overseas born nurses commented they visited their local doctor or paediatrician with their infants, however many of these also used the services of a clinic sister or mothercraft nurse. Fourteen nurses relied on ‘mothers groups’ for information and 9 used residential services such as Tresillian and Karitane. When asked who gave them the most useful information, 25 nurses said the clinic sister, 6 said their mother and 5 said friends and GPs. Most nurses felt confident looking after their newborn babies, however some made comments about the difficulties of caring for a newborn. Nurses made the following comments about accessing help:

“I think the Clinic Sister (as they were in those days) was the one who helped me most. I knew I needed more help and I was comfortable to ask her. I felt like I should have known what to do.....”

Part time child and Family health nurse

*“ I found it a **real struggle** to get the right advice, my baby had a cows milk allergy and I kept thinking I was doing something wrong.... sometimes I felt like ‘just another mum’”*

Part time child and Family health nurse

*“It took me **ages** to get up enough courage to bath him”*

Registered nurse

The majority of parents interviewed felt that when their baby was a newborn they received the most useful advice about infant care from midwives and early childhood nurses. Others commented that obstetricians and paediatricians were also very helpful in dealing with medical issues and reassuring parents in their parenting role. A large proportion of the parents reported taking their infants to the GP, but some felt the GP was too busy to ask detailed information on infant care. Others did not agree with this and commented that the GPs did provide useful information:

*“I am confident in my GP, but there are always so many (people) there I don’t like to waste his time, and **sometimes I feel like it is me that is not very competent**”*

First time mother

*“My GP gave me the **best information** about my baby crying. He said “pick her up”. I had been told to let the baby cry, and once I had permission to pick her up, things settled down.....I can’t believe it was that easy”*

Overseas born mother

*“My GP has **lots** of really useful brochures and pamphlets and I feel comfortable asking her about anything I feel I need help with.....she is really ‘switched on’”.*

First time mother

The Australian women in the focus group reported attending the Child and Family Health Centre with their infant at least once. Many of them commented that they had a home visit following the birth of their baby, although not all women had experienced this. The women spoke highly of the Child and Family Health Nurse, explaining that they were generally very helpful. Two mothers said that the nurses had made them feel as if they were ‘inadequate as a mother’, and ‘not very competent’ but on the whole these women also felt they could go to the Child and Family Health Nurse if they needed help with their baby.

*“My baby was slightly behind in the milestones, not badly so, but just on the lower side of average I guess, and **she** (the C&FHN) made me feel like I was not doing the right thing as a mother, and he (the baby) was **not quite up to standard**”*

Group 1 mother

*“I was having **real trouble** breastfeeding and asked whether I should go over to formula feeding. **I really got an earful** from the nurse, I felt like I had asked whether I should **poison** the baby !”*

Group 2 mother

The Arabic speaking women knew about the Child and Family Health Centres and some commented on the home visits by nurses following the birth of their baby. However many spoke of the isolation they felt at first, particularly where they did not have family support. One young mother said:

*“I have **only my husband** here, I met some friends later, but when my baby was young I was **very lonely** and went to the hospital if she was sick...I was **very scared**”*

Group 3 mother

Following this comment, many other women spoke about returning to the hospital if their baby was sick, or going to a GP who spoke their native language. Most felt nervous that

they could not understand enough English to accurately deal with the situation when their child was ill.

*“My doctor explain (sic) it to me in my own language, so **I know** what she is sick from, then **I know** what to do for her”*

Group 3 mother

Chinese women who were able to interact with a Chinese Child and Family Health Nurse spoke differently about the experience. Many Chinese women commented on how helpful it was to go to the Early Childhood Health Centre.

*“**I like to go to the Baby Clinic....there is a Chinese nurse there and she always looks after me and my baby, she tells me useful information for my baby”***

Group 5 mother

The majority (4/6) of the women had experienced a home visit following the birth of their baby, although this was not the case for all women. When asked about cultural issues pertaining to childbirth and infant care, the women became quite animated. They explained that things were quite different in China when a woman is pregnant and has a small baby.

Some of the Vietnamese women said they went to the Child and Family Health Centre, and some commented on the home visiting nurse, however they explained through the interpreter that they were often unaware of services until another mother told them about it, or until a GP or health professional who spoke Vietnamese referred them to a service. The women commented that they passed on as much information as they could to their friends, so that others knew what was available.

*“I tell my sister, and she tells her friend, then we all know that we can go to this place with our babies. **It is good to share information**” (translated)*

Group 6 mother

The Filipino women all knew about the Child and Family Health Centres and some had experienced home visits from the Child and Family Health Nurse. All felt comfortable taking their infant to the Child and Family Health Centre and commented they also visited the pharmacy and the GP when the children were unwell.

The Pacific Island women were keen to talk about the Samoan Child and Family worker employed specifically to work with the Pacific Island community.

*“She runs groups for us and we can ask her things when we have a problem. It is **good** to have this service”*

Group 8 mother

All women felt comfortable to visit the Child and Family Health Nurse and commented that she visited them in their homes as well. The women were familiar with the Child and Family Health Centre and many said they visit the centre when they need to get additional help or information.

(iii) Education & antenatal education

General Practitioners did not raise antenatal education as a potential source of influence on parents. The nurses commented that antenatal education classes were well attended by Australian born women, however it was difficult for many CALD women to attend. Asked to estimate the number of first time parents nurses thought attended ante-natal classes, most estimated around 75% although this ranged from 50% to 99%. The majority of participants (44/52) said in their experience women from a CALD background do not attend antenatal classes, due to poor knowledge of the system, the language barrier, cost of classes, differing customs, fear of what they would be told and reliance on friends and family for advice and information in their own language. Some nurses felt that CALD women would attend classes if they were accessible and promoted within the community. One nurse commented on the difficulty for pregnant CALD women:

“The trouble is the classes are often held at night, and it can be hard for CALD parents to get there if they don’t have a car at night. Many of the classes are quite expensive and if they are unsure whether they can understand the information fully why would they pay a lot to learn not much?”

Part time midwife

There are antenatal classes held in a range of languages in SWAHS, however many nurses felt these were not promoted sufficiently within the community and were often difficult to access. Many nurses (11) commented that the attendance at these classes varied quite a lot by suburb and culture.

Almost all of the nurse participants who were parents themselves (32) attended antenatal classes prior to the birth of their first baby. Most could not remember what the classes covered however two nurses remembered the beginning of involvement of fathers in the birthing process, and others remembered exercises and learning to ‘breathe properly’. Only two of the thirty six nurses interviewed said they had attended antenatal classes with a subsequent pregnancy.

For many ‘new’ parents attendance at antenatal classes is the first real exposure they have to the experience of parenting and infant care. Around two thirds (63/104) of the parents who were interviewed attended antenatal classes prior to the birth of their first born infant. Approximately half of those who did not attend were born in an overseas country (20/41). For the women born overseas, the main reasons given for not attending antenatal classes were: ‘felt I didn’t need to know *too* much’, ‘was nervous about what they would tell me’, ‘my English wasn’t that good then and the classes were not in my language’.

Four of the Australian women in the focus groups had not attended antenatal classes prior to the birth of their baby. Those who attended had done so at a range of venues, including the hospital where they delivered their baby and through private organizations. All women who attended classes felt they were valuable and provided women with detailed knowledge about the birth process, and were a good opportunity for partners to become involved.

*“It was **good** for my husband to be there too, I think it made him feel more a part of the whole process”*

Group 1 mother

All women who had older children as well as an infant had not attended antenatal classes for their second and subsequent babies. One woman commented:

*“I don’t think you **need** to go again (to antenatal classes) unless it is a long time between pregnancies....like years...my friend went eight years between....she went again.”*

Group 1 mother

Arabic speaking women were asked whether they had attended antenatal classes prior to their baby’s birth. The majority had not done so with only two women having attended and both these women had reasonably good English skills. When asked the reason for non-attendance at classes, the women gave the following reasons: most classes were held at night, and they were difficult to get to by public transport in the evening, they relied mostly on family and friends for information and support, they already had experience with another child and they had looked after siblings and other family members children.

*“I come from **very large** family....I always look after my brothers and sisters, so **I know** what to do with a baby”*

Group 4 mother

All but one of the Chinese women had attended antenatal classes prior to the birth of their baby. Most attended classes in English, but one woman said she attended a class provided in Cantonese. Conversely, none of the Vietnamese women interviewed had attended antenatal education prior to the birth of their baby.

The women born in the Philippines were all keen to talk about their experiences at antenatal classes. All but two women had attended classes with their first baby, however none had attended with second or subsequent babies, feeling that they had adequate experience with the first baby. The mothers also commented that once you have a baby, ‘you don’t have much time to attend classes’ which you have already attended once before. The women felt antenatal classes were a good idea, and said they would recommend them to any women they knew who was pregnant. They commented that men were becoming more involved in pregnancy issues in Philippine culture and some of their husbands had been at the delivery of their children. This was quite a change from previously where birthing had been seen as purely ‘women’s business’.

The Pacific Island women who participated in the focus groups were asked whether they had attended antenatal classes prior to the birth of their babies. None of the women in this group had attended antenatal classes; however all had previously had at least one child. The women were asked the reasons why they did not attend classes prior to the birth of the infant. Most said they relied on others to give them information. Two women commented at length:

*“We see pregnancy as a **normal part of living**, so we don’t see the doctor unless we are sick or have a problem. Then we go to the hospital when we need to. Many of the younger women are now going to the doctor throughout their pregnancy, but for us older ones **we know what to do**. Sometimes the classes give **scary information we might not want to know!**”*

Group 8 mother

*“We now have an child and family nurse who sees us women (sic) from the Pacific Islands, **this is very helpful**, so we know now there are sometimes risks in pregnancy and we should go to the doctor early.*

Group 8 mother

(iv) Literature & media

Only three of the GPs commented that parents were influenced by literature in relation to infant care. The nurse participants were asked whether there were any books or printed material they had ever given families or routinely provided for new parents. All nurses answered this question and a variety of responses were given. Each nurse seemed to have a favourite publication or handout they used for new parents. These included: ‘Baby Love’ by Robyn Barker, ‘Toddler Taming’ by Christopher Green, brochures on solids, settling, postnatal depression and breastfeeding, publications by the Nursing Mothers Association, Tresillian, Karitane and NSW Health. Five nurses mentioned the SIDS brochure produced by SIDS and Kids NSW, and eight nurses mentioned culturally specific publications for women from CALD backgrounds. There were many comments about the poor quality of translated information relating to a number of topics. Some nurses raised the poor literacy rates in CALD women in their own language as a barrier to receipt of information.

*“There are many **really** good publications for new families, the unfortunate thing is that most don’t get translated due to cost, and the wide variety of languages they would have to be translated into”*

Part time nurse

“In my experience many migrants don’t read books or magazines the way Australian women do. We provide a 34 page foolscap booklet in a range of languages, but many women don’t read well in their own language anyway”

Child and Family health nurse

The majority of nurses remembered referring to books to assist them with their own families and infant care, although most could not remember the names of the books they used. Those who could remember listed ‘Dr Spock’s Child Care’ and ‘Our Babies’ produced by NSW Health. As nurses, many referred to the notes provided in their nursing and mothercraft training.

Almost all parents interviewed referred to books and magazines for information during their pregnancy and recently for infant care. The most popular included: 'Kid Wrangling' and 'Up the Duff' by Kaz Cooke, 'Baby Love' by Robin Barker, and 'Babywise' by Ezzol Buckner. Parents also commented that they read lots of pamphlets produced by companies such as Johnson and Johnson and Milton, and others produced by NSW Health, Karitane and Tresillian.

“It is good to read books and magazines about caring for your baby. There are lots of magazines now, that give good information, there are lots of ads though... and they are quite expensive”

First time mother

Seven women from a CALD background said they had referred to pamphlets in their own language relating to infant care, although many could read English sufficiently to refer to publications printed in English.

The majority of the Chinese women (4) said that they learned most of their infant care information from ante-natal classes and information gained in books, brochures and pamphlets provided by health clinics, GPs and chemists. Women again commented on the wide range of information available in the Chinese language.

“I find lots of information on looking after my baby in Chinese. When I can't find it I ask and usually there is a brochure in Chinese I can read”.

Group 5 mother

(v) Culture

Many nurses interviewed raised the difficulties encountered by women from a CALD background when pregnant and caring for a new baby. Although many nurses believed that family and friends were the major influence on CALD parents, others raised the isolation these women felt where their support systems were poor or non-existent. Early childhood nurses said:

“There is a perception that the women from other cultures have large families and have lots of support, because they have lots of children, but that is not necessarily the case. Many of them are here on their own, and are really isolated”

Part time midwife

*“What happens is that the family pay for mother or mother in law to come out from overseas and assist while the baby is really young. She brings all her ideas and expertise with her and because they have paid to bring her out they **have** to listen to her....**she is the expert**....even if what she says is not what the professionals here say”*

Paediatric nurse

Six of the nurses who participated and had children were themselves born overseas. The nurses who came from non-English speaking countries spoke of the difficulties assimilating into a new country with little parental support. Nurses commented on the difficulties they faced when their mothers came to visit from overseas.

*“Mum couldn’t understand why I did things the way I did. There was a bit of **tension** around caring for my first baby”*

“There were definitely cultural differences between what I was shown to do here and what my mother wanted to do. It made me really worked up about doing things ‘right’ and trying to be perfect”

In addition to the social differences associated with being a parent in a new country, women from a CALD background were keen to express some of the feelings they had experienced since becoming mothers. Many women spoke about feeling isolated as a new mother in a different country. This isolation was not just from family and friends, but from the familiarity of their country and the services they were used to. Almost all CALD

women spoke of the difficulties negotiating the NSW Health system, and of the differences between hospitals and services located in different geographical areas. Many were not familiar with the services available, such as antenatal classes, or mothers groups. Others preferred not to go to groups unless they were specifically for women from their language group, feeling embarrassed that they would not fit in.

“It is hard for me, even though I speak fairly good English, when people talk quickly, it is sometimes hard for me to understand and I feel embarrassed to ask many times to repeat”

Indian born mother

“Many of these women know each other already, and I don’t know anyone so I am too shy to go on my own”

African born mother

Some women raised differences in cultural practices of infant care between their homeland and Australia and commented on the difficulties this raised for them. Many of the cultural differences women experienced related to childbirth and the birthing process, the structure of the NSW Health system and the differences in caring for infants. With regard to childbirth, many women spoke of the way they were treated in hospital, and the ‘medicalisation’ of their pregnancy and birth. One woman commented:

*“In my culture hospitals are **only for those who are sick**.....**people go to hospitals to die**, so when you have to go to hospital to have a baby.....it is a scary thing. Something inside you says having a baby is natural why do I need to be in a hospital?”*

New Zealand born (Maori) mother

Australian women in the focus groups were asked whether they had ever experienced any cultural issues raising their babies, and in this group this question related primarily to partners or family who may have been born overseas. Four women said they had

experienced difficulties with mothers in law, all of whom felt they were ‘doing things wrong’. One woman commented:

*“I knew I had to maintain the relationship, but **I stood my ground**, I just said, ” **this is the way the nurses tell us to do things now Nonna**”. It was about wrapping my baby up tightly, she told me the baby couldn’t breathe....”*

Group 2 mother

This led to a lengthy discussion in one Australian born focus group about the difficulties with in laws and family members. The women in this group all agreed that this was not a phenomenon that related specifically to cultural groups, but was more a generational issue between mothers and daughters or daughters in law. One woman explained:

*“My mother just thinks that because she had **six kids she knows it all**, and I have to let her think she does....but **I do things my way** when she is not there”*

Group 2 mother

Most of the women in the Australian born focus group commented that at some point they had experienced conflict with either a mother, mother in law or sister over the way they were caring for their infants. The main areas of conflict were around: use of dummies, food, breast and bottle feeding, picking up a baby regularly and letting a baby cry. Only one woman out of all the Australian born women focus group participants mentioned conflict over sleeping position.

Arabic women were asked whether they had any specific cultural practices differing from those in Australia, and if so whether this had been an issue for them. All women agreed that in Lebanon the role of giving birth and raising children is women’s business, where as here men are expected to be more involved. Three Muslim women commented that it was difficult for them in hospital to ensure they were ‘covered appropriately’ (with their traditional clothing) according to their beliefs, as there were men visiting other women in the ward, and this caused embarrassment sometimes. The women explained that home

birth with a midwife in attendance is more usual in their country than giving birth in a hospital.

Similar to the Arabic speaking women, the Chinese and Vietnamese women commented that pregnancy and childbirth is ‘women’s business’ and the involvement of men in this process is usually minimal. The Vietnamese women said they had many cultural traditions associated with birth and caring for an infant. Similarly to other cultural groups, the Vietnamese women stressed that in their culture ‘birthing and babies’ are ‘women’s business’. The women commented that men are not routinely involved with issues to do with pregnancy or childbirth, and women do not feel comfortable with men in the delivery room. Many of the women said they also felt uncomfortable in hospital when their English skills are limited.

*“My family brought traditional food for me in hospital, because **the hospital food was not nice**, but the nurses did not want me to eat my food.....because of the baby”*
(translated)

Filipino women also commented about the importance of pregnancy and infant care as ‘women’s business’. They commented that men were becoming more involved in pregnancy issues in Filipino culture and some of their husbands had been at the delivery of their children. This was quite a change from previously when birthing had been seen as purely ‘women’s business’. Many of the women in this group had been in Australia quite a long time, and spoke very good English. Observation suggested they were well educated and were well versed in the services available for pregnant women and new mothers. When asked about cultural issues impacting on their infant care practice, they struggled to think of these. Some said in the Philippines they ‘had more help’ from paid helpers and child carers, but there other than sometimes feeling isolated because they were not in their home country, the women felt things were very similar in both countries.

“We do things pretty much the same here. I used to have ‘help’ in my country but I manage well here. I have a lady who helps me clean so I can organize the children better”

Group 7 mother

When the Pacific Island women were asked what they felt was the biggest influence on how they cared for babies, they women all agreed it was their cultural influences. Traditions and rituals formed a large part of infant care in this community. The women commented that the way they cared for infants was ‘in them’, and it was an intuitive feeling that was helped by other extended family members and friends. The women said that they sometimes felt scared by the process of birth, until they had their first baby, but because life and rebirth is seen as such a part of Pacific Island life (including Maori traditions), it is a great joy to have a baby and care for it. Many women spoke of the conflict they feel in current society, particularly in relation to disciplining their children. Pacific Island children are used to harsh disciplinary methods, and this is sometimes seen as ‘child abuse’ in today’s child focused society. Other women with older children spoke of the conflict children experience growing up as the ‘generation between cultures’.

“My older children do not want anything to do with Maori culture, they want to be Westernised, but they cannot escape it...it is part of their being, and one day they will embrace it I am sure, for the moment.....it causes them heartache”

Group 8 mother

The women went on to discuss the changes in infant care and how they were caught between Western and Pacific cultures. The women commented on the relaxed approach they have to life and to pregnancy, and this conflicts with the workers beliefs that pregnancy should be monitored carefully.

*“We know we should seek medical help early, but we are **well and healthy**, so it does not seem necessary. There are **few** services that cater for us specifically, except the **PI (Pacific Island) workers**, and we do have a **more relaxed** approach....this (approach) is hard for many (workers) to accept”*

Group 8 mother

Most women felt the major influences on the way they cared for infants apart from their culture was firstly, religion and secondly, health professional workers.

(vi) Tradition

Three GPs highlighted the importance of tradition as an influence on new parents. Many nurses were keen to describe cultural traditions they had been confronted with whilst caring for women from CALD backgrounds. Some discussed rituals specific to certain cultures, such as keeping the placenta to take home and bury, and the mother not washing for two weeks after the birth of the baby. Others discussed practices they had witnessed, such as a father bringing a hot water bottle into the hospital nursery to put in the baby’s cot to ‘keep them warm’ and mothers refusing to drink cold water after the baby’s birth.

Nurses who were born overseas commented on cultural traditions that had affected them personally and others they had seen. Many commented on the conflict between cultures experienced by women from CALD backgrounds, and the insensitivity of many English speaking nurses when it came to patients practicing traditional beliefs.

It is quite usual for an Asian woman to refuse cold water after giving birth, but many nurses become quite irritated and try to make them drink. This also happens with showers, they are happy to have a wash, just not a shower”

Chinese born nurse

Some nurses discussed the conflict they had experienced with family members over differences in practice. One nurse explained an altercation between her and a grandmother, as she (the nurse) tried to stop the grandmother wrapping the baby in multiple blankets in the hospital.

*“She (the grandmother) couldn’t understand that the baby would get overheated. There were **three** bunny rugs around this poor little newborn, you could hardly see his face. I had to stand my ground and say ‘**NO**’ he will get too hot. She was very angry with me though”*

Paediatric nurse

Seven nurses commented on the possibility of parents using ‘home remedies’ or ‘natural’ and ‘traditional’ substances to help babies when they are unwell. One nurse discussed a situation she had encountered with a Pacific Island mother who was feeding her child with a herbal remedy. The nurse explained the difficulty she faced in not knowing what was in the mixture and whether it was harmful to the child. Another nurse raised the issue of Asian infants being given ‘teething powders’ that were imported from overseas, and were subsequently found to contain high levels of mercury.

Some Arabic women in each focus group spoke of the tradition of burying the baby’s placenta after birth, which is a religious tradition for them. Two women said taking the placenta home to bury had been facilitated for them through the hospital where they had delivered their baby. For others this had not been possible.

One Arabic woman commented:

*“I would **like to** have done this (take home the baby’s placenta), but I did not know I could ask, and I **felt nervous**”*

Group 4 mother

Many of the Chinese women spoke about following traditional Chinese customs and eating traditional foods during pregnancy and when the child is an infant. These include eating hot foods to keep the mother warm and staying indoors with the baby for one month following delivery. Most women said they breastfed their infants, however some women commented that many women who returned to work soon after the baby's birth would change to bottle feeding as it is more convenient.

The Pacific Island women commented on the cultural issues they experienced in Australia while caring for their infants. All made it quite clear that there were different cultural traditions for each Pacific Island country, and not all were the same. Most commented on the use of the 'fofo' or 'traditional healer', but many women said using a traditional healer is not done by all women. The women spoke about traditional herbs that are used to help babies with colic or who have a cold. The women 'elders' in the community often grow the herbs, and these elders have the knowledge to prepare them in special ways to help a sick infant. Most women knew where they could go to get traditional herbs and medicines in their local community. All women said they relied on extended family for help and support when they had a newborn baby, and as the baby grows. Some women commented on the loneliness and isolation they feel having a baby in a country other than their homeland. Two Pacific Island women specifically spoke of the 'sadness' they felt, being away from their homeland and families around the time of having a baby. While one spoke of the sadness at being away from family, the other commented specifically on missing nature, surroundings and the relaxed life of her homeland.

“I feel very sad that I do not have my mother here with me...in my country it is good to share feelings and experiences with your mother and sisters”

Group 8 mother

*“I miss the spirit of my country.....the peace and quiet and the beautiful nature and this makes me relaxed and happy.....to be near the ocean and to live life in a traditional way. But I am here now and these memories sometimes **make me sad** when I have a baby”*

Group 8 mother

The women explained that sometimes the ways they care for their infants is ‘frowned upon’ by Palagi (white) society, and the health professionals do not always understand the reasons for the cultural practices. The following statement highlights the cultural conflict between mother and professional in terms of ‘what is best for the baby’.

*“We have **many** members of my family living in my house, and we all take turns to look after the babies, so sometimes my boy sleeps with others.....this is **frowned upon** by the nurses and we are told this is bad for the baby. **We think this is good for the baby** because it is being loved and cared for”*

Group 8 mother

Two women from Pacific Island backgrounds commented on the practice of sharing a bed with their infants, and how this was common practice in their culture. Each reported being advised by the early childhood nurse not to do this, but still feeling intuitively that putting infants alone in a cot was not the best for the child. Both women spoke about the conflict that differences in cultural practice creates within the family structure, particularly where extended family are used to caring for infants.

“My sisters all raised lots of children...they are older now.....and they all slept in the same bed as them. If I tell my older sisters not to sleep my baby that way, they say “hey what do you know?”it’s a respect thing....you know....., I can’t tell them what to do”

Pacific Island born mother

Some women spoke of special herbs and medicines they give their infants when they are sick, and how they consult older women about these mixtures. One woman from a Macedonian background spoke of the special properties of ‘holy water’ and other medicines made up by traditional healers. Although women knew about these practices, not all used them, with many commenting on the ‘old’ versus the ‘new’ ways.

“For our mothers, there were lots of rituals and medicines they used, and the healers were often consulted if the baby was sick. But now we see the GP, and use Western medicine. We are more educated and know there needs to be evidence for what we do”

Czechoslovakian born mother

(vii) Previous experience & personal preference

Many of the GPs commented that parents were influenced by previous experience, and indeed some of the mothers commented that they worked out what was right for them and used their intuition and experience caring for siblings and other children. As one Filipino mother said:

“You have a baby once...it is the same next time !”

Group 7 mother

All of the women in the Australian focus groups agreed that they sometimes asked friends with babies for advice, but most commented that they didn't always follow this advice. Following a lengthy discussion, women in this group felt that most of them get advice from a variety of sources and then follow their instinct about what works best for them personally. One woman commented, and the others in the group agreed:

“One you have had one (baby)...intuition takes over, you just seem to know what to do and what works best”

Group 2 mother

Two Chinese women said they already had experience looking after babies in their family and looking after siblings. These women also commented that they spoke to friends in addition to seeking written information.

(viii) Socio-economic status

Participants in both the health professional and parent groups commented on the impact socio-economic status had on raising an infant. Parents raised the issues of increased pressure to "buy, buy, buy" and the pressure they feel from magazines, television, the Internet and the widespread increase of consumerism. One woman commented:

"I went to the mothers group at the clinic. But some of the mothers had really expensive stuff (sic), like prams, and baby clothes...most of my baby's things are second hand, so I felt a bit 'out of it'. I didn't go back"

Young mother

All nurses commented on the change to products such as cloth nappies, packaged foods, larger choice in clothing, prams, cots, toys and other baby products. Many felt that life was simpler for their mothers and mentioned the 'pressure' of modern living:

*"There was **much less pressure** then. Now there is a **lot of pressure** to 'have a nice house', have the 'right type of cot, pram, clothes,' and so on. Most women have to go back to work to be able to afford to provide the basics. But hey **lets face it**...the basics are **way beyond** what my mother would have called the basics!"*

Child and Family health nurse

Women from all cultural backgrounds commented that they used second hand clothes and blankets passed on from friends and family, and others then went on to describe other items that were passed down, such as prams, cots and change tables.

Women from a CALD background, were generally happy to be living in Australia, and commented on the easy availability of children's clothes, and the reasonable cost of these. One woman commented on the availability of cheap children's clothes and toys, and the ability for most people to be able to afford these. Another said she felt 'lucky' to be in Australia, and enjoyed being able to bring up a child here, all other mothers in the group agreed.

(ix) Society

All participants commented in the changes to society and how these had had a major influence on raising an infant. Older nurses, parents and grandparents commented at length on the changing expectations of parents, and how these had impacted on family structure and infant care practices. One nurse mentioned the impact of 'credit', and how this has had an effect on society.

*“The expectations were not as great then, you only had what you could afford. They all used cloth nappies, and they **made do**. Everybody knitted and made the baby clothes, and there was a sense of achievement in doing that. There was no credit or easy money, everyone saved for the things they wanted, and I think they appreciated things more”.*

Registered nurse

*“My mother didn’t work until I went to high school. She was **always** there when I got home from school, and I always had a ‘**home made**’ school lunch. I felt **very guilty** for working when my children were little”.*

Part time midwife

Nurses commented on how things had changed in society since they were children. They spoke about the increase in pressure, the lack of time and the constant 'rush' to do all the things around raising and supporting a family.

*My style of parenting is much more relaxed than that of my Mum...she always had to have everything ‘spick and span’, and she made do.....I feel there is **more pressure now** to buy the right things, make sure my baby keeps up with developmental milestones and has all the right toys and such.....but she (my mother) also had **much less support** from my Dad, she had to do things herself.....”*

Second time mother

*“We know so much more now about good nutrition, but we use convenience foods and snack foods.....we are all **pushed for time** so I think generally there is more use of canned and pre-packaged food and they are not really good for children”*

Working mother

*“Family and quality time is important, but there is a lot of guilt associated with going back to work, and **a lot of pressure** to go back to work. There used to be more time (to spend) with your children and do things like toilet train them.....now it all has to be done **in a rush**.*

Second time mother

4.4 RESEARCH QUESTION 3

Is there inconsistency between knowledge and practice concerning ways to safely care for infants?

One of the largest contributors to inconsistency in practice around infant care has been the extraordinary amount of change to practice and recommendations for nursing and infant care over time. Changes include: i) changes to knowledge about SIDS, ii) changes to nursing practise, iii) changes to medical practise, iv) societal change, v) changes to infant care practice, vi) changes since the 1940's and 1950's.

(i) Changes to knowledge around SIDS

Around one third (17/52) of the nurses commented on the increased knowledge of SIDS by parents and health professionals. One nurse felt that many doctors were not up to date with current recommendations, saying a local GP had told a mother to sleep the baby on the side to prevent a flattened head. Others commented about the way mothers went to extremes to monitor their children, using baby monitors and sleeping them next to the bed. Two nurses commented about their own feelings in relation to changes to practice to prevent SIDS.

*“I did some of my training for ‘middy’(midwifery) in a hospital, and I will **never forget** the little old midwife that taught me how to position babies on their tummy and side. Her teachings I will never forget. They were so plausible and sensible”*

Part time midwife

*“I **still** feel some conflict with the new guidelines and what we did before. I **know** the SIDS incidence has declined, but part of me says we didn't do that. Still I have to be loyal to the guidelines....”*

Nurses and parents commented on practices that have altered as a result of increased knowledge around SIDS.

“I used to sometimes take my baby into bed with me and feed him, my mother would never have done that....there was this unspoken rule that you never got into bed with your parents”

Paediatric nurse

“Mum used to put us out in the sun for a ‘sun bath’, you would be shot now for doing that ! They believed in ventilation more too, you know, lots of fresh air and making sure the windows were open”.

Part time midwife

(ii) Changes to nursing practice

The nurses were eager to comment on the changes to practice over time, and to discuss some of their observations of new mothers and the issues that affect them on a day to day basis. There have been many changes to nursing and hospital delivered systems of care in the time the nurses since the nurses completed their training. The following comments highlight the variety of changes that have occurred in nursing practise over the last 50 years.

“There are lots of things we don’t do anymore. We don’t routinely circumcise boys, we don’t put metho on the cord....things have changed a lot”

Registered nurse

*“We used to have really rigid visiting hours, to make sure the mums got enough rest, now anyone can come in pretty well anytime. We used to have to take all the flowers out at night, and we kept first time mums in sometimes a week. Now they are discharged **before their milk has even come in!** Bathing used to be a ritual, now you are lucky if you get a demonstration of how to bath a baby. There are disadvantages to going home early.....it can't be good for them. We are in such a hurry to move everybody through”*

Part time midwife

“We used to suck babies out and put them on their side or tummy to drain the mucus. We used to give babies glucose for the first few days and I think this made them ‘mucousy.’ We also used to tilt the cot so their heads were down and the mucous ran out. We recommended 4 hourly feeds, with 10 minutes on each breast....it was fairly rigid. We weren't allowed to give dummies either...any nurse caught giving a baby a dummy was instantly dismissed !”

Retired midwife

*There have been lots of changes to midwifery. We used to leave the babies with the mother in the daytime and collect them all at night. The way the training is carried out is very different too, now they take midwives by direct entry so you don't have to be a nurse first. There has been a huge effect because technology has improved so much. It is hard to keep up to date with all the new equipment. The nurses and midwives who trained in the ‘old way’ **do** see things very differently from the newer graduate nurses who trained through the universities. **I think** we (the older nurses) are more practical and patient focused”*

Full time midwife

“We used to see a high number of teenage pregnancies, you don’t see that so much now, the mothers are getting older all the time. I think years ago the women relied on what the clinic sisters said more. Now they go and ask lots of questions, read a magazine and look up the Internet and then make up their own mind”

Part time child and family health nurse

(iii) Changes to medical practice

Some nurses commented on the changes to medical care:

*“There have been **huge changes** in immunization. I can remember my mother being **mortified** that I would give a little baby so many needles, but **I stood my ground**. Back then, they just dealt with the diseases that we brought home from school”.*

Child and Family health nurse

*“I can remember my mother being annoyed that I put my baby on her tummy to sleep. She told me she **should be on her side or back**. It is interesting that things have gone full circle isn’t it.....with regards to SIDS ?”*

Part time midwife

(iv) Societal change

All nurses raised issues of infant care that had changed markedly over time. The most common response was in relation to sleeping position and SIDS prevention. Other practices that had changed included the decreasing use of cloth nappies, increased rates of breastfeeding, more involvement of fathers in birth and infant care, increased reliance on childcare facilities and changes to feeding and daily routines. One nurse commented on the flexibility mothers have to have due to work and outside home commitments. However babies are also expected to be flexible. One retired midwife commented she was aghast that women take new babies ‘to the shops’ and ‘out to dinner’, stating that in

her day, “you (the parents) worked your life around the baby’s routine, and now the baby works its routine around you (the parents)”.

The nurses made comments relating to many other things they had noticed change over time. These included an increase in the number of children experiencing allergies, particularly to peanuts, more children drinking juice and soft drink, a reduction in the amount of water children drink, an increase in obese children, a decrease in family size leading to more and more children with no siblings and a decrease in children participating in imaginative play. Six nurses noted that many mothers do not know how to play creatively with their children, and instead use television and computers to distract children. Two nurses mentioned the lack of ‘outdoor time’ many children are exposed to, instead spending time with parents in shopping malls and restaurants. Many talked about the feelings of guilt associated with being a ‘working mother’. The pressure to be a ‘perfect mum’ and ‘do everything right’ was also raised by many of the nurses, who also commented on the high expectations around being a mother in the 21st Century. Some nurses commented on the societal pressure on them to provide their babies with ‘the best’ clothes, equipment and toys, and for their families to have ‘a nice house’ with all the ‘right’ furnishings. These pressures often have a negative impact on family relationships and are often associated with family breakdown. One nurse commented about this at length:

*“I think in my mothers day they were **poorer materially**, and they probably didn’t know as much about infant care and the reasons why they did things (they just knew they worked), but I think overall they were **much happier**. There was **more time to play** and to interact with siblings. We used to have **great fun** making up games with cardboard boxes. We had lots of **imaginative play**. We were really **creative too**.....I learned to knit when I was five years old. **Can you imagine teaching a five year old to knit now?** They want to play the computer not knit !!*

*I think families in my mother's day were **emotionally richer**, and they certainly had more time. It is ironic, that these labour saving devices have only served to give us **more time to rush around**".*

Paediatric nurse

Three nurses commented on the advancing age of the nursing workforce and the decreasing numbers of nurses. One nurse commented that almost all early childhood health nurses were 'over 40' because they could work part time and the work was not nearly as strenuous as ward based nursing. Another commented that early childhood nursing was a 'wonderful career' and many nurses who got a position in the area stayed there until they retired. All the nurses who responded to the questionnaire were genuinely keen to talk about their experiences and provide honest and heartfelt responses to the questions asked.

Grandmothers commented on the differences to child care from their day, and highlighted the changes to clothing, equipment and foods that children eat:

*"When my daughter was little I didn't work, I was quite house proud and spent most of my day cleaning and cooking. I used to do lots of 'fancywork' and sew my children little outfits. Everything now is so cheap, you can buy beautiful clothes for children at reasonable price...**why would you bother** doing anything else?"*

Grandmother carer

*"There are so many cute little toys, and educational ones too, we relied on books for our children, although there are some **wonderful books** around now too"*

Grandmother carer

*"I think one of the biggest changes has been to foods. Almost **anything you want** now comes in a can or bottle or package. I used to mash all my baby's food through a 'mouli mix', it was a sort of grinder, and everything was fresh. I prepared it all as he ate it, and added a little butter and milk. **No chemicals or preservatives in that !!**"*

Grandmother carer

Some grandmothers thought the lifestyles of their children were more difficult than they experienced and on the reasons for this:

*“I had more children, but **I seemed to have more time**. My children are **always rushing** to somewhere or another. They are always at the shops, we only used to go to the shops once a week to buy our food, but **it’s different now**, shopping is much more a social occasion”*

Grandmother carer

*“I wouldn’t like to be trying to buy a house now...the prices are **terrible** and the **pressures are great**. In our day things were tight, but there were only so many things you could buy. We had lots of old stuff handed down from our parents. Now you can buy **anything** you want, and everything has to be new and shiny...**they don’t like the old stuff anymore!!**”*

Grandmother carer

The two grandmothers who were born overseas commented that things were very different for their children than they were for them. Both commented on the changes to hospitals and medical services for childbirth. One woman born in Italy talked about her extended family and the importance of everyone being involved in the child’s care. She lamented the fact that this was not the case for her daughter as she worked and did not have as much time for family gatherings as her mother did. This woman saw her grandparent caring role for the infant as a responsibility to her daughter, saying “*One day my daughter will care for me*”.

(v) Changes to infant care practice

There were many key differences in infant care practice raised by the nurses.

“I think one of the main differences was in the way they approached a baby. My mum told me ‘never to pick up a crying baby’. They didn’t check on the baby’s comfort as much as we did. I carried my baby around during the day....my mother was horrified. I can remember my father being really annoyed that I put the baby first.”

Part time paediatric nurse

“I think we are more nurturing, we have closer contact with our children, more of them are breastfed and we have more interaction. I think it is because back then there were bigger families. Our mothers were spreading themselves thinly between lots of kids.

Full time midwife

“My mother was ruled by the clock ‘4 hourly feeds’, sleep, feed, sleep, feed. I was much more flexible. They were happy to supplement feed or use formula, I think we feel much more guilty about doing that now.

Part time child and family health nurse

Interviews with nurses and midwives highlighted a recent practise now regularly used by many parents. This practice involves covering the front of a baby’s pram or stroller with a blanket, often pegging the blanket tightly around the pram, and appears to have become more prevalent since the introduction of the Cancer Council’s Position Statement for Sun Protection in Infants (Cancer Council of Australia, 2005). Of concern, were comments by the nurses and midwives that parents use blankets to cover prams even when there is no evidence of sun likely to burn their infants, including while shopping and indoors. In an attempt to elicit any other reasons for the use of blankets over the front of prams and strollers, all parents were asked whether they used this practice, and if so the reasons why.

Of the 92 parents interviewed, the majority (80) said they had ever used a muslin wrap or blanket to cover their infant's prams and strollers. The reasons for this practice were varied and were not limited to preventing sun from burning the baby's skin. In addition to protecting the baby from the sun and wind, women listed a range of reasons for using blankets over a pram or stroller. The most common reason for using a blanket to cover the pram when indoors or shopping was to help the baby sleep, to prevent people 'touching' the baby, to reduce stimulation and keep the baby asleep and to prevent objects touching or injuring the baby. One woman told of a friend's experience while out with her baby in a stroller.

"My friend was shopping when someone flicked hot cigarette ash... it burned her baby's hand.....sure, it was accidental but it happened"

First time mother

Another mother commented on the height of rails and baskets holding products in supermarkets and shopping centres. The mother explained if she put a muslin wrap over the baby's pram and a rail or basket stuck out towards the baby, the wrap would be caught first alerting her to the possibility of something sharp projecting near the baby.

The parents listed a range of products used to cover prams. Many said they used muslin wraps as advised by the Cancer Council. These wraps are a fine, light cotton weave and allow air to circulate through the fibres. Others used commercially available nets and purpose built pram covers made of black mesh, allowing air to circulate around the baby's head. Around one third of the parents (26) said they routinely used a blanket or bunny rug to cover the pram. Many of these parents believed that the thicker blanket protected the baby from noise, enabling them to sleep more easily, and 'kept them warm' when the weather is cooler.

One interesting point raised by seven of the participants was the change in pram and stroller design over time. Many commented that the new strollers faced away from the mother allowing people to come up close and touch the baby, a practice parents found very worrying. Others commented that strollers facing away from the parents meant they

could not see what the infant was doing, and exposed the baby to getting grit particles in the eyes when conditions were windy. Nurses raised the issue that many women cover their babies in prams for other reasons, and that this needed to be investigated further.

Comments included:

*“I know the light wraps are to prevent the sun but they also stop the fresh air and any stimulation the baby should have. I am not sure why mothers do this indoors.....
in shopping centres”*

Retired midwife

“Many parents peg blankets around the pram. I think they do it to settle them, and make the baby sleep. The Chinese do it especially...”

Part time child and family health nurse e

“Parents cover babies with a blanket over the pram. You never used to see that before. My pram had moveable handles so you could face the baby toward you and watch them, most prams go the other way now”

Paediatric nurse

Many women raised the changes to feeding practice since the days when their mothers had children, and commented on the increased likelihood of women today breastfeeding their infants. Many women commented on their mother’s use of formula and supplements including carnation and condensed milk, and how frowned upon this practice would be now.

*“I was **horrified** when my mother told me she fed us on condensed milk when her milk ran out. **No wonder we all had tooth decay !!!”***

*“I am quite comfortable (breast) feeding my baby in public. I am reserved and make sure I am covered up and everything, but it doesn’t bother me ...my mother on the other hand is still quite uncomfortable with this, it **certainly** wouldn’t have been done in her day”*

Second time mother

Mothers — CHOCOLATE IS
food



★ Yes . . . pure chocolate is good for growing children. It provides in a compact, inexpensive form essential body-building proteins and carbohydrates. Good chocolate is rich in iron. . . . It provides phosphates and calcium for building good teeth, bone and muscle. Chocolate is quickly assimilated in the blood stream and is easily digested. Medical men have proved good chocolate supplies vitamins A, B, C, D and E. MacRobertson's Chocolate is prepared under the most hygienic conditions. Its delicious flavour and smooth texture is unequalled. Ask for it at any confectioners.

MacRobertson's

MAKERS OF *Quality* CHOCOLATE

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FIGURE 11: *Advertisement from 'Our Babies', 1942, (p 62) promoting the value of 'Chocolate as Food' for babies.*

Many parents also raised their parents' opposition to dummies, and commented on conflicts arising because they (the new parents) had decided to use a dummy:

*"I don't think there is **anything** wrong with a dummy, my mother on the other hand was **really** against us using it, she quoted all the facts about flies and germs and increased gastroenteritis because of dummies. As long as you keep it clean I think it is OK".*

First time father

THE DANGEROUS DUMMY

THE DANGEROUS DUMMY

THE DUMMY IS UNNECESSARY AND DANGEROUS. No properly nourished, wisely-managed baby needs a dummy. If he did, nature would have provided him with something to suck continually.

It is practically impossible to keep this unnecessary and objectionable article clean. It is rarely cleansed even once a day, and it is usually attached by a ribbon to the baby's frock, where it is constantly exposed to dust and flies.

Frequently, the "dummy" is carried in the mother's handbag—perhaps rolled in her pocket handkerchief—and may thus become the means of conveying infection to the baby. Again, it is not an uncommon practice for the mother to moisten the "dummy" in her own mouth before placing it in that of her baby. A most unhygienic and dangerous habit.



The "dummy" is liable to become a dirt-collecting toy.

DUST AND FLIES

Though not seen with the naked eye, a germ-laden dust is continually circulating in the air and settling on every exposed article, including the moist dummy. The fly is a dangerous and most persistent enemy of the baby. He breeds in manure, excreta, garbage, or similar materials, and his body and limbs being covered with minute hairs readily become contaminated with this filth.



From the manure-heap to the baby's "dummy" is a pleasure trip for the fly.

A fly is unable to use solid food. Consequently, AS SOON AS HE ALIGHTS HE VOMITS, AND THEN WORKS THIS VOMIT INTO THE BREAD, SUGAR OR OTHER FOOD UPON WHICH HE HAS SETTLED. By this means some of the food-stuff becomes dissolved or softened, thus enabling the fly to suck up a portion thereof, leaving the remainder of the vomit on the food.

In this way, as well as by the deposition of filth from the surface of his body and legs, the germs of many diseases, such as gastro-enteritis (summer diarrhoea), typhoid fever, etc., are transferred to human beings.

Since the fly is particularly fond of sweet milk food, he is ever watchful of the "dummy" which has fallen from the baby's mouth. On this he deposits filth brought from his breeding ground as well as some of his own excreta and vomit, all laden with deadly germs. Is it any wonder that so many babies die in the fateful first year of life!



A mosquito-net over cot protects baby from flies.

The Dummy—the unsuccessful mother's confession of failure.

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FIGURE 12: Excerpt from 'Our Babies' NSW Department of Public Health 1942 (page 107)

(vi) Changes since the 1940s and 1950s

All participants were asked what they thought the biggest changes were since the 1940s and 1950s (when their mothers were raising children).

*“My mum didn’t have formal reading matter or go to classes, she **was one of eight children** so she already knew how to look after a baby, she had done it for her brothers and sisters”.*

Full time midwife

*“My mother didn’t breastfeed, and **certainly would not have done so in public !** She used carnation milk, and always told me it was a good ‘standby’ if my milk ran out. I don’t think overall they had a great deal of knowledge of infant care, they just learned from experience and other mums and if it worked they did it”*

Neonatal nurse

*“My mum tells great stories about the ‘Baby Health Sister’. She was sort of **revered, and terrifying** all at the same time. I know that for women in the country, the clinic was the **main source of information** and contact with others who had babies”.*

Paediatric nurse

*“In a way I think my mother was **more** isolated than I was. She had moved into a new suburb with poor transport, and she didn’t drive. They only had one car anyway. She used to **walk nearly three miles** to the Baby Health Clinic with us!”.*

Full time midwife

All nurses commented on the change to products such as cloth nappies, packaged foods, larger choice in clothing, prams, cots, toys and other baby products. Many felt that life was simpler for their mothers and mentioned the ‘pressure’ of modern living:

*“The expectations were not as great then, you only had what you could afford. They all used cloth nappies, and they **made do**. Everybody knitted and made the baby clothes, and there was a sense of achievement in doing that. There was no credit or easy money, everyone saved for the things they wanted, and I think they appreciated things more”.*

Registered nurse

*“My mother didn’t work until I went to high school. She was **always** there when I got home from school, and I always had a ‘**home made**’ school lunch. I felt **very guilty** for working when my children were little”.*

Part time midwife

4.5 KEY FINDINGS

There were a number of key issues raised by the participants in the study. These included the major factors participants believed impact on ‘current day’ infant care practice, including culture, educational level, socio-economic status and level of knowledge, as well as key themes participants highlighted as affecting their infant care practices. These themes included isolation, sadness at being away from family, feelings of incompetence, confusion, feelings of being under pressure and lack of time.

Major influences

Data collected during the course of this study provide a rich pool of evidence detailing the opinions and beliefs on the major influences on infant care, of three key groups of infant care providers.

It is clear from the information gained from the participants that the major influences on infant care can be divided into three key areas, described broadly as:

- Evidence-based learning / influences
- Experiential learning/ influences and
- External influences

Evidence-based learning and influences

For many, the ability to care for an infant in a way known to be safe, healthy and in accordance with current recommended guidelines is achieved through the application of knowledge gained in published texts, medical literature, health information and educational sessions (including antenatal classes or in-service training). The data collected in this study highlighted the value of evidence-based information in keeping GPs, nurses and parents up to date with current health messages and practice.

The data suggest that evidence based written and oral information is widely accessed by those with good English skills, and good literacy skills in their own language (where information is provided in other languages). This was highlighted in the GP data, where over two thirds of those who could not list any SIDS reduction strategy were born in a non-English speaking country. This tendency was reflected in the parents and carers data, with women from CALD backgrounds who did not speak English well less likely to attend antenatal classes and in nurses and midwives who commented that in their experience, women from CALD backgrounds were less likely to attend antenatal classes due to language barriers, cost and cultural reasons. The importance of providing appropriate literature in a variety of languages and formats is further outlined in the discussion section of this thesis.

Experiential learning / influences

Almost all the participants in the study mentioned the importance of experience in actually caring for an infant, and the impact this has on the way people practise infant care. This was evident in data collected from each group, with GPs commenting that even though women were given information it was nurses, friends, family and those who had actually cared for a baby who often proved more influential when it came to infant care. Interestingly, although one third of GPs had previously cared for an infant who later died

from SIDS, not all of these GPs were able to list the SIDS reduction strategies. This may be due to the many changes to recommended SIDS reduction practice over time, and the heavy caseload of GPs.

Women themselves expressed the belief that once they had already cared for a baby ‘intuition took over’ and there was no real need for them to attend antenatal classes or thoroughly investigate the process of infant care through books, and unless there had been a ‘long time’ between pregnancies, previous experience was considered adequate knowledge.

Nurses and midwives also discussed the value of experience and explained that their professional experience is the reason so many women consult them about infant care. Interestingly, although nurses were very much driven by ‘evidence based’ infant care recommendations, many still harked back to their own experiences and professional experiential learning when caring for infants. This was most evident in comments by two nurses who found it difficult to change their thinking to ‘back sleeping position’ after being trained by experienced midwives to use the tummy and side position when putting infants to sleep.

External influences

There were four obvious instances where external factors influenced infant care practice. These were most notably society, culture, religion and observation.

Society (and peer pressure) was raised as one of the strongest influences on new parents in current day Australia, particularly those who were Australian born. All categories of participants commented on the influence of media, particularly television and magazines in driving the pressure on parents upward and the pressure to ‘buy, buy, buy’. This was particularly the case with ‘Childcare Magazines’, television and the Internet.

Many of the parents interviewed spoke of the pressure of ‘having the right baby equipment, toys, clothes and accessories’, and the importance of ‘having a nice house and

living environment'. These pressures increase the need for women to work as well as men, and place more pressure on the parents as they then try to find appropriate childcare. The pressure of 'having the best of everything' did not appear to be a major factor influencing most CALD groups interviewed, probably due to their lower socio-economic status as a result of migration.

'Culture' was thought by all participant groups to have a major influence on infant care practice. Culture was believed to influence not just 'practise', but the whole process of parenting and raising a child. Religion was an external influence to a lesser degree, but still played a large part in some rituals and traditions for some cultural groups, including Vietnamese and Arabic cultures.

Nurses, and some mothers, noted observation of others' practise as an external influence on their own behaviour and practices. An example of this can be seen in the relatively recent practice of 'draping the pram with a blanket' adopted by many parents. Many nurses raised concerns about this practice, all commenting that they did not encourage mothers to do this unless they were 'out in the sun'. Women commented that they have seen other mothers use blankets and wraps on the pram, and thought this a 'good idea', to protect infants from sun, wind, prying strangers, sharp objects, and to help babies sleep in the pram. None of the parents interviewed said they had been advised to do this by any health professional.

Key themes

The key themes identified were raised by both nurses and parents, and focused primarily on the emotional effects of caring for a new infant. Sadness and isolation were clearly expressed by women from a CALD background, but were also raised as a significant issue by Australian born women who did not have close family or support networks to assist them in the early days as a parent.

Feelings of incompetence and confusion were expressed by many participants, particularly in regard to 'the right way' to care for infants. Many of the feelings of incompetence arose as a result of conflicting messages around ways of caring for an infant, and rapid changes to infant care messages over the last 10 - 15 years. Participants commented that changes to society, a reduction in family size and the subsequent decrease in skills caring for infants (as a result of fewer siblings) led to increased feelings of incompetence and insecurity when it came to caring for infants.

Pressures of day-to-day living, juggling work and family life and increasing costs of raising a family were all raised by participants as a major influence on the time parents spend on infant care.

CHAPTER 5 - DISCUSSION

*“The observer listens to nature –
the experimenter questions and forces her to reveal herself”*

Georges Cuvier 1769 – 1832 Naturalist and anthropologist

5.1 DEFINING SUDI AND SIDS IN 2008

The initial impetus for this research study was the identification of an elevated number of infant deaths classified as SIDS in specific suburbs of Western Sydney known to be home to diverse cultural communities, and the desire to explore the reasons for this. Although SIDS was a major contributor to infant deaths in the period 1960's – 1990's, there is strong research evidence to suggest that the 'Reduce The Risks' campaign of the early 1990's has significantly reduced the number of infant deaths due to SIDS not just in Australia, but around the world (Dwyer and Ponsonby, 1996; Hiley and Morley, 1994).

Just prior to the commencement of the preliminary work for this study, the NSW Commission for Children and Young People established the Child Death Review Team. This reference group consists of experts and child health professionals who review all infant deaths in NSW. Its establishment has meant that many of the deaths previously attributed to SIDS have subsequently been identified as a result of other causes, including child abuse and misadventure. The Child Death Review Team now classifies an infant who dies unexpectedly in NSW as experiencing 'a 'SUDI' Death' (Sudden Unexpected Death in Infancy) until further review of the circumstances surrounding the death are determined. There are nonetheless, as a subset of SUDI deaths, infants who die as a result of SIDS in Western Sydney.

At the present time in NSW, there is no requirement to identify the cultural ancestry of an infant who dies, on any of the documentation associated with an infant death (Calvert, 2003). This includes the police report, coroners report, death certificate and any

associated investigation by the Child Death Review Team. As a result, it is impossible to ascertain whether there is an increased incidence of infant death (due to any cause) in a particular cultural group. Thankfully, the number of 'SUDI' deaths in NSW is small (54 in 2006 with the majority (25) due to SIDS) however recording cultural ancestry would enable researchers to examine data for trends over time. Any identified trend linked to specific cultural groups could then be the focus of education and information, or a reorientation of health service delivery (such as increased Sustained Home Visiting to vulnerable CALD mothers etc). In a ten year study investigating deaths in children and young people, the Child Death Review Team found that SUDI deaths were more likely to occur in families from a low socio-economic background, although no data on cultural ancestry was available (Child Death Review Team, 2008).

5.2 VARIATIONS IN KNOWLEDGE OF SIDS IN SWAHS

Research question one aimed to assess whether there was variation in knowledge between health professionals and parents around ways of preventing sudden and unexpected death in infants. The results of the study indicate that there is considerable variation in knowledge around prevention of sudden and unexpected deaths (including SIDS) between health professionals and parents living and working in Western Sydney. By far the most substantial difference is between the level of knowledge of SIDS prevention in GPs and that of nurses working in the area.

It is of concern, that one third of GPs who responded to the anonymous questionnaire could not detail any SIDS reduction strategy. It is also surprising that GPs admitted not knowing the current recommended guidelines, which was probably due to the anonymous nature of the questionnaire. It is interesting to note that all respondents who could not list any SIDS reduction strategy had trained prior to the introduction of the Reduce the Risks Campaign, and as an older group of GPs, may be more in need of targeted education around safe sleeping. Although the majority of GPs who participated in this study had been practicing medicine in the area for at least 2 years, with the average length of

practice 18 years, there was one third who said they had never participated in any medical or in-service training addressing SIDS reduction.

Increasingly, general practitioners in Australia are being recruited from overseas countries. In addition, many more medical trainees in Australian universities are born overseas, however the level of knowledge around key issues such as prevention of infant mortality should be standardized in all countries. While these practitioners provide an essential and valuable service to families who speak the same native language, local guidelines and health promotion campaigns may not be uppermost in their mind when speaking to clients, particularly now SIDS rates have declined. There is good evidence to suggest women from a CALD background are more likely to seek medical treatment from a practitioner who speaks their native language, accessing other health information at the same visit (Chalmers, 2006). Targeted education around SIDS reduction to overseas born GPs would ensure women with poor English skills are up to date with current recommended guidelines and strategies for SIDS reduction.

There were differences in knowledge of SIDS reduction strategies between male and female GPs. It is possible that female practitioners (as mothers) are more likely to retain knowledge around SIDS, and pass it on to new parents in the course of their practice. In the opinion of some GPs, the nurse or midwife has the main responsibility for providing safe sleeping messages to new parents. Many GPs clearly indicated their belief that new parents took more notice of health messages from the child and family health nurse than they would from a GP.

Nurses and midwives interviewed were all relatively up to date with current Safe Sleeping messages, although some did admit to practicing methods not recommended. The nurses and midwives who were currently working stated they gained knowledge about SIDS reduction strategies through ongoing clinical training, NSW Government policy and as part of their core business dealing with families. Two of the paediatric nurses commented on the 'Children's Hospital at Westmead' policy outlining the way to make up a baby's cot, and how this had improved parental compliance with infant

sleeping position while staying in the hospital. Although NSW Health has a ‘Safe Sleeping in Infants’ policy, not all nurses interviewed were familiar with the policy document.

There were differences in knowledge of safe sleeping messages in women born in Australia, and women born overseas. Women who were born in Australia and spoke good English were more likely to have accessed antenatal classes, read brochures and accessed parenting magazines than those who had migrated to Australia and did not speak English. From the focus group discussions, there did appear to be a difference in safe sleeping knowledge between women who were well educated and those who were not, although this is difficult to quantify, as levels of education and income were not collected on focus group participants. Overseas born women commented they followed traditional practise, and were more likely to access the GP for information in the early months of their infant’s life.

There are two additional factors possibly impacting on the variation in knowledge of SIDS reduction strategies and safe sleeping messages in health professionals and parents. These factors are confusion and complacency.

Confusion

It is evident from the responses of GPs and also some nurses and parents, that there remains confusion about the knowledge of SIDS reduction strategies, in spite of the intense media presence of ‘SIDS and Kids NSW’. This confusion can be linked to the rapid change in messages for SIDS reduction, promoted since 1994. Initially it was considered acceptable to place babies on the ‘back and side’ to sleep (Appendix 14), however this was altered to ‘back sleeping only’ around 1996 (Appendix 15). Early SIDS brochures promoted breastfeeding as a SIDS reduction strategy (Appendix 16), and although breastfeeding is encouraged and promoted, there is no evidence to suggest it is protective for SIDS, and it is not listed on the current SIDS brochure as a preventive strategy. During the course of this study, the number of SIDS reduction messages described in the SIDS and Kids prevention brochure changed from 5 to 3, and although

the messages were not altered, the method of presentation changed substantially. The most recent publications address 'Safe Sleeping' as an overall message, rather than 'SIDS prevention', with the information promoting the positive benefits of sleeping safely; in a cot with the feet to the foot, lying on the back with no accessories in the cot, and in a non smoking environment (Appendix 17). It is this constant change of wording and presentation that has served to confuse parents and health professionals alike.

The confusion of GPs around SIDS reduction messages found in this study is consistent with the findings of studies undertaken in the USA (Moon et al., 2002). One difference between the Western Sydney study and Moon's study was the number of GPs in Western Sydney who were from a non-English speaking background and were not familiar with the latest SIDS reduction strategies. Of concern is the fact that around one third of those GPs who responded, listed a mixture of correct and incorrect messages regarding SIDS reduction, including six who listed tummy and side sleeping as preventive for SIDS. In view of the massive media campaign conducted by SIDS and Kids each year as 'Red Nose Day', and the availability of in-service training and written literature about SIDS, it is surprising that there were still GPs who were unsure about the correct sleeping position for infants, and some who were giving incorrect information.

Nurses were generally clear about the recommended sleeping position for infants, and could correctly list most of the safe sleeping messages. This is probably because they are professionally bound to follow and implement the mandated NSW Health policy on Safe Sleeping, released in 2003 and updated in 2005 (NSW Health, 2005), whereas GPs in private practice would have no such knowledge of this policy. Although all of the nurses interviewed for this study knew the risk factors for SIDS, there was still confusion around positioning and safe sleeping practices. In her study conducted in 2004, Jeffery investigated the importance of nurses as role models for new parents particularly around infant care practices (Jeffery, 2004). Whilst the majority of nurses interviewed in the Western Sydney study were conversant with the reasons for placing infants in the supine position to sleep, there were still some who admitted to placing infants on the side 'if they were snuffly' a known risk factor for SIDS. Of particular concern were the nurses

who trained in hospitals under the guidance of older trained midwives and more experienced nurses, and believed that the experience they gained and practised (in relation to prone sleeping position) was stronger than the evidence for back sleeping position. Although the two nurses who made this comment admitted they followed the recommended guidelines, it begs the question as to how many similar nurses (retired or otherwise) with this belief are still caring for infants.

There was evidence of confusion around safe sleeping practice in the parents and carers interviewed in the study. The majority of women who had attended antenatal education and spoke good English had knowledge of safe sleeping practice (including back sleeping, no smoking near baby and no accessories or toys in the cot) even if they admitted to not practicing all of these. By far the most practiced safe sleeping strategy was back sleeping. Many women however, admitted they used a combination of side and back sleeping position, and commented that these messages came from nursing staff, parents and friends, and prior knowledge. Whilst it is impossible to make everyone use the correct technique for safe sleeping, the reasons for doing so should be available to all new parents and caregivers.

Older parents and grandparents often practise the techniques they used to put their infants to sleep many years ago. If the child was born prior to 1991, parents and grandparents were more likely to use the prone position or a combination of prone and side sleeping position when putting infants to sleep. This practice highlights the need for specific education and media campaigns around safe infant sleeping for older parents and extended family members. Until people are in the situation of caring for an infant, they do not usually heed media campaigns around infant care. For this reason, aiming media campaigns at specific groups of individuals such as child-care workers, nanny's and grandparents is an effective way to spread the safe sleeping message and influence key infant care providers.

Complacency

General Practitioners are increasingly required to attain knowledge and skills in the broad practice of medicine. Keeping up to date with current medical practices and guidelines is time consuming and often repetitive; factors leading to reluctance to attend medical updates and seminars. Risk reduction and prevention of SIDS has been on the medical agenda since the introduction of the Reduce the Risks campaign in 1991. The longevity and familiarity with the SIDS campaign, coupled with the reduction in the total number of SIDS deaths annually has the potential to lead to complacency in GP practices around SIDS education for new parents.

Although one third of GPs who responded to this survey had cared for a baby who later died from SIDS, many of these practitioners could not list the SIDS reduction strategies. The reduction in SIDS numbers since 1991 is a possible reason for GP's failure to consider knowing the SIDS reduction messages a priority. It is also possible that the increased service provision to new families through the NSW Health Child and Family Health Service has led to complacency around infant care on the part of GPs, believing that these families are already well catered for by NSW Health Child and Family Health Services.

5.3 FACTORS INFLUENCING INFANT CARE

Research question two sought to identify the major factors influencing health professionals and parents in the way they care for infants. The participants in the study identified nine key factors they believed influenced infant care practice. These were; family and friends; health professionals; literature & media; antenatal education & educational level; culture; tradition; experience & personal preference; socio-economic status and twenty-first century society.

Family and friends

All groups of participants in the study felt that family and friends had a major influence on new parents. Parents themselves differed on this perspective depending on where they were born. Australian born parents reported visiting health professionals including GPs Child and Family Health Nurses and allied health professionals if an infant needed medical attention, whereas CALD women were quite open about seeking assistance from family and friends first, before visiting a health professional for advice or treatment. When they did visit a health professional, CALD families reported that they preferred to visit a practitioner who spoke their native language. This data is consistent with that of Chalmers et al, who studied CALD families in relation to their health care utilization preferences in relation to parenting (Chalmers, 2006). Conflict was raised as an issue for all new parents; with most commenting the conflict was usually with family members, most commonly between the mother and mother in law. Conflicts were usually around specific infant care practice including; sleeping position, smoking near a baby, feeding, dressing, comforting and settling techniques. Parents who were born in Australia tended to stand their ground, and follow the methods of infant care they thought best, however those from traditional, CALD communities were often caught in a cultural / social conflict between parents' wishes and local practice.

Health professionals

Health professionals are ideally placed to deliver health protection (including SIDS prevention) messages in the course of their day-to-day work. Each of the practitioners who participated in the study worked closely with new families and had the opportunity to provide up to date and accurate information to a range of clients on SIDS prevention.

The level of knowledge around SIDS minimization strategies in GPs was lower than anticipated prior to the commencement of the study. Interestingly, a few nurses raised their concerns about GP levels of knowledge, citing incidents where GPs had given families incorrect information regarding sleeping position. Many nurses expressed concern that parents were 'overly concerned' about protecting children from SIDS, using

monitors and special equipment designed to reduce the risks of SIDS. In the opinion of the nurses, this over concern was due to inadequate or incorrect information. Most parents interviewed had confidence in health professionals and the services they could provide. Many women spoke highly of the services of the Child and Family Health Nurses and commented that they formed a bond of trust with the nurse when they saw them a few times about caring for the new infant. There has always been a notion that the 'Clinic Sister' was an 'expert' consulted by parents so they would know 'what to do', however the more recent change to working in partnership with parents has changed the relationship between parents and the Child and Family Health Nurse in a positive way.

Literature and media

There is evidence to suggest that parents, particularly women, have relied on written material to assist them with infant care for a considerable period, and there are many examples of early publications written by 'lay experts' or medical professionals to which parents referred for advice on infant care. Nurses discussed the increased use of magazines by young parents, eager to learn new information, but 'time poor' and unable to read lengthy books as part of their day-to-day lives. Many of the nurses said that new parents were keen to read 'all they could' about having and caring for a baby. This of course only refers to the parents that the nurses care for as part of their professional role, and does not account for those women who do not access educational literature, either because it is not available, or because of poor literacy levels.

Brochures and pamphlets are an integral part of educational evidence and are an easy and non-threatening way to disseminate information broadly throughout the community. It should be remembered however that there are many women who do not access services where these brochures are provided. It was surprising to note in this study that many of the women had not seen the SIDS and Kids Safe Sleeping Brochure, and of those who had, some had not read it thoroughly. One of the key points around information is that it should be accessible and delivered in an appropriate format. One interesting result of this study was the number of GPs who reported that they did not have posters and brochures

in their surgeries. This may be a reflection of the cost of such brochures and posters, and the financial impact of having these available in a range of languages.

Educational literature does have limitations, particularly where parents are socially isolated, young, single, time poor, have poor English literacy levels or cannot access material to read as a result of inadequate transport or poor English skills. SIDS and Kids NSW produces many brochures, posters and other advertising material clearly detailing Safe Sleeping messages (Appendix 18). Brochures and posters are distributed in a rather ad hoc manner, to those who request them from the SIDS and Kids office.

Advertisements outlining Safe Sleeping messages are placed in magazines aimed at parents, such as Sydney's Child. In many hospitals, the Safe Sleeping brochure is distributed with the Personal Health Record, previously known as the 'Blue Book', although this is not the case in all hospitals, and where distributed is only in English. Many private hospitals distribute the SIDS and Kids 'Safe Sleeping Door Hanger' (Appendix 19), although again, this is not the case in public hospitals where purchasing such items is a complex and expensive process.

The results of this study indicated that just under half of the GP respondents did not have any SIDS brochures or posters in their surgery for parents to access while they waited for the doctor which is a concern. There are several possible explanations for this, including the cost of brochures and posters, and the belief that advertising and marketing of safe sleeping messages is best conducted by nurses, midwives and mass media. Although surprising, in view of the mass campaigns conducted by SIDS and Kids, these results are consistent with the study undertaken by Moon and colleagues in 2002, highlighting the low numbers of medical practitioners who provide patients with written literature about SIDS (Moon et al., 2002).

It was pleasing to note that nurses who participated in the study and who were currently working in the NSW hospital system said there were posters and brochures available through the centres or hospitals where they worked. None of the nurses interviewed gave brochures routinely to parents while they were in hospital, although making this practice

routine in all NSW hospitals would ensure all women regardless of ethnic background would receive a brochure about Safe Sleeping in infants.

Child and Family Health Nurses commented that they generally provided women with Safe Sleeping brochures at the first Universal Health Home Visit, although nurses also commented that there were lots of other ‘things to address’ at the first home visit. Many of the women who participated in the study commented that they had received a brochure on SIDS either in the baby’s Personal Health Record or from the Child and Family Health Nurse, although this was not the case with all parents.

In this study, women from a CALD background were less likely to have seen a brochure outlining Safe Sleeping messages. It is possible that women from a CALD background are disadvantaged when it comes to receiving information about Safe Sleeping. Child and Family Health nurses, who visit CALD women in the home as part of the Universal Health Home Visiting Program, usually require an interpreter to translate all the information required by the mother at this visit. Using an interpreter is a slow and time consuming process, and often only the most pertinent issues for the mother will be discussed at this visit due to time constraints. This means that there is a strong likelihood that information around SIDS will be forgotten or left until a later visit. This process is not the fault of the Child and Family Health nurse, but highlights the pressing circumstances under which nurses’ work when visiting families in their homes.

Many women spoke of the influence of television and the Internet on their lives. While most parents were not dependent on media for detailed information, they did imply that these technologies now consume much more of their time than previously, and they were a ready source of information when one ‘needed to know something quickly’.

Interestingly none of the women interviewed said they had used media such as videos or DVD’s to assist them in caring for their baby, although evidence suggests that there are many of these products available for parents to purchase. Although access to detailed information on infant care is available in a variety of languages on the Internet, not all

CALD parents are confident, or financially able to access computer generated information.

Education & the role of antenatal education

Low levels of paternal education are known to be a risk factor for SIDS (Sullivan and Barlow, 2001). Many of the women involved in this study commented that they would prefer to access information from other women or family members and friends than from books and literature. It is possible that this is as a result of the low literacy level and educational status of these women. As an optional question study participants were asked to provide their highest level of education. The majority of parents interviewed had attended high school, with only one third proceeding on to tertiary education. This was particularly evident in the women from a CALD background, many of whom had only completed primary school education.

Although there is a vast array of literature and electronic information available, many people who care for infants are not familiar with the current recommended guidelines on infant care, or choose to ignore them and care for their infants in the way they think most appropriate. These methods are often based on traditional practice, cultural and religious requirements, 'intuition', or alternative ways of parenting.

Educational classes and educational sessions around pregnancy and infant care are an integral way of providing detailed information to parents in a comfortable environment. As statistics for Western Sydney show (confirmed in the participant interviews), many new parents, particularly those from CALD backgrounds do not attend early antenatal care and do not attend antenatal classes. There are many antenatal sessions available for parents in the Western Sydney area, provided through hospitals, private organizations and community service organizations. The classes are generally targeted at first time parents, which may be another reason why many women do not attend with subsequent pregnancies. Classes in languages other than English are limited, and for most CALD women are difficult to access. The nurses in the study note the value of providing

educational classes to all parents, and commented that including classes for CALD women as part of mainstream care is essential. Many of the CALD women highlighted they 'did not want to know too much', indicating many are fearful of birth and parenting for the first time. These women are more likely to source information from family and friends, in the mistaken belief that it is more accurate than health professional information. It should also be remembered that many CALD women are also not literate in their native language, and as a result may feel uncomfortable in classes where literacy is a key component of learning.

Culture, religion & tradition

One of the major influences on new parents in this study was that of cultural background and tradition. The Pacific Island women in the study who spoke of the 'spirit' of their culture expressed this very clearly. Other cultural groups such as the Vietnamese women mentioned religious practices and referring to spirits for assistance to keep the baby safe, but Chinese and Filipino women did not elaborate on these traditions at length. Of particular note was the term used by almost all CALD groups interviewed, that of pregnancy and infant care being predominantly 'women's business'. For most of the CALD groups, the involvement of men in pregnancy and infant care was a strange phenomenon, and this may in part explain the reluctance to attend antenatal classes where 'couples' are encouraged to participate. Many of the CALD women expressed their reluctance to attend classes because of their limited English skills, and the fear of 'knowing too much'. This may also be a reflection on the level of education and literacy in their own language, and a preference to obtain information from those with whom they can converse easily.

While providing parents with information on Safe Sleeping and SIDS around the time of birth of their infant is appropriate, it appears that this is a time of great stress and challenge for women from a CALD background, and for those with little English, it is also a time when much information can be misunderstood. Although SIDS and Kids and NSW Health produce information on SIDS and Safe Sleeping in a range of languages,

many of the parents in this study were not familiar with the SIDS brochure, or had never seen one in their native language. The success of a formal education program in specific languages has been evidenced in the 'Cross-cultural Worker Program' operating in South Eastern Sydney Illawarra Area Health Service. This Program links new mothers from Arabic and Indonesian backgrounds with a community worker who is specifically employed to deliver early parenting training to groups of women in their native language. Discussions with women from a CALD background who participated in this study indicate that many still use the side sleeping position when putting their baby to sleep. Others comment that they use a combination of back and side sleeping position. This practice is known to put infants at increased risk of SIDS. There is however, no data collected on the cultural background of infants who die from SIDS in Australia (other than Indigenous infants). Although SIDS deaths are small in number, it is possible that collecting data on cultural background may provide an insight into any cultural variation in SIDS deaths.

Cultural traditions (such as taking the placenta home for burial after the baby has been born) are increasingly becoming accepted in NSW hospitals, although this is not the case in all facilities. Nursing staff commented on feeling 'out of their depth' with some cultural groups, not knowing the appropriate behaviour or courtesies expected by specific cultures. To deal with this, many nurses treat everyone the same, often upsetting people in the process. Many CALD women speak little English, even when they have lived in Australia for some time. This group may not be highly literate in their native language, and require additional assistance with the aid of an interpreter. One of the biggest difficulties raised by the women interviewed in respect to interpreters was that they are often 'known to the family'. This causes embarrassment and conflict, and results in the woman only giving information for translation that she would not mind repeated. Sensitive issues or difficulties with infant care that make the new mother feel incompetent or embarrassed are unlikely to be raised with an interpreter who knows the family, in case the information is not kept confidential.

In cultures where the whole community assumes responsibility for childrearing, traditional ways are generally practiced and there is less compliance with local health education programs and messages. The Pacific Island born residents interviewed in this study reflected these patterns of childrearing and these results are similar to those of Fa'alau et al in the study of SIDS in Pacific Island communities in Aotearoa (New Zealand), and in the subsequent program developed by Finau to address this issue (Fa'alau et al., 2003; Finau et al., 2003).

Experience & personal preference

Many of the parents interviewed commented that they obtained their information on infant care from a variety of sources and 'used what worked'. This indicates the preference for many parents to 'do it their way'. One mother commented that 'everyone has an opinion, and they all think they are right', an indication of the pressures that other parents and family members put on the new parents. Many in this situation will prefer to source their information from books and magazines, ask lots of questions of health professionals, family and friends and put into practice that which they feel best suits their circumstances, lifestyle and value systems. Some parents choose to care for their infants in a more alternative manner, and this preference is their right as a parent, although there are some parenting styles that are not recommended as being in the best interest of the child.

One of the major influences on new parents is through others who have already had parenting experience. Most of those interviewed said that throughout their pregnancy they had spoken at length with others who already had children, and referred to them frequently when caring for a new baby. The most common sources of 'experience' were from the mother or mother in law, sisters and friends who already had children. Women who had previously had children were very unlikely to attend antenatal classes with their second or subsequent pregnancies, due to time constraints and experience gained in parenting the first child. Many women from a CALD background placed the majority of their trust and faith in the experience of their mother or mother in law, as can be seen by their invitation to spend time living with the family while the infant is young.

One of the concerns about referring to those with experience is that although their experience in child rearing may be excellent, methods and evidence of safe infant care may have changed since they had their infant. In this situation, wrong information may be passed on, and infants placed at risk. This is particularly the case with parents who are used to placing infants on their tummy to sleep, and know the infant sleeps well this way, thereby passing misinformation on to new parents who are not familiar with the SIDS Safe Sleeping messages, or who are having difficulty getting enough sleep.

Socio-economic status

Investigations by leading SIDS researchers highlight the association of poor socio economic status with SIDS (Kraus et al., 1989; Sullivan and Barlow, 2001). It was also evident in the results from this study that socio-economic status has a major influence on the type of baby products parents use. Parents who are unemployed, young, single or from a CALD background often struggle to provide basic items for their infants, and may use items passed on from others, many of which may not meet current safety standard guidelines. As part of ‘day to day’ work, all nurses who participated in this study commented on situations where they noticed the effect of poverty on infant care practice. Many of the nurses conducting home visiting had experienced situations where they felt the baby they were visiting was not sleeping safely. Making recommendations that were not possible to achieve by some families (such as purchasing a cot that meets required standards, or ensuring the new baby has a mattress unused by other children to minimize SIDS risk) put a great deal of pressure on nurses working with families. Many nurses highlighted instances where they had visited families who could not afford cots or bassinets for a new baby, allowing the baby to sleep with the parents or other siblings (a known risk factor for SIDS). Many Child and Family Health Nurses commented on the way they promote breastfeeding as a ‘free’ source of total nutrition to encourage women to continue breastfeeding infants and reduce the costs associated with purchasing infant formulas.

Although the Australian Government introduced the ‘Baby Bonus’ in July 2004, none of the participants interviewed since that time spoke at length about the payment. Some

commented that it had assisted them to purchase items for the baby, however most spoke of the payment as a way of improving life for the family.

Twenty-first century society

The declining birth rate and subsequent declining and aging workforce were two factors raised by participants in the study as having an impact on the way parents, in particular women, care for their infants. Older participants of the study commented on their early experiences caring for siblings, cousins and other infant members of the extended family, and many raised the point that 'these days' young women from small families do not often have the opportunity to care for infants until they have their own children. This insecurity about caring for infants was raised by many Australian born women in the study, with comments such as '*I was too scared to bath him*' and '*I felt incompetent*'. One of the interesting findings of the study was that on the whole, women from CALD backgrounds (where larger families are more common) were more confident looking after a new baby. Many of them expressed loneliness and isolation, but this was primarily because they were living away from familiar surroundings and support networks. Many nurses and Australian born mothers who had older children commented that they had cared for siblings and others children through an extended family network. This group believed that children in small families are more likely to be 'spoiled', and are less used to the interaction and creative play of families with multiple siblings.

Although in a cross-sectional qualitative study such as this, it is not possible to establish statistical associations, it did appear that older participants were less likely to be up to date with current SIDS reduction messages. Young women who are well educated and who access health services and printed information are more likely to be familiar with current SIDS reduction messages than those who are young and left school early, or do not attend health services during their pregnancy. There were few very young women in this study, although there is a reasonably high level of young parents in the Western Sydney area. Grandparents, older GPs and those with older children were more likely to report using the side sleeping position, or the back and tummy position when placing

infants to sleep. Many parents who have older children, in addition to infants, received their information on infant care some years ago, and for this reason may be out of date with current sleeping position recommendations. This could be a safety issue in view of the number of parents who said they relied heavily on their parents, family and friends for information and support when they had a new baby. Women who bring their mothers or other relatives from overseas as ‘the expert’ in child care to assist them when the baby is very young, are more likely to find these older relatives are not up to date with current SIDS reduction messages.

One of the most common issues raised by parents who participated in this study was the pressure on young mothers to return to work. While many would like to spend more time at home with their infants, some are forced through social circumstances to return to work to pay high mortgage or rent and other expenses while the baby is still very young. Although many parents spoke of the desire to have a family, all were conscious of the necessity of many to return to work and spoke of the fine balance of caring for a family and working at the same time.

Many parents who participated in this study commented on the importance of sleep, and the ramifications and impact on the whole family if the parents are denied adequate sleep. Nurses too, commented that women these days expect babies to sleep and ‘fit into the mothers schedule’. This necessity for babies to sleep and mothers to continue their daily activities (such as shopping and meeting up with other mothers) appears to be one of the main reasons for women covering prams with drapes when in shopping centres. Families living in poor social circumstances are more likely to smoke, partake in alcohol and live in poorer quality housing, all factors known to be associated with an increased risk of SIDS.

The degree to which families engage with others in the community has an impact on the way they function as a family and raise children. Many of the women from a CALD background expressed feelings of loneliness, and sadness as a result of leaving family and friends in another country. Most women become emotionally labile and experience mood

changes around the birth of a baby as a result of fluctuating levels of hormones. This process may be exacerbated in women from CALD backgrounds as a result of lack of social support, homesickness, loneliness and feelings of inadequacy as a mother. Social support systems enable women to connect with others and discuss issues relevant for them, and many women interviewed commented on the value of social groups and meeting with other women from similar backgrounds.

5.4 INCONSISTENCY IN KNOWLEDGE ABOUT SIDS

Research question three sought to investigate whether there was inconsistency between knowledge of safe infant care and the practices health professionals and parents actually used. The results from this study indicate that there is inconsistency between knowledge and practice in health professionals and parents who care for infants.

The main areas where inconsistency between knowledge and practice was observed was in nurses who, in spite of in depth medical knowledge about the reasons for sleeping infants supine, continued to use the side sleeping position when they believed they could justify the practice (the infant was 'snuffly' or 'refluxy'). The comments of parents who openly expressed that nurses had modeled this method in hospital indicate that the inconsistency in nurse's practise is a concern. Other inconsistencies in practice were evident in parents who knew the correct methods of infant sleeping position, yet used either prone or side sleeping to assist babies sleep, and promote parents sleeping as a result. It is possible that because current parents have not seen the effects of a high death rate due to SIDS, they are unaware of the potential effects of incorrect sleeping position, (much like people who refuse vaccination, due to unfamiliarity with the consequences of contagious diseases).

Parents who come from a CALD background also exhibit inconsistency in infant care practice, due primarily to the conflicting practices of their traditional culture and those recommended by local health professionals. CALD families are difficult to influence, as the practices and traditions around infant care are ingrained into culture and often have religious significance.

Changes in practice

Many of the inconsistencies in practice can be attributed to the rapid changes in infant care methods over time, and the generational influence of family and friends on new parents. Whilst it is easy to follow changes in medical practice due to documentation of

many of these in the medical literature, changes in advice to mothers is more difficult to quantify. This is primarily because few early guidebooks aimed at mothers survive today, as the rapid change to infant care recommendations rendered the publications obsolete (women were told to throw the old version away when a new version was released to maximize safe practice for their infant). These early publications were produced in paperback format, or as small booklets, and few have survived due to time and the fragility of the papers used. Some guidebooks do survive and provide an insight into early parenting practice in the 1900's (as evidenced in Appendix 19). Nurses and midwives commented that one of the most important influences on practice has been the rapid change in technology and evidence-based medicine. Rapid changes to recommendations and guidelines may also be responsible for the confusion around clear knowledge of SIDS reduction messages.

One of the biggest changes to equipment used for infants has been around the design of the 'pram' and 'stroller'. In the early twentieth century, perambulators (prams) were used to take baby out in the 'fresh air' and to walk to the Baby Health Clinic and social activities. Many women in this era did not have a car, or did not drive, and walking the baby in the pram was a common event. Prams were usually high sprung, had a deep sleeping section and a hood to protect the infant from sun and the weather. Infants always faced the mother. As technology increased post World War Two and there was a rapid boom in the production of motorcars, there came associated difficulties in transporting 'the pram'. Non-portable and cumbersome, prams were not able to be dismantled and could not be transported in cars. The result was a change in design to the 'stroller' a smaller, more easily transportable device that could be folded to fit into the boot of a car. The design of the stroller, however, meant that the infant faced away from the mother able to see more of the world around it. Initially prams with a removable sleeping section were still used for very small infants, and once a baby could sit up, they were transferred to a stroller. One of the disadvantages of the stroller is that the baby faces away from the mother and is not able to see the mother constantly as is recommended and described by Bowlby, in his theory of attachment of infants (Bowlby, 1977).

Following statistics indicating that infants were at high risk of death if involved in a car accident, recommendations were made for the transportation of infants. The introduction of safety standards for transporting of infants saw the development of the 'Baby Capsule' and the 'Baby Seat', designed to protect infants and children when traveling in cars. The additional bulky equipment required to transport a baby in a car, reinforced the need for small, compact strollers when a family reached their destination.

As the pace of life increases and support networks become stretched, parents increasingly take their infants with them on activities such as shopping, visiting and social events. The recent practise of draping the pram with a blanket, seems to have been borne out of advice to protect a child from the sun, but has been extrapolated to promote infant sleeping, and to stop people 'coming up and touching babies'. Parents commented that they needed to shop or go out, and the baby also needed sleep. In times gone by, the parents would have arranged their shopping time around the baby's nap time, but the current trend is for the parents to attend to their needs, with the baby fitting around these. Hence the increased need for babies to 'sleep on the run' rather than have a dedicated nap time at home. This phenomenon has added to the increased usage of blankets over prams to reduce stimulation and keep babies 'in a darkened environment' where they can sleep. Older style prams and strollers facing the mother had hoods to protect the child from the weather, promoted sleeping as they faced the mother, kept the child secure and content and prying strangers at length, preventing them from looking into the pram. Researcher observation suggests that there is a recent swing back to the older style of pram and stroller facing the mother, however this is not supported by any evidence or statistics.

One of the dangers of 'draping a pram' is that infants may become overheated. Particularly where heavy blankets are used, oxygen levels may be decreased and these factors may have an impact on decreased respiratory function. The latest research suggests that infant levels of vitamin D are not meeting recommended levels, possibly as result of the recommendations to minimize the exposure of infant skin to the sun to reduce burning and subsequent skin cancer and melanoma incidence (Munns, 2006). Routinely draping prams with blankets and wraps reduces incidental sun exposure to the

infant and predisposes them to an increased likelihood of vitamin D deficiency, and possible effects of increased carbon dioxide around the face.

Parents commented on the differences in practice since the days of their mothers, specifically commenting in the increased 'rush' of daily living as having a negative effect on parenting compared to the past. Nurses commented that they were constantly under resourced, and 'stretched to the limit' providing services for new parents.

In relation to SIDS, there have been many changes to recommendations since SIDS was first given an ICD code in 1979. Research into the sleeping position women used to place their infants to sleep in the early part of the twentieth century indicates, that prior to the development of intensive care technology, guidebooks and infant care manuals showed babies lying supine, and this was the position the majority of parents used. It was not until research into improving the outcomes of premature infants was undertaken, that prone sleeping was recommended as being beneficial to infants, improving sleep and oxygenation.

Changes have taken place in the production and composition of clothing and bedding used for infants. The composition of blankets and any possible relationship to SIDS has not been studied. It is known pure wool or cotton blankets were used for wrapping infants until the introduction of synthetic fibres in the 1960's. Since the introduction of synthetic fibres, infant blankets are now available made from acrylic, nylon and polar fleece (a form of spun plastic). Each of these products is known to trap heat and reduce airflow between the skin and the fibre. It is possible that synthetic blankets cause overheating and may increase the risk of SIDS.

Many nurses mentioned the 'aging workforce' as one of the key changes to nursing over time and felt this had an impact on the way services were provided to new parents. Western Sydney has always had a nursing workforce focused on providing home visiting to new mothers. Although many of the other area health services abandoned 'home visiting' after the review of services by Juliet Corn in 1980, Western Sydney continued

this practice, in a generalist nursing model (where community nurses visit clients in their home for medical attention). The re-introduction of Universal Health Home Visiting in Western Sydney meant a reorientation of the nursing workforce, but enabled service delivery to be prioritized based on the importance of supporting vulnerable families in the area.

5.5 STRENGTHS AND LIMITATIONS

Assumptions

This study involved the use of self-completed questionnaires, telephone interviews and focus groups to elicit information from general practitioners, nurses and parents. All responses were anonymous (except for names listed on focus group Consent Forms), and it is assumed that the respondents were truthful when answering the questions in the questionnaires, telephone interviews and focus groups. It is also assumed that the child-care practices described by the respondents reflect actual practice.

Strengths

One of the strengths of this study is that GPs were selected randomly and the response rate was high for this target group (20%). The GP response rate was consistent with that of Moon and colleagues who found similar GP response rates in a study of over 3,000 physicians' knowledge of SIDS reduction strategies in 2002 (Moon et al., 2002). It is possible that GPs who are well versed in the area of SIDS reduction strategies were more likely to answer a questionnaire, and those who are unsure of the current guidelines may fail to respond. In order to reduce this possibility, the questionnaire was anonymous, and no identifying features were included on the return envelopes to the researchers.

Another strength of this study is that GPs appeared to be answering honestly when reporting their levels of knowledge about SIDS and SIDS reduction strategies. In view of the number of GPs who were willing to admit they were not up to date, or were confused about SIDS reduction messages, it is possible that this situation is more widely occurring than one would reasonably expect of GPs, considering the level of medical training they

can access on a regular basis. Overall, the response rate to the questionnaire was adequate in terms of sample size to obtain a cross sectional snapshot of the knowledge of GPs in the SWAHS area about SIDS and their opinions on the major influences on women with infants (Nulty, 2008).

The percentage of nurses from each discipline interviewed was representative of the numbers of nurses in each discipline working in the area. All nurses who replied to the recruitment advertisements were female, highlighting the overrepresentation of female nurses in the nursing specialties dealing with mothers, infants and families.

Advertisements were placed in a number of journals and newspapers indicating broad advertising coverage. The numbers of nurses required for the study was attained easily through the advertising methods used. It is a strength of the study that the participants provided verbatim responses, and were able to freely and openly discuss their feelings and perceptions of pregnancy and infant care practice. Nurses and parents were particularly insightful in their answers around practice, and the changes to practice over time and there was good representation from parents and carers in this study, with all recruitment targets met.

A strength of this study is that it provides an historical perspective on infant care which is currently only available in a limited way in the literature. Most historical investigations have been around particular topics or related to specific nursing disciplines and are located in nursing journals. As part of this study the researcher was able to locate and obtain child care literature usually difficult to obtain due to the age and fragility of the publications. This literature provided an insight into past infant care practices, but also highlighted the differing attitudes and expectations of both nurses and parents in the early twentieth century.

One of the strengths of this study is the number of variables on which information was collected. The study took a holistic approach to data collection, and investigated not only practical influences on parents such as literature, education and expert knowledge

transfer, but the sociological influences such as societal change, family size, housing, financial responsibilities and social connectedness.

Limitations

Although all questionnaires and interviews were conducted anonymously, it is possible that, due to the sensitive nature of SIDS, many respondents who were aware of current recommended SIDS prevention guidelines did not give accurate responses if their practise did not reflect this knowledge. As the researcher did not visit any participants in their homes to observe sleeping infants, the results are purely based on self reported practices.

General practitioners across the SWAHS were sent an invitation to participate in this study. It is possible that some GPs were more likely to respond to a questionnaire about SIDS, due to previous experience or an interest in infant health. It is unclear whether the sample of GPs in this study is representative of all GPs, and therefore it is not possible to generalize the results of this study to the entire GP population. There was a slight over-representation of female GPs in the study. Discussions with the Australian General Practitioners Alliance indicated that women make up around 35% of the NSW GP workforce. There are many possible reasons for this including: female GPs may be more likely to pass on SIDS reduction messages to other women, based on previous experiences with their own children, or women with new babies may be more likely to visit a female practitioner for ongoing medical care and advice around maternal and infant health issues.

There was a high number of GPs who had cared for a baby who later died from SIDS participating in the study. This suggests a bias towards a self-selected group of practitioners who were particularly interested in SIDS, completing the questionnaire. It is possible however that some GPs view small scale questionnaires as of little value in their overall work practice and choose not to complete them. Knowledge of the postcode of the respondents would have provided good data for targeting future SIDS messages education, but in the interests of anonymity and increasing response rates, this

information was not collected. Some GPs from a CALD background may not have wanted to complete the survey, for fear of identifying any particular CALD group within the population as having less knowledge of SIDS reduction strategies. It is assumed that all GPs from a CALD background had sufficient levels of written English to have been able to read and complete the questionnaire.

There were some limitations in the method of nursing recruitment used. This method provided a self-selected population of survey participants, and excluded nurses who do not have time to read local papers or read journals or belong to Nursing Associations. Motivated and interested nurses were probably more likely to respond to a survey of this nature, although nurses are generally interested in helping others, particularly through participation in research. Only nurses who had easy access to a telephone and were prepared to commit at least 20 – 40 minutes of time would respond to a study of this nature and this is a potential source of bias.

There are limitations to recruiting and collecting information from parents and carers in the manner conducted in this study. The newspaper advertisements were all printed in English language, so it is reasonable to assume that the women from a CALD background who responded to the advertisements were competent in English and able to locate services providing information on infant care. This issue is partially addressed through the use of data collection from focus groups with parents and carers from a CALD background.

Many women return to work following the birth of their infant, and may be more at risk of practising adverse infant care behaviour, due to tiredness and lack of time. These women may be too busy to respond to advertisements for research, and thus not have participated in the study. There were adequate numbers of parents in this study to gain a broad perspective of the influences on infant care, but the respondents were motivated and interested in aspects of infant care.

It was anticipated more non-parent carers would respond to the invitation to participate in the study, and the relatively low numbers of carers could indicate that this group are extremely busy, or do not access the areas where advertisements were placed. It is also possible that 'grandparent carers' do not see themselves as 'carers', but more as grandparents looking after grandchildren as a joy not a responsibility.

Many of the women from CALD backgrounds who were interviewed could speak quite good English, and for the purposes of this study, this made data collection much easier. Translations using interpreters in focus groups were slow and sometimes difficult, and at times it was thought that some important information may have been missed or not mentioned by the participants due to time constraints. Parents who speak very little English are probably more likely to be isolated, have less information on infant care and be disadvantaged in terms of their knowledge of SIDS and safe sleeping. Parents from disadvantaged communities were probably less likely to participate in this type of study.

Finally, this study was conducted using a self-selected sample in one geographical region of NSW, which limits the generalisability of these results to other populations in other geographical locations.

CHAPTER 6 –

CONCLUSION & RECOMMENDATIONS

*“Few can foresee whither the road will lead them,
till they come to its end”*

J.R.R.Tolkien – Lord of the Rings

This cross-sectional study of health professionals, parents and others caring for infants in Western Sydney highlights a number of issues around infant care practices and the major influences on new parents living in a multicultural community.

Results of this study show there is a large variation in knowledge around Safe Sleeping Practice (including SIDS reduction strategies) in all the groups studied. Although there is variation in the level of knowledge of safe sleeping knowledge between health professionals and parents, there is also significant variation in knowledge within each category studied.

Of greatest concern is the poor knowledge of safe sleeping and SIDS reduction messages in GPs who were born in a country where English is not the first language. In this study, as in previous research, women from a CALD background indicated they primarily access GPs who speak their native language, for health care. Where GPs have poor knowledge of safe sleeping, and brochures and posters about SIDS in the appropriate language are not available for parents, the families accessing these services are at greater risk of using unsafe sleeping practices for their infants.

Nurses are bound by mandatory Health Department policy to use safe sleep positioning for infants in their care. In spite of this there were still nurses who admitted to using

unsafe sleeping positions in a hospital setting, justifying these on the condition of the infant. Previous research has indicated that nurses are one of the most powerful role models new parents can have (Young, 2003; Jeffery, 2004; Bullock, 2004). The nursing workforce is aging, and many older nurses continue to use methods they learnt many years ago. It is therefore essential all nurses be kept up to date with safe sleeping messages, either through in-service presentations or targeted strategies delivered to the nursing workforce.

Although widespread educational campaigns about safe sleeping are conducted regularly, many parents and others who care for infants are confused about the key safe sleeping messages, and many still admit to using infant-sleeping positions considered unsafe. One of the possible reasons for the confusion experienced by parents is the changing nature of the SIDS reduction messages over the last 15 years (Appendix 12 - 17). It is also possible that parents are receiving mixed messages from family and friends who are older and not up to date with current messages: from GPs who are not up to date, and nurses who are modeling incorrect practice.

It is clear from the evidence collected in this study that women from a multicultural community are more likely to practise traditional cultural methods of infant care. This includes co-sleeping, smoking, bed-sharing, care by extended family members and herbal remedies. While these practices are difficult to influence and almost impossible to change in some communities, the research provides evidence which Universal Health Home Visiting Nurses can use when visiting families from a CALD background. An increased awareness of these practices, which may place infants at risk of sudden and unexpected death, can be detailed fully in a home visit with CALD families.

The study highlights the difficulties in dissemination of clear, accurate and consistent educational material to all members of the community. While SIDS and Kids NSW, and SIDS and Kids Australia are extremely active in promoting safe sleeping through the Red Nose Campaign, the knowledge of safe sleeping in some communities is less than ideal. It is acknowledged that providing educational material in pamphlet form is expensive and

sometimes questionable in value. It is imperative that all families with a newborn infant have access to information in their native language, and / or in graphic form. The provision of a clear graphic in the infant Personal Health Record would ensure that all families received consistent, accurate and understandable safe sleeping messages.

The study highlights a relatively recent practice, not previously documented or reported in the medical literature. This practice is to cover infants' prams with a blanket when the child is in the pram. Based on previous evidence indicating that infants require fresh and moving air, it seems reasonable to suggest that the practice of using heavy blankets in this manner may be detrimental to the infants breathing and arousal status. Covering infants prams with heavy blankets on a regular basis may also be a contributing factor to Vitamin D deficiency in some children. In the March 2008 edition of the Neonatal, Paediatric and Child Health Nursing Journal, a discussion paper was published as a result of this study, highlighting the possible detrimental effects of covering prams with heavy blankets (Wilson, 2008) (Appendix 18). It is suggested that further research be undertaken to ascertain the level of air quality around the head of an infant when in a pram and covered by a heavy blanket, or blankets made of synthetic material that do not have the 'breathing' capacity of natural fibres such as cotton. Until such time as clear evidence is available for the implications of this practice, it is suggested that recommendations be made for parents to only cover infants when in the sun, and then to do so with a light, muslin cloth.

This study highlights deficiencies in the NSW Health data collection systems. The Midwives data collection is not fully automated in all areas and, as a result, available data on births and perinatal deaths can be up to two years out of date. No system is currently in place for the collection of ancestry of infants who die from SIDS in Australia, even though the Child Death Review Team has the capacity to collect this data through their investigation of all child deaths. With the increase in migration to Australia, collection of ancestry in infants who die would enable trend data to be monitored in specific cultural groups.

The results of the study also highlight deficiencies in data collection systems in the NSW Police Department and Coroners Offices, neither of whom collect data on the race or ancestry of any child who dies in NSW.

The results of this study lend themselves to the development of six key recommendations for enhancement of service delivery. These recommendations complement, enhance and support those of the 2005 report prepared by Malins (2005).

1. Through collaboration with SIDS and Kids, local Divisions of General Practice and the Australian General Practitioners Alliance, general practitioners (particularly those from a non-English speaking background) need to be encouraged to:
 - Regularly participate in updates around infant care and SIDS reduction
 - Utilize opportunities within their daily practice to promote Safe Sleeping (such as immunisation visits, infant check ups, and all infant care visits)
 - Promote Safe Sleeping as ‘everybody’s business’ (For example, promote good infant sleeping practice with new grandparents, new fathers and all pregnant women)

2. SIDS and Kids in collaboration with key external partners such as GP Divisions, the GP Alliance and Kids Health at the Children’s Hospital at Westmead, develop and implement:
 - A targeted Safe Sleeping strategy (e.g. Seminar Series, or Professional In-service) to provide GPs and other health professionals with up-to-date information on Safe Sleeping and SIDS reduction strategies,
 - A novel, promotional item (such as a Magnet) outlining the key SIDS messages be prepared for dissemination to all GPs in Western Sydney in a range of languages.

3. A joint project between The Children's Hospital at Westmead and SIDS and Kids NSW be undertaken with the aim of disseminating the Safe Sleeping Messages to all women who give birth in NSW each year (approx 90,000). This project could

investigate the feasibility of printing Safe Sleeping Messages on hospital Birthcards, or producing an additional page to be included in the ring bound Personal Health Record. The page for the Personal Health Record would depict safe sleeping messages in graphic form suitable for families from all language backgrounds.

4. The Kids Health Promotion Unit at the Children's Hospital at Westmead should be encouraged to produce a 'Factsheet' for parents, discussing the benefits of interacting with infants with regard to early infant attachment and discussing the potential dangers of covering infants in prams with blankets and wraps unless they are in direct sunlight, and then to only use light muslin wraps.
5. That an educational tool, designed to raise awareness of cultural birthing and parenting practice be developed for nurses and midwives working with CALD families to assist nurses and midwives care for CALD women in hospital and in community settings.
6. The Commission for Children and Young People through the Child Death Review Team be encouraged to establish a register of deaths of infants, collecting the cause of death and the ancestry of infants who die as a result of SUDI.
7. That an Interagency Working Group be convened to address the inconsistencies in data collection through the NSW Police Department and Coroners Offices, through the development of a SUDI Reporting Form and Training Manual along the lines of the SUDI Reporting Form and Training Manual developed by the Centres for Disease Control and Prevention in the USA.

APPENDICES

APPENDIX 1



PARTICIPANT INFORMATION SHEET –

Study Title: Caring for Infants in Western Sydney –

Study No: No: 11-2004/3/7873

About this study:

The ‘Caring for Infants in Western Sydney’ study is a research project investigating the major influences on parents who have children aged less than 12 months of age.

Investigators from the study team will collect information from GPs midwives, early childhood nurses and paediatric nurses and new parents about their experiences with infant care.

The study consists of four parts and will be conducted using a variety of methods. We will be:

- asking GPs to complete a questionnaire about their experiences with parents who have infants
- asking Early Childhood Nurses, Midwives and Paediatric Nurses about changes in infant care practice over time using a telephone interview
- Asking parents and carers of infants aged less than 12 months, what influences them to care for their infants the way they do (also using a telephone interview and
- Conducting a series of focus groups in parents with infants.

It is well known that a range of factors influences new parents when they have a new baby. Cultural background plays a large part in the way parents care for their infant, with many parents combining traditional and modern methods of parenting.

Who is carrying out this study?

The study is being conducted by Leigh Wilson, a student of the University of Sydney, and will form the basis for the degree of Doctor of Public Health under the Supervision of Associate Professor Susan Quine in the School of Public Health.

What does the study involve?

Participation in this study is completely voluntary. The study involves answering some questions by telephone interview at a time suitable to you. You will only be asked to provide your first name and your postcode. All your responses will remain confidential.

How much time will the study take?

If you are answering the questions using a telephone interview, this will take approximately twenty minutes. A convenient time can be made to suit both you and Leigh Wilson. The interview is a 'one off', and does not require continuous interviews.

Can I withdraw from the study?

Your participation in the study is completely voluntary and you are not under any obligation to participate. You are free to withdraw from the study at any time.

Will the study benefit me?

The study will not benefit you directly, but will provide information which may help inform future health care practices.

Can I tell other people about the study?

Yes, you can tell other people you know about the study. If they wish to participate they should ring Leigh Wilson on 9894 8478 (and leave a message which will be returned as soon as possible) for more information.

What if I require further information?

When you have read this information, Leigh Wilson will discuss it with you further and answer any questions you may have about the study. If you would like to know more, please feel free to contact Associate Professor Susan Quine, School of Public Health, University of Sydney on 9351 4371.

What if I have a complaint or concern?

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics Administration, University of Sydney on (02) 9351 4811

This study is funded through a Grant from The Children's Hospital at Westmead
This information sheet is for you to keep.

29th September 2005

Dear Doctor,

This letter is to invite you to take part in a research study investigating the major influences on child care practice in women who have babies under the age of 12 months, and who live in Western Sydney.

We are interested in studying the changes in infant care practice recommendations over the past 50 years, and the influence of traditional cultural practices on infant care. We are particularly interested in investigating the knowledge of parents and health professionals with regard to Sudden Infant Death Syndrome (SIDS) prevention messages.

The study is being conducted by Leigh Wilson a student of the University of Sydney and will form the basis for the degree of Doctor of Public Health, under the Supervision of Professor Susan Quine in the School of Public Health. This study has been approved by the Ethics Committee of the University of Sydney, and is funded by a Grant from Kids Health at The Children's Hospital at Westmead

We would like to invite you to participate in this study. Participation is voluntary, and involves the completion of an anonymous two page questionnaire. Enclosed is a reply paid envelope for the return of the questionnaire.

Should you have any questions regarding this study, please do not hesitate to telephone either Leigh Wilson (Study Coordinator) on 9845 3590 or A/Prof Susan Quine on 9351 4371.

Thank you for your participation,
Yours truly,

Leigh Wilson
Study Coordinator




Dear Practice Manager or Receptionist,

If you are opening this mail on behalf of your employer, would you please ensure this Research Study information is passed on to the Doctor to whom it is addressed.

Many thanks for your assistance





The University of Sydney
Australia

Attention: Nurses, Midwives, Early Childhood Nurses

We are interested in talking to Nurses, Midwives and Early Childhood Nurses who are:

- currently working, or have worked, with women and infants, and
- who live and / or work in Western Sydney.


If you meet the above criteria, we would like to invite you to take part in a research study investigating the way people care for babies.

For further details or to register your interest to participate please telephone Leigh Wilson on: 9894 8476

This study has been approved by the Ethics Committee of the University of Sydney. (No: 11-2004/3/7873)

(A project funded by Kids Health, The Children's Hospital at Westmead)

B0706q



The University of Sydney
Australia

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☎ 9894 8476

This study has been approved by the Ethics Committee of the University of Sydney. (No: 11-2004/3/7873)

(A project funded by The Children's Hospital at Westmead)

Advertisements to recruit nurses were placed in the Lamp (top right), the Parramatta Advertiser (top left) and the Neonatal Paediatric and Child Health Nursing Journal (bottom right)



The University of Sydney
Australia

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- currently working, or have worked, with women and infants, and
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This study has been approved by the Ethics Committee of the University of Sydney. (No: 11-2004/3/7873)

(A project funded by The Children's Hospital at Westmead)



CALLING ALL EARLY CHILDHOOD NURSES, PAEDIATRIC NURSES AND MIDWIVES

This letter is to invite Early Childhood Nurses, Midwives and Paediatric Nurses to take part in a research study investigating the major influences on child care practice in women who have babies under the age of 12 months, and who live in Western Sydney.

We are interested in studying the changes in infant care practice recommendations over the past 50 years, and the influence of traditional cultural practices on infant care.

The study is being conducted by Leigh Wilson a student at the University of Sydney and has been approved by the Ethics Committee of the University of Sydney. (Study No 11-2004/3/7873). The study is funded by a grant from 'Kid's Health' at The Children's Hospital at Westmead.

Participation in the study is voluntary, and involves the completion of an anonymous questionnaire over the telephone. **If you would like to participate, you can register your interest by leaving a message with your telephone number and first name only, on Ph: 9894 8476.**

Please mention you are a nurse (as we are also interviewing parents).


Should you have any questions regarding this study, please do not hesitate to telephone either Leigh Wilson (Study Coordinator) on 9477 9019 or A/Prof Susan Quine on 9351 4371.

Thank you for your participation,

Yours truly,

Leigh Wilson
Study Investigator

Advertisements for parents and caregivers were placed in local newspapers including the Parramatta Advertiser, and the Hills News (top), and magazines including Sydney's Child (bottom).



The University of Sydney
Australia

Calling all Mothers, Fathers, Grandmothers, Grandfathers, Aunties and Child Care Workers

Are you?

- aged between 18 and 75 years and
- currently caring for a baby aged less than 12 months and
- living or working in Western Sydney


If you answered YES to all of the above questions, you may be eligible to take part in a research study investigating the way people care for babies.

For further details or to register your interest to participate please telephone Leigh Wilson on: ☎ 9894 8476.

This study has been approved by the Ethics Committee of the University of Sydney (Study No 11-2004/3/7873)

(A project funded by Kids Health, The Children's Hospital at Westmead)

B13069



The University of Sydney

Calling all..... Mothers, Fathers, Grandmothers, Grandfathers, Aunties, Uncles, Carers & Child Care Workers

Are you? • aged between 18 and 75 years **and**
• currently caring for a baby aged less than 12 months **and**
• living or working in Western Sydney?

If you answered YES to all of the above questions, you may be eligible to take part in a research study investigating the way people care for babies. For further details or to register your interest to participate please telephone Leigh Wilson on: **9894 8476.**

This study has been approved by the Ethics Committee of the University of Sydney (No: 11-2004/3/7873)
(A project funded by The Children's Hospital at Westmead)

S0606



Mothers Fathers Grandmothers Grandfathers Aunties

Are you?

- aged between 18 and 75 years and
- currently caring for a baby aged less than 12 months
- and living or working in Western Sydney

If you answered YES to all of the above questions, you may be eligible to take part in a research study investigating the different ways people care for babies in the community. Participation in the study requires you to answer some questions over the telephone. The survey takes about twenty minutes and is anonymous. We would particularly like to talk to people who were, (or whose parents were) born outside Australia.

For further details or to register your interest to participate please telephone Leigh on 9894 8476.



This study has been approved by the Ethics Committee of the University of Sydney
(No: 11- 2004/3/7873)

Uncles Friends Carers Mothers Fathers Grandmothers

PARTICIPANT CONSENT FORM

I.....give consent to my participation in the research project:
(Name. please print)

TITLE: “Caring for Infants in Western Sydney”

In giving my consent I acknowledge that:

1. The procedures for the project have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the participant information sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that I can withdraw from the project at any time, without affecting my treatment or my relationship(s) with the researchers now or at any time in the future.
4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

Signed.....

Name.....

Date.....

Witness.....

Infant Care In Western Sydney

Version 1

1st November 2004

INFANT CARE PRACTICE STUDY

QUESTIONNAIRE FOR GENERAL PRACTITIONERS

Instructions for completion:

Please circle the appropriate response or write in the space provided.

Question	Question	Choice or response		Yes	No
1	In what year did you commence your training as a medical doctor?				
2	Where did you train to become a medical doctor?				
3	What is your gender?	M	F		
4	Where were you born?				
5	Do you live in Western Sydney?			Y	N
6	How long have you been practicing as a General Practitioner in Western Sydney?				
7	In your estimation, what percentage of your patients are mothers with babies under the age of 12 months?				
8	Of these patients, what is the main reason for their presentation? Please rank these from 1 to 5.	Feeding problems			
		Infections			
		Immunisations			
		General check-up of baby			
		Other.....			
9	Do mothers/parents ever ask you about ways of preventing Sudden Infant Death Syndrome (SIDS)?			Y	N
10	Do you have brochures and posters about SIDS Prevention in your office or practice?			Y	N

Question	Question	Choice or response	Yes	No
11	Was SIDS Prevention ever taught in your medical training?		Y	N
12	Have you attended educational sessions whilst in general practice, where SIDS prevention was discussed?		Y	N
13	Have you ever cared for a baby who later died from SIDS?		Y	N
13a	If Yes, do you provide bereavement counselling for the family or refer them to a specialist counsellor?		Y	N
13b	If you referred the family for specialist counselling, who did you refer to?	Private counsellor	Y	N
		SIDS Australia	Y	N
		Other	Y	N
14	Are you familiar with current SIDS Prevention Guidelines?		Y	N
15	Can you list the latest recommended SIDS prevention strategies? (If yes, please list 5 prevention strategies)		Y	N
16	In your estimation, what percentage of the mothers and babies you see are from a Non English Speaking background?			
17	Who do you think has the most influence on the way mothers/parents care for their babies? Please rank these from 1 to 5.	Medical Doctors		
		Baby Health Sister		
		Friends and family		
		Intranet/Books		
		Other.....		

INFANT CARE PRACTICE STUDY – NURSE QUESTIONNAIRE

TO BE DELIVERED BY INTERVIEWER OVER THE TELEPHONE:

Section	Question	Question	Choices or Response	Yes	No	
Demographics	1	Are an Early Childhood Nurse ? or a		Y	N	
		Midwife		Y	N	
	2	In what year did you commence nursing training?				
	3	Do you live or work in Western Sydney? <ul style="list-style-type: none"> ◆ What Suburb ◆ Postcode 		Y	N	
Eligibility				Y	N	
	4	Are you currently working as either an ECHN or a Midwife? If yes please go to Q5		Y	N	
	4a	If you are not currently working as either an ECHN or a Midwife, please state your current occupation.	Other Health	Y	N	
			Nurse in private company	Y	N	
			Retired	Y	N	
			Not working	Y	N	
			Other (please specify)	Y	N	
	4b	How long is it since you worked as an ECHN or Midwife?				
	5	If you are working, do you work Full time or Part Time?			Y	N
						Y
	6	Where did you do your nursing training?				
7	Where did you do your ECHN or Midwife training?					
8	In which country were you born?					
9	In which country was your mother born?					

Section	Question	Question	Choices or Response	Yes	No
	10	How do/did you show mothers to put their baby to sleep?	On their back	Y	N
			On their side	Y	N
			On their tummy	Y	N
			In more than one position	Y	N
	11	Why do/did you place the baby to sleep this way	Sleeps best this way	Y	N
			Experience	Y	N
			Prevention of SIDS	Y	N
			Less chance of choking	Y	N
			Have seen others do it	Y	N
			Other.....	Y	N
	12	Do/did you ask mothers/parents what type of cot they have at home?		Y	N
	12a	If yes, What type of cot/cradle or bassinette do/did you recommend parents use for their babies?			
	13	Do/did you talk to mothers/parents about cot bumpers, blankets and other bedding ?		Y	N
15	Do/did you recommend babies sleep with a pillow		Y	N	
16	Do/did you talk to mothers/parents about sharing the bed with their babies ?		Y	N	
17	Do/did you talk to mothers/parents about smoking near their baby, or in the household with their baby.		Y	N	
18	Do/did you ever talk to mothers/parents about heating in the baby's room?		Y	N	

Section	Question	Question	Choices or Response	Yes	No
	19	In your estimation, what percentage of the parents you see/saw were first time parents?			
	20	In your estimation, what percentage of first time parents have attended pre-natal classes?			
	21	In your experience, do parents from a Non English Speaking Background attend pre-natal classes?		Y	N
	21a	If No, why do you believe this is the case?	Language barrier	Y	N
Cost			Y	N	
Other.....			Y	N	
	22	In your estimation, what percentage of the mothers/parents you see would be from a Non English speaking background?			
	23	Do you recommend any books or printed material to parents, on how to care for their baby?		Y	N
	24	If yes, what are these books or printed material?			
	25	Who do YOU think has the most influence on new mothers/parents, with regard to caring for their newborn baby?	Early Childhood Nurse	Y	N
			Midwife	Y	N
			General Practitioner	Y	N
			Obstetrician / Gynae	Y	N
			Family and friends	Y	N
			Literature / Internet	Y	N
			Other.....	Y	N
	26	Do you have children? If No, please go to Q 58		Y	N

Section	Question	Question	Choices or Response	Yes	No
About your OWN FIRST Child	27	In what year was your first baby born?			
	28	Whereabouts was your first baby born?	Hospital.....	Y	N
			At home	Y	N
			Other.....	Y	N
	29	Who delivered your baby	A specialist Obs/Gynae	Y	N
			General practitioner	Y	N
			Midwife	Y	N
			Other	Y	N
	30	Did you and your partner attend educational classes before the birth of your first baby?		Y	N
	30a	If Yes, who ran these classes?	Hospital	Y	N
			Clinic / Community Centre	Y	N
			Other.....	Y	N
	30b	If Yes, what did they cover?	The birth Process	Y	N
			Pain relief	Y	N
			Partners involvement	Y	N
			Coping at home	Y	N
			Breastfeeding	Y	N
Bathing baby			Y	N	
Can't remember			Y	N	
31	Did you read any books to help you to care for your baby?		Y	N	
31a	If Yes, can you remember what they were? (Please specify)		Y	N	
32	Have you ever gone to the Internet for information to help you care for your baby?		Y	N	

Section	Question	Question	Choices or Response	Yes	No
About your OWN FIRST Child	33	Did you (or your partner) seek any advice from anyone about caring for your baby after your baby was born?		Y	N
	33a	If yes, who did you consult for advice?(Answer as many that apply)	Doctor/ GP	Y	N
			Doctor/ specialist	Y	N
			Midwife	Y	N
			Clinic sister	Y	N
			Mother	Y	N
			Sister	Y	N
			Friends	Y	N
			Tresillian	Y	N
			Karitane	Y	N
	Other.....	Y	N		
	34	Who do you consider gave you the most useful advice?			
	35	Did you feel confident caring for your baby?		Y	N
	36	Did you (or your partner) have family or extended family close by for support when you had your baby?		Y	N
	37	Did both you and your partner return to work when your baby was less than 12 months of age?		Y	N
37a	If Yes, how old was your baby when both parents had returned to work?				
38	Did you (or your partner) breastfeed your baby?		Y	N	
38a	If Yes, for how long?	Less than 6 weeks	Y	N	
		6 weeks to 3 months	Y	N	
		3 months to 6 months	Y	N	
		6 months or longer	Y	N	

Section	Question	Question	Choices or Response	Yes	No
About your OWN FIRST Child	39	What influenced you (or your partner) to stop breastfeeding your baby?	Age of baby	Y	N
			Difficulty feeding	Y	N
			Loss of milk supply	Y	N
			Return to work	Y	N
			Baby's failure to thrive	Y	N
			Other (specify)	Y	N
	40	What influenced your decision to bottle feed your baby?			
	41	How do/did you place your baby down to sleep?	On his/her back	Y	N
			On His her side	Y	N
			On his/her tummy	Y	N
			In more than one position	Y	N
	41a	If more than one position please specify which combination of positions you use(d)	Back and side	Y	N
			Tummy and side	Y	N
			Back and tummy	Y	N
	42	Where does/did your first baby sleep?	In a cot	Y	N
			In a bassinet	Y	N
			In a cradle	Y	N
			In bed with you	Y	N
			In your room	Y	N
	43	What sort of mattress did/does your baby have?			
	44	Do or did you ever prop your baby on their side with a rolled up nappy or towel?		Y	N
44a	If yes, why do/did you do this?				
44b	Who told you or showed you to do this?				

Section	Question	Question	Choices or Response	Yes	No
About your OWN FIRST Child	45	Did/does your baby have a pillow?		Y	N
	45a	If Yes, what was/is it made of?			
	46	Did/do you wrap your baby tightly?		Y	N
	46a	Who advised you to do this?			
	47	What material were/are your baby's blankets made out of?	Cotton	Y	N
			Wool	Y	N
			Acrylic	Y	N
			Polar fleece	Y	N
			Other material	Y	N
	48	Did you smoke while you were pregnant with your baby?		Y	N
49	Did/do you smoke in the house when the first baby was less than 12 months old?		Y	N	
50	Did your partner smoke while you were pregnant with your first baby?		Y	N	
51	Did your partner smoke in the house while your baby was less than 12 months old?		Y	N	
About your own SECOND or SUBSEQUENT babies	52	Did you attend prenatal classes before your second or subsequent babies were born?		Y	N
	53	Did you refer to any printed material to assist you to care for your baby?		Y	N
	53a	If Yes, can you remember what they were? (Please specify)		Y	N
	54	Did you consult anyone about caring for your second or subsequent babies after birth?		Y	N

Section	Question	Question	Choices or Response	Yes	No
About your own SECOND or SUBSEQUENT babies	54a	If yes, who did you consult?	Doctor/ GP	Y	N
			Doctor/ specialist	Y	N
			Midwife	Y	N
			Clinic sister	Y	N
			Mother	Y	N
			Sister	Y	N
			Friends	Y	N
			Tresillian	Y	N
			Karitane	Y	N
			Other.....	Y	N
	55	Did you feel more prepared to care for your second or subsequent baby than with your first		Y	N
	56	Describe what YOU think are the biggest differences between the way your mother cared for you as a baby, and the way you care(d) for your first baby.			
	57 &57a	Did/have you ever experience(d) any problems with any family members over ways of caring for a baby?If Yes, with whom did you have problems?		Y	N

Section	Question	Question	Choices or Response	Yes	No
Cultural background	58	Were either you or your husband born in a Non-English speaking country? If NO go to Q 62		Y	N
	58a	If Yes, where were you born?			
	58b	If Yes, where was your partner born?			
	59	Do either you or your partner have any traditional cultural practices which influence the way a baby is cared for?		Y	N
	59a	If yes, what are these practices?	Taboo foods	Y	N
			Women only rituals	Y	N
			Placental burial	Y	N
			Naming traditions	Y	N
			Traditional medicines	Y	N
			Specialised massage	Y	N
Keeping the baby inside			Y	N	
	Other.....	Y	N		
60	Which of these traditions do you still practice?				
61	Do you tend to follow the 'old' traditional ways of practice, or do you follow current local practices?	Expand on this on separate sheet			
General Questions	62	How many weeks pregnant were you when you first went to see the Doctor about your most recent pregnancy?			

Section	Question	Question	Choices or Response	Yes	No
	63	Did you attend prenatal classes before your last baby was born?		Y	N
	63a	If no, what influenced your decision not to attend?	Language barrier	Y	N
			Not thought necessary	Y	N
			Difficult to get to	Y	N
			Too costly	Y	N
			Not aware of any	Y	N
			Relied on others for help	Y	N
			Already experienced	Y	N
			Other.....	Y	N
	64	Did you attend the Clinic, or have a nurse visit you at home, when your last baby was very young?	Clinic	Y	N
			Home Visit	Y	N
	65	Do/did you meet up with other mothers to get together and discuss your babies?		Y	N
	65a	If yes, where do/did you meet other mothers?	Friends houses	Y	N
			Baby Health Clinic	Y	N
			Community Centre	Y	N
			Church group	Y	N
			Playgroup	Y	N
			School group	Y	N
			Other.....	Y	N
	66	As a Health Professional, do you think it is difficult for some women to combine traditional and modern Australian practices?		Y	N


Section	Question N	Question	Choices or Response	Yes	No
Cultural background	67	As a Health Professional, have you experienced problems with family members over differences in ways of caring for a baby?		Y	N
	67a	If yes, who do you think is most likely source of conflict?	Mother	Y	N
			Mother in Law	Y	N
			Other family	Y	N
			Other in Laws	Y	N
SIDS Specific questions	68	Do/did you talk to mothers/parents about ways to prevent Sudden Infant Death Syndrome (SIDS, Cot Death)?		Y	N
	69	Do/did you give parents a brochure about SIDS?		Y	N
	70	Do/did you have posters in your workplace about ways to reduce SIDS?		Y	N
	70	If Yes, where is this poster?	Maternity Hospital	Y	N
			Children's Hospital	Y	N
			Community Health Centre	Y	N
			Baby Health Clinic	Y	N
			Doctors surgery	Y	N
			Other health clinic	Y	N
	Other.....	Y	N		
	71	Can you tell me the current recommended practices to help reduce SIDS or Cot Death?	Back sleeping	Y	N
Feet to foot of bed			Y	N	
No pillow			Y	N	
No bumpers			Y	N	
No smoking near baby			Y	N	
Firm mattress			Y	N	
Other stated.....			Y	N	

Section	Question	Question	Choices or Response	Yes	No
	72	Do you have any other comments you would like to make about the changes to baby care practices and how they have changed since your nursing training, if at all?			
	73	How many people live in your household?			
These questions are OPTIONAL	74	What is your highest level of education	Nursing Training in hospital setting	Y	N
			University/college trained	Y	N
			Additional University or college study	Y	N
	75	What is the average income of your household?	< \$19,999	Y	N
			\$20,000 - \$49,999	Y	N
			\$50,000 - \$69,999	Y	N
			\$70,000 - More	Y	N
	76	In what year were you born?			
		THANK YOU FOR COMPLETING THIS QUESTIONNAIRE ALL RESPONSES ARE CONFIDENTIAL			

FOCUS GROUP QUESTIONS:

1. How many people attended parenting classes with their first baby?
2. Did anyone attend the Baby Health Clinic with their baby?
3. Has anyone ever had a home visit from a Community Nurse?
4. Have there been any cultural issues raising your babies?
5. If yes, what are these?
6. What sort of sleeping arrangements do your babies have? eg.
 - a. Do they sleep in bed with you?
 - b. Do they have their own cots?
 - c. What sort of blankets do your babies have?
7. Have you seen this brochure? (Show brochure on SIDS)
8. Do you know the best ways to prevent SIDS in babies? Can you tell me these?
9. Who do you think was the biggest influence on how you have cared for your babies?
10. How are things different now from in your mothers day, with regard to caring for babies?

Reducing the Risks of SIDS



To Reduce the Risks of SIDS

- Sleep baby on the back or side.
- Keep your baby in a smokefree environment during pregnancy and for at least the first year after birth.
- Do not let your baby get too hot.
- Breastfeed your baby, if possible.

Early Victorian brochure recommending back and side sleeping as a way to prevent SIDS (National SIDS Council of Australia 1995)

Put your baby on the back to sleep.



The risk of SIDS is increased if babies sleep on their tummies. The best position for babies to sleep in is on their backs. Research shows that healthy babies placed to sleep on their backs are no more likely to regurgitate their feed and choke on vomit.

If you choose to sleep your baby on the side, make sure that his or her lower arm is well forward to stop rolling onto the tummy. The side position is unsafe for babies if they roll onto their tummies during sleep.

However, if your baby has certain medical or other conditions, side or tummy sleeping may have been recommended by your doctor or nurse.

Make sure your baby's head remains uncovered during sleep.



If a baby's head becomes covered during sleep the risk of SIDS is increased. Loose bedding can cover your baby's head. Tuck your baby in securely so that he or she can't slip under the bedclothes (see diagram). Quilts, doonas, duvets, pillows, soft toys and cot bumpers should not be placed where your baby sleeps during the first year.

Keep your baby smokefree, before birth and after.



The risk of SIDS is increased if the mother smokes during pregnancy. There is also some evidence to suggest that if fathers smoke while the mother is pregnant the risk of SIDS is increased. In fact, if both parents smoke then the risk is doubled. It is best for both parents not to smoke at all, but the less you smoke, the lower the risk of SIDS.

Babies exposed to tobacco smoke after birth are at an increased risk of SIDS. To keep baby smokefree, don't let anyone smoke near your baby - not in the house, the car or anywhere else your baby spends time.

It is often hard to quit smoking so ask for help. Call the Quitline on 131 848 or ask your doctor, midwife or infant health nurse for information and advice about quitting.



**KIDS & SIDS.
THREE WAYS
TO REDUCE
THE RISK.**

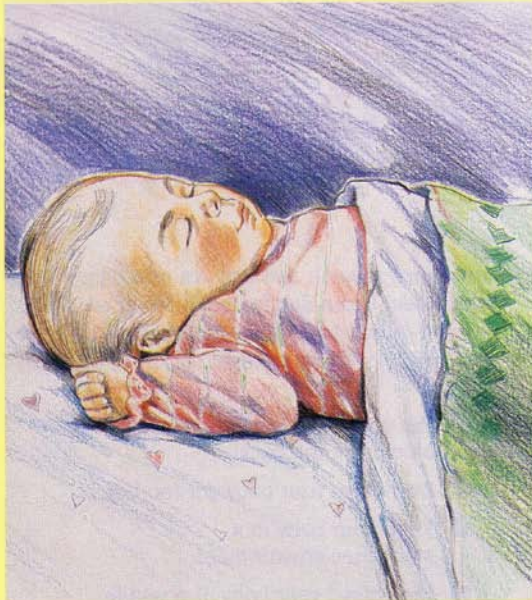
THE AUSTRALIAN COLLEGE OF PAEDIATRICS

NATIONAL SIDS COUNCIL OF AUSTRALIA

SIDS and Kids brochure produced in 1999 providing three clear messages, and recommending back only sleeping for infants

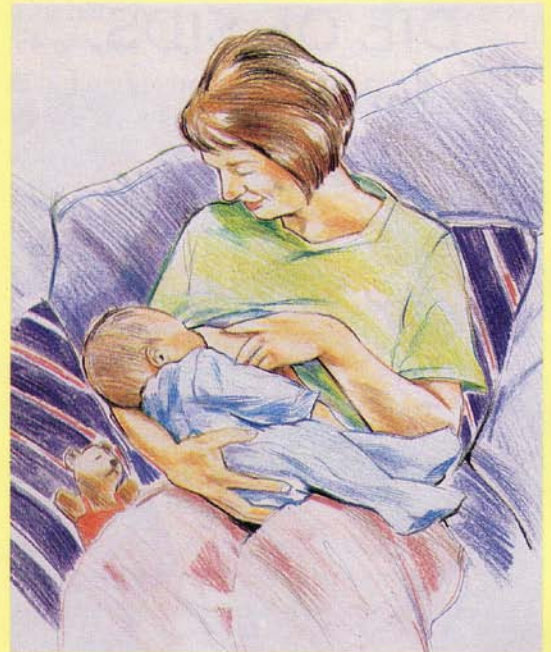
PUT YOUR BABY TO SLEEP ON THE SIDE OR ON THE BACK.

- Recent research suggests that babies who sleep on their tummies may have a higher risk of cot death.
- To sleep your baby on the side place the lower arm well forward so that your baby cannot roll onto the tummy (see picture on front cover).
- A few babies may need to sleep on their tummies for medical reasons. Ask your doctor if this applies to your baby.
- Sleep your baby on a firm mattress without a pillow.



BREASTFEED YOUR BABY.

- Breastfeeding your baby may reduce the risk of SIDS.
- Breastmilk is the best food for your baby.
- Breastfeed your baby if possible.



Note: These are only RISK FACTORS - they are NOT CAUSES, and they may or may not contribute to any one death. Research must continue to find the causes of SIDS. By reducing the risks we may reduce the number of Australian babies who die of SIDS each year.

Early SIDS brochure (1994) showing recommendations to sleep on back AND side and to breastfeed baby as a SIDS reduction strategy.

Cigarette smoke is bad for babies

- Cigarette smoke harms babies before birth and after. 
- Babies have a much higher risk of SIDS if there was smoking in pregnancy and they bedshare.
- Try not to let anyone smoke near your baby.
- If you need help to quit smoking, call the Quitline on 131 848 or ask your doctor or nurse for information and advice.

For more information

- Talk to your doctor, Child Health Nurse or support worker
- Call SIDS and Kids on **1300 308 307**
- Visit the SIDS and Kids website www.sidsandkids.org

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safe sleeping

🎵 Lullabies aren't the only things you'll need to know to put your baby to sleep.

SIDS and Kids latest brochure (2007) advocating ‘Safe Sleeping’ instead of SIDS reduction.

An advertisement for SIDS and Kids. The background is a photograph of a cot with a baby's head visible. The text is overlaid on the left side of the image.

How to reduce the risk of SIDS

- Put baby on the back to sleep, from birth
- Sleep baby with face uncovered
- Cigarette smoke is bad for babies
- Put baby's feet at the bottom of the cot
- Tuck in bedclothes securely so bedding is not loose
- Ensure quilts, doonas, duvets, pillows and cot bumpers are not in the cot

For a free SIDS and Kids Safe Sleeping Brochure contact:
1300 308 307
www.sidsandkids.org

sids and **kids**

SIDS and Kids advertisement in Sydney's Child Magazine July 2006



SIDS and Kids Door Hanger, containing three clear Safe Sleeping messages



Discussion paper: The great pram cover-up – a cautionary tale

Leigh Wilson MPH, Grad Cert Clinical Research Management, Dr Public Health Candidate (University of Sydney)
School of Public Health, University of Sydney, NSW

Abstract

In the early 20th century, infant care recommendations were vastly different from those of today, with practices such as a daily sunbath for a new baby commonly used by mothers^{1,2}. More recently, research evidence suggests the practice of deliberately exposing the skin of babies and young children to the sun is dangerous, and may increase the risk of skin cancer in later life³. To reduce the chances of sun damage to infant skin, the Cancer Council of Australia recommends parents cover strollers and prams with a light cloth to reduce infant sun exposure when outdoors³. Observations of parents indicate that these recommendations are being taken seriously, with parents covering prams and strollers; however, it has been noted that parents often use a drape when sunlight exposure is not an issue, such as in shopping centres and public places. A particular concern is the practice of 'pegging' heavy blankets around both the front and back of the pram or stroller, reducing adequate ventilation.

Much has been written about the quality of air in, and around an infant and the importance of adequate ventilation to help minimise the risk of sudden infant death syndrome (SIDS)^{4,5}. To date, no detailed studies have been undertaken to establish the quality of air a baby breathes when enclosed in a pram covered by a heavy blanket. Until further evidence is available, it is suggested that health professionals advise parents not to use fabric to drape prams or strollers unless their infants are in direct sunlight, and then to only use light sheets, muslin wraps or commercially available net covers designed to fit strollers and prams.

Key words: Sudden infant death syndrome; infant care; attachment; air quality; sun exposure.

What is already known on this topic

The Cancer Council of Australia recommends that babies in prams should be protected from direct sunlight by fabric casting a shadow to protect infant skin from ultraviolet radiation and possible skin cancer later in life.

Research has been undertaken investigating the effect of air quality around infants and suggests that covering prams or strollers with heavy blankets may in fact be harmful to an infant.

What this paper adds

This discussion paper highlights the increasingly observed practice of draping babies prams and strollers with heavy blankets, in some cases completely enclosing the baby

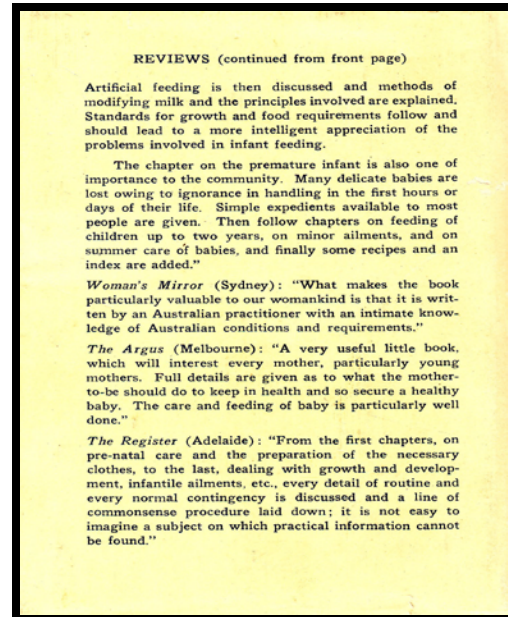
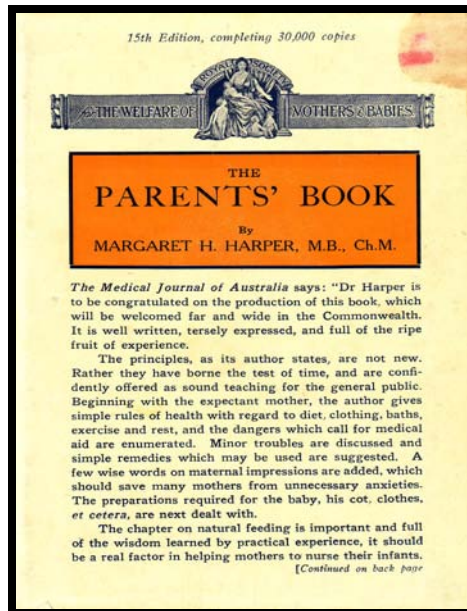
The paper also discusses the potential for adverse infant health outcomes as a result of a misinterpretation of evidence-based information.

Introduction

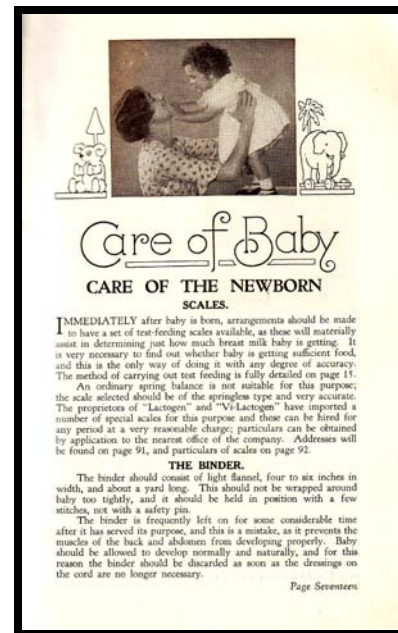
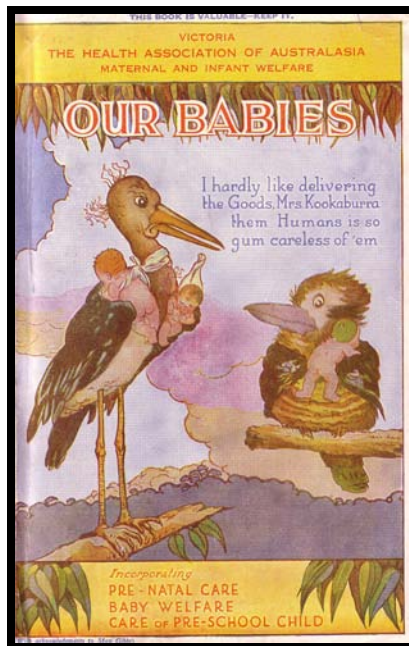
In the early part of last century, 'infant welfare work' as it was then called, was one of the main areas addressed by health workers in New South Wales. Infant care recommendations were vastly different from those of today, with practices such as 'feed by the clock' and 'daily sunbaths for optimal health' listed as essential knowledge for all new mothers^{1,2}. Most babies were wheeled in prams, lying recumbent facing their mother, a method which is now supported based on evidence

of 'attachment theory'⁶. 'New fangled' items such as 'push carts' or 'strollers' were considered inappropriate (if somewhat dangerous), for babies under the age of 12 months⁹.

The ensuing years have seen significant changes to the way in which we care for infants. Rapidly developing medical technology following the Second World War, and the subsequent increase in medical research, led to a greater body of research evidence on which guidelines and recommendations for practice could be based. In addition, a



ABOVE: Front and Back cover of 'The Parents Book' Dr Margaret Harper (1938)



ABOVE LEFT: Cover of 'Our Babies' (1942)

ABOVE RIGHT: Baby Care instructions taken from 'The Lactogen Mother Book' (1938)

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