

**Mothering the Technology Dependent Infant: A  
review of the literature.**

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## **Abstract**

**Background** - The role I am investigating for the purpose of this report is that of the mother to the Technology Dependent (TD) infant in the Waikato DHB region who demographic statistics inform us is likely to be of European or Maori ethnicity. Whilst TD infants were historically cared for in hospital, a shift in healthcare policy transferred the responsibility of care to family caregivers in the home – from the public arena to the private.

**Aim** – The aim of this paper is to provide a comprehensive literature review on mothering the TD infant living at home to identify what support can truly make a difference.

**Method** - The study reviews the primary research, relating to the experience of mothering the TD infant, using a theoretical lens informed by critical social theory and feminism. It was conducted via keyboard searches using various electronic databases. The articles were examined for commonality

**Conclusion** - This inquiry clearly demonstrates that there is inadequate societal support for TD infants and that the responsibility for caregiving provision is inequitable, as the extraordinary demands of these children are placed almost entirely on the mother. The commonalities extracted from the data were grouped into four themes: invisibility/visibility, absolute involvement, burden of care, and agency and mothering. Care delivery appropriate to each individual family will improve outcomes for the infant, caregiver and family.

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# CHAPTER 1

## *Purpose*

The purpose of this research project is to encourage medical professionals, supporting mothers who are caring for a technology dependent (TD) infant at home following discharge from the Neonatal Intensive Care Unit (NICU), to deeply reflect on their service delivery. And to consider how the presented recommendations could be implemented within their practice to ensure support provision is meaningful and significant for each family. The recommendations were developed by synthesizing and critiquing current understandings and knowledge to illustrate how support is currently delivered, and after identifying what is the role of the mother of the TD infant. An understanding of the mothers experience within this role was imperative as the directive influencing changes to care delivery.

## *Aim*

The aim of this paper is to provide a comprehensive literature review on mothering the technology dependent infant living at home to identify what support can truly make a difference.

## *Background*

### **How the Technology Dependent Infant evolved**

Society influenced the way premature and sick infants are cared for with the introduction and ongoing development of what is known as the Neonatal Intensive Care Unit (NICU) in the 1960's (Davis, Mohay & Edwards, 2003). Prior to the establishing of these units at risk infants largely were the responsibility of the family who cared for them palliatively at home until they died or miraculously survived. This role, predominantly carried out by the mother, was transferred to the hospital in the mid 1970s with the institutionalization and professionalization of infant care of the technology dependent infant which resulted in large part from the extensive technological advances of that time (Davis, Mohay & Edwards, 2003). NICUs were regionalised and situated only in the main city centres, which meant infants needed to be transported, often long distances, away from family and friends (Ministry of Health, 2004). The act of caring for fragile infants became medically controlled bringing with it the initiation of a dependence on technology for the survival of the

infant, hence the classification of infants who were ‘technology dependent’ (TD). At this early time the principles of care in the unit “stressed cleanliness and sterility to the exclusion of active maternal involvement” (Davis et al., p. 580). While survival rates for the infants improved dramatically major side effects arose due to maternal-infant separation, including absence of maternal-infant bonding and delayed infant developmental progress. In some instances obstetricians had difficulty persuading mothers to take their children back (Davis et al.). Different ways of caring for these infants needed to be found that promoted maternal involvement so the idea of home as an alternative to hospital was contemplated.

A parallel and perhaps even greater concern was the creation of an unsustainable funding dilemma within the health budget for the medical intervention costs, which necessitated a drastic rethink for care provision of this group of infants (Peter et al., 2007). Iatrogenic complications were also becoming evident in this population of hospitalised infants for whilst survival rates were reaching all time highs, the prognoses for these tiny infants were not improving, with an extremely high proportion of the infants requiring ongoing nursing care (Peter et al). Options for this ongoing care were investigated with home being the most economically viable. Government adopted the policy to transfer the responsibility from the hospital to the home and the ensuing financial cost of caring for these infants transferred to the invisible welfare system of family caregivers (McKeever, 1999; Wang & Barnard, 2004). Care provision varied dependent on the resources of the individual family, both financial and socially.

The New Zealand government adopted this shift in healthcare policy in the 1990s and since then the country has seen a continual growth in the provision of medical and nursing care in the home (National Advisory Committee on Health and Disability, 2010). This report examines the home care for TD infants by looking closely at the experiences of mothers caring for a high needs infant. Technology dependent infants can also be described as ‘medically complex’, ‘medically fragile’, or ‘infants with special health care needs’. The Waikato District Health Board (DHB) describes the medically fragile infant as:

A child with a medical condition who is under the care of a paediatric specialist and requires daily nursing care and/or has significant risk of a life-threatening event in the next year and is either;

- Technology dependent in terms of a medical device to compensate for loss of bodily function, or
- Requiring substantial daily skilled nursing care to avoid death or permanent disability, and/or
- Families or whanau who face extraordinary demands in caring for their special needs child(ren) related to the complex and combined effects of a chronic illness, that is a family whose coping skills and family functioning are being eroded to an extreme degree causing repeated crisis” (Waikato District Health Board, 2004).

The United States Congress’ Office of Technology Assessment (OTA) definition is very similar and states “Technology dependent children require ‘a medical device to compensate for the loss of a vital bodily function and substantial and ongoing nursing care to avert death or further disability’ (United States Congress, Office of Technology Assessment, 1987, p. 3). These definitions epitomize the TD infant, illustrating the complexity of needs, determining the care provision necessary.

For the purposes of the study data collected by myself over a 12 month period in 1996 showing the numbers of medically fragile infants who discharged home from the NICU at Waikato hospital. The range of diagnoses indicates the diverse needs of the TD child which vary greatly in both their characteristics and their level of need.

<b>Medically Fragile Infants Discharged Home from Waikato Hospital NICU in 1996.</b>	
Cystic Fibrosis	1
Tracheostomy	2
Ileostomy/Gastroschisis	7
Cardiac	15
Blood disorders	3
Spina Bifida	3
Failure-to-thrive (nasogastric tube)	11

Neurological	13
Home O2	12
Syndromes/ Other	14
<b>TOTAL</b>	<b>81</b>
(Waikato DHB, 1996).	

The average number of infants born in the Waikato region each year is around 5000. Of these births 49% will be European, 41% will be Maori<sup>1</sup> and 10% other ethnicities. The proportion of Maori infants born in the Waikato compares to a National average of 30%. Preterm birth rates are noted to be significantly higher for Maori babies (6.31 per 100 live births compared to 5.54 for European). Extreme prematurity and congenital anomalies are the leading cause of neonatal mortality in the Waikato DHB and these mortality rates are consistently higher for Maori infants. A large number of these children live rurally 23% compared to 15% for the rest of the country. Demographically the Waikato region has a high Maori population but relatively few Pacific Island or Asian families. 1 in 4 children live rurally. For every 625 children born each year in the Waikato 1 will be “Medically Fragile”. These figures tend to suggest that “as a result of its demographic profile Waikato might expect higher rates for conditions for which socioeconomic disparities are most marked, as well as higher rates for conditions which ethnic disparities for Maori children are prominent” (Craig, Anderson, & Jackson, 2008, p. 11).

In New Zealand, between 1986 and 1997 a period of huge growth in social inequalities was seen, in particular an increase in income related health disparities (O’Dea & Howden-Chapman, 2000, cited in Tobias & Howden-Chapman, 2000), with Maori being disproportionately affected by the changes (Chapple, 2000). The government of this time adopted neoliberal economic and social policies that resulted in major structural changes in New Zealand society including economic deregulation and the privatisation of state assets especially in forestry, mining and transport, sectors which had traditionally employed many Maori (Chapple, 2000). Maori unemployment rates rose rapidly, reflected in a subsequent drop in overall socioeconomic status. The way New Zealand society is organised reflects the colonial past and continues to favour the majority ethnic group (Pakeha) perpetuating the

1. Maori means a person of the Maori race of New Zealand; and includes any descendant of such a person (Maori Purposes Act 1974).



historical inequalities between ethnic groups (Tobias & Howden-Chapman, 2000). Important here is a greater understanding of how these factors of inequality shape people's perceptions of their identity and the links between that identity and their health behaviour (Kearns & Moon, 2002). It is clear that policy development needs to reflect a cultural awareness of the socio-economic inequalities and subsequent health disparities that are experienced by Maori.

### **Who will care for this infant?**

Data informs us that every year approximately 81 TD infants from the Waikato region transition from the newborn unit to be cared for in their own home. A high proportion of these infants will be Maori (Craig, Anderson, & Jackson, 2008). The discharge from hospital occurs as soon as the infant is determined medically stable and protocols based on American research provide guidelines for the timing of the discharge (American Academy of Pediatrics, 1998). It is at this stage that a transfer of responsibility for the ongoing care occurs. Professionals assume that parents will want to be involved in the nursing care of their infant and literature suggest that parents are in a powerless position from which to negotiate caregiving roles and that it is the mother who takes on the most arduous tasks of caring (Goodhead & McDonald, 2007; Kirk, 2001; McKeever, 1999). National research reveals

that informal caregiving can place a heavy burden on those involved, that this burden falls disproportionately on women, and there is debate over whether the care of those with long term disability should be primarily a public cost or a private one. (Goodhead & McDonald, 2007, p. 5)

Informal caregiving in general is an issue that has been targeted by researchers and policy makers over the last 30 years in many countries including New Zealand. The National Advisory Committee on Health and Disability (NAC) first highlighted the needs of informal carers in 1998 in its report *How Should we Care for the "Carers?"* (National Advisory Committee on Health and Disability, 2010). However, 12 years later it appears the same issues raised in that report are still evident today. In particular the government has a responsibility to address Maori health as part of honouring the partnership between iwi and the crown under the Treaty of Waitangi, and the Maori Health Strategy provides guidance for Maori policy development (King

& Turia, 2002). Informal care is provided without payment by the caregiver and time spent delivering care varies greatly depending on the needs. It makes sense for government to invest early in protecting the health and well-being of this unpaid workforce by provision of necessary supports, including financial, respite, social and other. There is a direct cost saving to government in recognising the unpaid contribution of carers to the economy and investing early in protecting carers' health and wellbeing. The "unpaid contribution of informal caregivers to our economy is likely to be significant, in a similar manner to unpaid child care and domestic work" (NAC, 2010, p. 9). If informal carers are not provided with adequate services to support them to carry out their role in a sustainable way, they are likely to become more reliant on the health and disability system in the future than if the right supports were provided in the first place (NAC, 2010).

Whilst this transfer of care sees an avoidance of fiscal crisis in the health sector it creates another dilemma for female caregivers that cannot be ignored. Infants now require extensive care at home that is expensive (for the family), labour intensive, medically complex, and emotionally draining. It is clear this shift of responsibility for care from the hospital to the home produces a range of issues that require psychological, social, ethical, financial and policy solutions (Wang & Barnard, 2004). These issues must be considered in conjunction with the benefits of home care provision before a move to home occurs.

### **Mothering Ideology**

The mother is likely to assume the primary responsibility of caring for her TD child following discharge from the NICU (McKeever, 1991). In order to participate confidently in this role she must first establish an identity as a mother in order to gain agency within this role (Esdaile & Olson, 2004). So what does this mothering role look like and what are the influencing factors that allow her to participate fully in it? My thoughts are that biology alone does not make someone a mother but rather it is a social role taken up by women (Kukla, 2005). Influencing factors which shape this role include cultural, demographic, historical, socio-economic and many others. More specifically the mothering role I am investigating for the purpose of this report is that of the mother to the TD infant in the Waikato DHB region and as demographic statistics have informed us she is likely to be of European or Maori ethnicity.

The dominant mothering ideology in New Zealand can be described as ‘intensive mothering’ (Hays, 1996). This is a

child-centered, expert-guided, emotionally absorbing, labour intensive, financially expensive ideology in which mothers’ are primarily responsible for the nurture and development of the sacred child and in which children’s needs take precedence over the individual needs of their mothers. (Hays, p. 46)

This dominant construction creates unsustainable role expectations (Glenn, Chang & Forcey, 1994; Johnston & Swanson, 2004; Williams, 2006). Unfortunately while the all-consuming role of motherhood is an unobtainable goal many mothers feel compelled to strive to be the ideal mother based on how the dominant societal values dictate the mothering ideology. Rothman (1990) suggests that we need to reflect back to previous generations when “mothering was not something women did it was what women were” (p. 7). Where motherhood used to be an accepted part of everyday life we now have to seek “training” and “expert” advice to mother our children. However “mothering from a book” can exacerbate the anxiety and guilt because you don’t learn to trust yourself (Brasovan, 2010).

Within the public discourse on mothering there is widespread exposure to the increasing amount of information on mother-child attachment (Esdaile & Olson, 2004). This exposure reiterates the myth of the perfect mother and the belief that mothers are directly or indirectly responsible for her child’s emotional, social, physical and intellectual well-being (Tummala-Narra, 2009). The process of emotional bonding first appeared in the mid 1970s and by the 1980s was an accepted term within the maternal world (Tummala-Narra). It has since developed into a hegemonic discourse within medicine and society that has the ability to create guilt for new mothers because of the implications it inflicts on the child rearing process (Aston, 2008). The term bonding is used interchangeably with attachment and together they have been extensively researched, particularly in the areas of nursing, psychology and medicine. Attachment theory was first formulated by psychiatrist and psychoanalyst John Bowlby. The theory proclaims that strong bonds need to be developed primarily in infancy with at least one primary caregiver for social and emotional development to occur normally (Bowlby, 1982). Debate surrounds this theory and research has

significantly modified its content but in general its concepts are adopted by today's society and used in the formulation of social policies (Berlin, Zeanah, & Lieberman, 2008).

Attachment can be described as a relationship and the relationship can be disrupted by life events (Holditch-Davis, Schwartz, Black & Scher, 2007; Poehlmann & Fiese, 2001; Teel, 1991). Mothering a TD child has the ability to cause a major disruption to the attachment relationship (Teel). Holditch-Davis et al inform that positive relationships promote improved interaction between mother and child which directly influence health and developmental outcomes. For attachment relationships to develop and remain strong there must be mutually satisfying interactions between a mother and her child, as this essential infant-mother relationship develops in a reciprocal, bidirectional manner over time (Poehlmann & Fiese). Mothers of TD infants must work harder to initiate and maintain interactions yet at the same time they receive fewer positive responses from their child (Holditch-Davis et al.). Bowlby (1982) argues that the first six months after birth is a crucial time for an affective tie to form between infant and mother. Other authors hypothesised that it is as early as the first hour that is essential (Klaus & Kennell, 1976 cited in Fegran, Helseth & Fagermoen, 2008; Schore, 2000). Either way literature alerts that close contact between a mother and her infant must occur as soon as possible after birth and separation should be avoided whenever possible (Grant & Kearvell, 2008; Leifer, Leroerman, Barnett & Williams, 1972). Evidence shows that hospitalisation interrupts the natural attachment process between an infant and mother and can affect their ability to bond reciprocally (Bowlby, 1982; Fegran, Helseth & Fagermoen, 2008; Grant & Kearvell, 2008).

Motherhood is associated with ambivalence caused in large part through mothering in isolation (Esdaile & Olson, 2004). Esdaile and Olson describe how isolation is a contradiction of female development as connectedness is essential and its absence in motherhood potentially becomes a misery of loneliness. Isolation and the infant's overwhelming health challenges compromise the mothers' ability to overcome obstacles and limit her ability to participate fully in the mothering role.

### **Myself as a Nurse who is also a Mother**

In my role as a Neonatal Homecare nurse I am in the useful position of entering the private domain of these women's homes. What is covered up and hidden to the outside world becomes exposed and visible to me. I look back to when I was working in the public hospital arena in the Neonatal Intensive Care Unit where my work was very much task orientated. Every working day was spent learning the tasks required for me to become an expert nurse - swiftly changing central venous lines, accurately monitoring closely and reporting any changes in vital signs, giving crucial medications quickly and competently and the many, many other tasks all became second nature to me. My days were spent largely in control of complex medical situations, in a high profile role that was easily visible to the public. Job satisfaction and personal confidence were high as I was continually commended by those surrounding me on jobs well done. I believed too that I practised family centred care by including the mother as much as possible in the care of her hospitalised infant. I 'told' the mother that if she came to the nursery every four hours she would be invited to help with her infant's care. Many a time I remember being frustrated because the infant's mother had not arrived at the allocated time and as the clock struck the hour determining the time to commence I would competently perform these infant cares without her.

In 1999 the opportunity arose to work in the community as a Neonatal Homecare nurse. I had twenty years of experience in the NICU and I was ready to take these skills into the community, in what I thought would merely be a continuum of the care I had given to these infants in the hospital. I was extremely competent with equipment so technology would not be a problem; nasogastric tubes and gastrostomy tubes were easily cared for, medication could be monitored and altered swiftly following a quick consultation with the paediatrician, and growth and weight could be achieved through revision of feeding plans and additives. I foresaw very few problems and predicted this role would be easy.

What I did not count on was the change in power relations once the infant was transferred home. Care that had previously been dictated unconsciously by me was now being determined by the infant's mother. Information supplied by me was now being questioned and no longer taken for granted by the mother as being the best for

her infant. A typical scenario might see the prescribed four hourly feed time roll around and the infant's mother still trying to get her other three siblings dressed and off to school. The family car might be broken down and no money to fix it so the mother and children walk the three kilometres to daycare and school. Perhaps one of the children is unwell and really needs to see a doctor but an outstanding debt at the medical centre means the family are not welcome. Scenarios like this made it a little clearer why this 'unreliable' mother had not been coming in to do the 8am feeds as expected of her when the infant was in the NICU.

The longer I was in the role the more frustrated and worried I became, as planned infant care constantly needed to be revised. Infants often did not progress as quickly as predicted and optimum growth and health outcomes were not easily achieved. I observed ever-increasing home life dilemmas as these mothers fought for control of a role that, according to our society's paternalistic view should have come naturally to her.

### ***Conclusion***

My frustrations at wanting to do good but struggling to do this in today's economic climate was a constant concern. I was invited into these families homes but under the condition that I was just that, an invited guest. My knowledge and advice was respected and listened to but not always taken in the exact way I prescribed it. Mothers as caregivers made their own diagnoses of how their infants were and structured and changed care as they deemed best. Also I had not expected what I saw in many homes and was astounded at the level of responsibility and the workload placed on mothers caring for the TD infant. In my role as Clinical Nurse Specialist for Neonatal Homecare I argue that the work of the mother caring for the TD infant at home is invisible and unvalued by society and it is this invisibility that denies it the societal support it needs. Background reading has provided evidence to support this assumption and the inquiry seeks to expose the experiences of the mother caring for her TD infant at home to promote reflection on practice and ultimately create new ways of providing support.

### ***Summary***

Chapter One presented the background of how the phenomena of the TD infant evolved and how its conception dramatically increased fiscal costs within the health

system. Alternative ways of care provision were investigated and the notion of caring for this medically fragile infant in the home environment was initiated, supported by evidence that hospitalisation compromised the mother-infant bond. Debate surrounds whether this care is placing the entire burden on one person, the informal caregiver who is predominantly the mother. The dominant ideology of motherhood and the mother-child bond were reviewed. Socio-economic and ethnic inequalities within New Zealand's health system were highlighted. Personal experience as a Clinical Nurse Specialist in the area of Neonatal Homecare was presented and thoughts and experiences described.

Chapter Two introduces the methodology this inquiry adopts to review the literature, presents ethical considerations and identifies limitations of the approach.

## **CHAPTER 2**

Chapter Two provides an overview of the research question, “how can support be improved for mothers caring for TD infants at home”, and establishes the most appropriate methodology to answer this question. It discusses the methodological approach the study will take and the cultural and ethical considerations of the study. Study limitations are identified.

An important focus in nursing is the advancing role of qualitative research and its contribution to clinical practise. This type of inquiry is able to explore the relationship between health and social factors, such as socio-economic position, ethnicity, gender and education. Using this method researchers are able to uncover factors that cause health disparities between groups of people. For this inquiry I have chosen to use a Critical Social Theory framework that is informed by feminist principles with literature that has come from a qualitative paradigm.

Critical social theory has origins in the Marxist orientated Frankfurt school in Germany in the 1920s and is inspired in large part by the writings of Marx, Habermas and Friere (Weaver & Olsen, 2006). Underpinning this philosophy is the belief that society is structured by meanings, rules, convictions or habits that are historically and socially constructed (Fulton, 1997). The dominant social group imposes these traditions highlighting the power relationships that inform what is known or what constructs knowledge. These rules are adhered to by social beings and in time become taken for granted (Boutain, 1999). Critical social research aims to “identify and overcome oppressive structures by exposing power imbalances and assisting the oppressed to take action” (Young, 2008, p. 96). Freire (1996) adds that for the oppressed to surmount the situation of their oppression they must first critically recognise its causes. Once the causes are exposed, through the best suited form of inquiry, a new situation can be created. This inquiry seeks to identify those causes and in doing so have the potential to inform social change by critiquing current understanding and knowledge to illustrate how support can be improved for mothers



caring for a technology dependent infant. Critical theory informs us that outside forces with greater power, prestige and status control oppressed groups, and for this group of mothers those forces are societal institutions' ability to determine how they will or will not support her in this altered mothering role. Cudd (2006) suggests that whilst oppression originally was applied as personal violence and enslavement the term has evolved to take on a more social connotation. The author describes institutionally structured constraints such as wealth income, social status, legal rights as causative factors for oppression, but of particular relevance to informal caregiving are the constraints of obligations and burdens. Arguable relieving portrayed burdens and obligations will assist in preventing oppression in mothers of TD infants.

Hartrick Doane and Varcoe (2005) use the term relational nursing practice as a nursing approach that sees the world through a relational lens, which is "always assuming and looking for how people, situations, contexts, environments, and processes are integrally connecting and shaping each other" (p.51). Therefore the nurse who incorporates relational theory into homecare practice is able to ascertain what is relevant and significant for the mother and assist in overcoming oppression.

According to Landes (1998), in western tradition the state is the public arena and is the site where people contest laws, policies, and contracts that govern personal and social conduct. In contrast the private realm is defined as the home and it portrays family, comfort and individual identity. Historically the public realm was the domain of the male and the private realm that of the female, who within this realm assume the responsibility of the upbringing of healthy, socially and morally correct children. Crucial to the relegation of men and women to different realms were the ideas of inherent characteristics. Male characteristics portrayed rationality, thought and production, while women portrayed delicacy, caring, and dependence. It was these gender-specific connotations that relegated women to the private domain due to her supposed biological unsuitability for public life (Landes). By being confined to the private, domestic sphere women's lives and work were to a large degree made invisible, a universal cause of women's oppression. An example is that of housework. Because it is unpaid it can make women dependent on men and therefore devalued since their work is outside the meaningful sphere of public economic production. Historically feminist discourse has a long standing concern with the segregation of the private and public spheres and as such it continues to intensely preoccupy the

women's movement and feminist research (Marshall & Anderson, 1994). Greater recognition, validation, and social support for care work is needed to elevate the importance of the private domain and to achieve empowerment and emancipation. As a result of economic changes and people's expectations of material goods modern women are largely in paid work. Not being able to work because of caregiving requirements in the home may be a source of oppression. Feminist research can achieve this goal as its core themes include studying women from their perspective, it is politically motivated and it has a major role in changing social (gender) inequity (Harding, 1991; Putnam Tong, 1998).

My work around mothering aligns itself with the work of Ann Oakley who is a distinguished British sociologist, feminist, and writer. Her interest in feminism began in the late 1960s when, as the mother of two young children, she realised how deeply undervalued and isolating the work of mothering was and her research in this field began. Her more recent research interests have increasingly been in the area of social science methodology and the contribution of the social sciences to public policy. It is for this reason I turn to these writings to guide my work and provide the lens through which I will review the literature. In her most recent work she analyses the current 'paradigm' war about 'qualitative' and 'quantitative' methods, and argues that this is an example of a broader gendered division of labour between the social and natural sciences (Oakley, 2000). Oakley explores the history of experimental 'ways of knowing' and the applicability of this approach in the social policy field. She also develops methods for systematic research reviews that have the ability to deliver relevant and reliable research evidence to policy-makers and the public.

### ***Method***

The method chosen for this project was a critical review of primary research inquiries. The focus of the inquiry is on women. It is intended to explore the experiences of women but does not seek to devalue the contribution that male family members may make towards the care of children. Because the review is based on a body of completed works it is essential that it is conducted with the same rigour to ensure results portray an accurate and balanced summary of all research on the topic and provide direction for future research. A review of the literature was used with distinct

stages including the search for relevant studies (data collection), critical appraisal, data extraction and data analysis (Mulrow & Cook, 1997).

### **Data Collection, Critical Appraisal and Data Extraction**

The review was conducted via keyboard searches using electronic databases and included CINAHL, Proquest, Google Scholar, Ebscohost, Science Direct, MEDLINE, Pubmed and Nursing Reference centre. The reference path used the key words “mothering” or “informal caregivers” and “technology dependent infants”, “medically fragile infants” or “infants with special needs” in relation to home and support. The time frame of articles to be reviewed was 1990 to the present time. Initially the research was planned to include only articles from 1999 but relevant articles written by McKeever provided deep insight into the research question and were too valuable to exclude. A further secondary online search of McKeever’s works produced two articles that are more relevant. In addition the reference list of relevant articles were scanned and the ensuing publications were included if useful.

The primary research studies reviewed were critically appraised to determine the validity, such as determining whether the original methods used could be trusted to provide a genuine accurate account of the phenomena being studied. Particular emphasis focused on bias (for example in the selection of participants), the rigour of the methodology and the methods used during the data collection and analysis. The areas examined were relevance, clarity of the research question, appropriateness of the framework, context, sampling, data collection and analysis and reflexivity of the account (Mays & Pope, 2000). A total of 16 articles that met the criteria were included in this review.

### **Analysis of the Data**

The major tenets of feminist theory were used to form the theoretical framework for this inquiry. “Feminist research aims to interpret, explain and validate women’s experiences, concerns and approaches to their world. It is important therefore that analysis of the data does not diminish the very thing it is seeking to expound” (Scheider, Elliot, LoBiondo-Wood & Haber, 2004, p. 211).

The analysis is influenced by the work of critical theorists, in particular the writings of Paulo Freire. Ann Oakley's work also influences this inquiry because while much of her research focuses on medical sociology and women's health she has also made important contributions to debates about sociological research methods.

The primary research was read and analysed, with particular emphasis on viewing the data through a critical social, feminist lens, and the identified themes extracted and placed into table format (see Appendix 2). These themes were then analysed and discussed. Care was taken in the extraction of the data to minimise the risk of transcription errors and to ensure the extracted data provided an accurate and balanced summary of all research on the topic.

### ***Cultural and Ethical Considerations***

Because this study is a critical review of the literature ethics approval from Wintec and Waikato District Health Board ethics committees were not required. However, there are ethical considerations to be taken into account. In the representations of the mothers, with whom I work in my role as Clinical Nurse Specialist – Neonatal Homecare, I acknowledge the small amount of TD infants in the Waikato region and the very real possibility of reader identification of the family. To ensure anonymity was withheld examination of the concept was explored revealing anonymity must evoke an absolute lack of connection between a fact or an act and a person (Finocchiaro, 2006). Also considered was the principle of informational self-determination, a similar principle to the right to privacy. Weston (1970) pens this as “the right of the individual to decide what information about himself should be communicated to others and under what circumstances” (Westin, 1970). Scenarios, therefore, are an amalgamation of several clients and therefore not based on any one family.

As previously shown Waikato DHB statistics indicate that a large proportion of the mothers living in this region are of Maori ethnicity. Maori infants who are born prematurely are also highly represented (Craig, Anderson, & Jackson, 2008). As a nurse who is not of Maori descent I am ethically aware of the Treaty of Waitangi and the partnership it promotes between Iwi and the Crown (constitutional system of government) when addressing the unique health needs of Maori (Tolich, 2001). The

Maori Health Strategy “He Korowai Oranga” provides background and guidance for this review and the recommendations that evolve from the inquiry will be informed by the Whanau Ora Health Impact assessment approach where they have impact on Maori carers (Ministry of Health, 2007). This approach involves facilitating positive and adaptive relationships within the whanau and recognises the interconnectedness between health and other contributors. As an assessment tool it is a formal approach used to predict the potential health effects of a policy on Māori and their whānau and is intended for use by policy makers from the health sector, including the Ministry of Health, District Health Boards and others. As identified in the background Maori are statistically far more affected by economic policy (Chapple, 2000).

### ***Significance***

This research aims to contribute to a wider visibility of the position of women caring for a medically fragile infant as these fragile children are being cared for in the home in all regions of New Zealand (Cust, Darlow & Donoghue, 2003). Many of these families live in geographically remote areas, are isolated from community supports, and are more likely to be Maori. Background data informs this report that mothers caring for their TD infants are not well supported by society and the role they play in society is largely invisible and unrecognised. Resulting information will be made available to government policy planners, health professionals and families caring for these infants in order to actively promote social change by recommending how support can be improved for mothers. The results will be reported to

- Wintec as a Masters project
- Nursing and medical professionals via conference presentation and articles presented to appropriate journals for publication
- Community Child Health service providers
- Mothers of TD infants who, as a result of clear identification of support needs, will experience improved health outcomes for their infant, themselves and their family.

### ***Limitations***

Finally, this review aimed to summarise both New Zealand and International literature, although because of the very limited number of New Zealand studies, the international research was relied on heavily. Studies included in this review were conducted in Iceland, United States, Sweden, United Kingdom, and Canada.

The study has not taken into the account the effects of socioeconomic status, age of the mother, family size and structure, maternal education level and other variables, which would be a study in themselves.

Data relating to Maori mothers caring for a TD infant is scarce and therefore very limited in the review. The devastating effects of the colonisation process over many decades resulted in social, economic and health inequalities that cannot be ignored (Ballara, 1986; Davis, Graham & Pearce, 1999). A recent study documenting experiences of Maori SIDS mothers provides powerful descriptions of personal lives and social environments that create “non-modifiable” health risk factors (McManus, Abel, McCreanor, Haretuku, & Tipene-Leach, 2005). Constructing these experiences as non-modifiable risk factors hinders the development of policy and health promotion interventions that could improve the conditions in which Maori mothers live and raise their babies (McManus, Abel, McCreanor & Tipene-Leach, 2010).

### ***Summary***

Chapter Two examined the methodology that provides the frame work for reviewing the literature. As a researcher I have an ethical obligation to ensure cultural awareness is shown of the known socio-economic and subsequent health disparities experienced by New Zealand Maori. Chapter Three will present the literature in three identified themes – government policy, gender inequalities and medicalisation.

## CHAPTER 3

Chapter Three summarises 16 reviewed primary research articles that met the selection criteria for the review and which provided data for analysis that meet the aim of this study. Four common themes were identified from the literature – ‘invisibility/ visibility’, ‘absolute involvement’, ‘burden of care’ and ‘agency and mothering’ – and each theme is discussed separately.

### *Themes*

#### **Invisibility/ Visibility**

One of the main themes to emerge from reviewing the literature is the extent to which government policies affect the capacity of mothers to care for their TD infants in the home. In the late twentieth century individual families held responsibility for healthcare and institutional care was unheard of (Bjornsdottir, 2002). Bjornsdottir describes how in the early twentieth century charitable organisations offered an alternative for the provision of healthcare. Over time the welfare state was developed through the introduction of taxes, and healthcare became the responsibility of the state. Scientific knowledge rapidly became the dominant discourse and this empirical way of knowing advised that hospital was now the best place to receive medical and nursing care (Bjornsdottir). With this new form of health provision came inflated fiscal costs as rapidly advancing scientific knowledge and technology saw an increase in the survival of patients and a corresponding increase in chronic health conditions. Government called for a restructure for healthcare delivery, which has seen in the early twenty-first century a complete turnaround seeing care responsibility placed back into the home (Bjornsdottir).

Authors agree there are ethical implications and gender disparities that have arisen since public policy changes promoted home care for medically fragile infants (Bjornsdottir, 2002; Henry, 2008; McKeever, 1999; Mentro & Steward, 2002; Thyen, Kuhlthau & Perrin, 1999). These issues are highlighted in Goodhead and McDonald’s (2007) report prepared for the National Health Committee exploring the roles of informal caregivers caring for a family member in the home in New Zealand. Data

obtained from critically reviewing the literature indicates that corresponding reports in Iceland, United States, Sweden, United Kingdom, Canada, and Australia correlate closely with issues identified in New Zealand. Whilst there are limited local or New Zealand research articles that have explored experiences of mothers caring for their TD infant in the home there is a significant amount of other New Zealand data pertaining to informal caregiving (of any family member) and ensuing government policy (Goodhead & McDonald; Ministry of Health, 1998; NAC, 2010). Goodhead and McDonald argue that there is reason for concern with the cost-shifting measures adopted by government to move caregiving recipients from the public sphere of health institutions to the private sphere of families. International sources support this and agree that the move is concerning and that it is the invisibility of this form of caregiving that prevents it from societal recognition and subsequently receiving the support it warrants (Bjornsdottir; Glasscock & Hayes, 2000; Henry; Kirk, 2001; McKeever, 1991; 1999; Mentro & Steward).

Most sources (Bjornsdottir, 2002; Kirk, Glendinning & Callery, 2005; McKeever & Miller, 2004; McKeever, 1999; Thyen et al., 1999) agree that informal caregiving is not a career recognised by society as a worthwhile pursuit, nor is it viewed as a productive part of the health system. This leaves the care provider socially, financially and legally marginalised (Bjornsdottir; Glasscock & Hayes, 2000; Henry, 2008; Kirk, 2001). The outcome of this marginalisation process further places the informal caregiver in an ambiguous social position, one that is subordinate to those in the public sector who influence/establish policies and practice (McKeever, 1991). Again this lack of recognition down plays the work of the already invisible carer and therefore assumes no part in policy making. McKeever acknowledges this fact when she states that competition for scarce resources is huge and visibility is central to the establishment of public policy. Henry (2008) suggests that there is a need to establish databases that identify the TD infants in the community and their specific needs to inform future policy development.

Nurses supporting mothers who care for their TD infant at home have both experiential and theoretical knowledge and as such are in the ultimate position to help shape and influence policy development and practices related to this homecare (Bjornsdottir, 2002). McKeever argues that the enormous social value of caregiving



work is finally being acknowledged, discrediting a clear division between the private and the public domain and creating the concept of an “intermediate domain”. This domain would “complement, parallel, compete with, or replace unpaid work in the private domain” (McKeever, 1999, p. 188). Therefore mothers, as caregivers to TD infants, conceptually have the ability to simultaneously hold positions of power within both the private and public domains and then use these positions as a source of control to “provide a powerful avenue for bargaining and exchange” (McKeever, p. 18). If nurses and caregiving women act together, it would strengthen their chances of gaining public acknowledgement and encourage the development of policies that are consistent with our country’s egalitarian values.

Bjornsdottir (2002) highlights the role of the nurse in ‘persuading’, “encouraging” and “educating” families (society) that the policy shift which directed the move to home health care is in the best interests of the patient and the family. It is essential that the nurse when using her power of persuasion to encourage the family to care for the TD infant at home, does so in a manner that is consistent with the caring component of nursing and not because it is the best financially viable option. In acknowledgment of this Chambliss (1997) informs that the nurse simultaneously holds three positions; a caring individual, a professional and a relatively subordinate member of the health organisation and that conflict between these positions challenges the nurses’ agency. The home environment is complex and uncertain and the TD infant cannot be seen as autonomous but in a bigger context which is part of a family. The nurse must move beyond focusing on the individual and move to a practice influenced by a relational approach to family nursing (Hartrick Doane & Varcoe, 2005).

### **Absolute Involvement**

A recurring theme running through much of the reviewed literature was the claim that women as mothers are oppressed. This necessitated a review of extra background literature. Heffner (1978) and Oakley (1980) both agree that the very act of becoming a mother serves to oppress women, as it is the nurturing aspect of motherhood that opens the way to exploitation. Wilson, Morse and Penrod (1998) discuss the theme of absolute involvement with mothering the TD infant. The connotations buried in the language of the term ‘absolute involvement’ relate to the depth of these women’s commitment to their infant. “The intense emotional response to the needs of another,

evoked in a mother, invites the idea that her own needs are of no consequence ..... making her vulnerable to the abuse of her nurturing impulses by those around her” (Heffner, 1978, p. 18). Women who are seen to engage in the mothering role may be undervalued, by themselves and by other members of society and as a result may not feel entitled to self-esteem or self-worth. McKeever (1999) argues that women must learn how they can be in a nurturing role but not be exploited.

McKeever (1999) highlights the fact that because the caregiver is predominantly female and is the mother of the infant redistributive healthcare practices and other societal influences, have perpetuated gender inequalities. The fact that this informal caregiving work has no specific name is a reflection of its social invisibility and low status (Graham, 1983). The need to provide constant care and attention to the TD infant leaves women with few choices (Bjornsdottir, 2002). If women’s autonomy is to be gained at the risk of the child then many women may surrender their own well-being and subsequent identity (Heffner, 1978; Oakley, 1980). Olsen and Esdaile (2000) believe that “when the case is urgent and the action on behalf of dependent others, especially a women’s own children, women’s agency is readily visible” (p.18). Mothers have voiced in the reviewed literature the ways in which they have worked to claim their agency to overcome obstacles in order to participate fully in their mothering of the TD infant (Black, Holditch-Davis & Miles, 2009; Glasscock & Hayes, 2000; Kirk, Glendinning & Callery, 2005; McKeever 1991; McKeevr & Miller, 2004; Mentro & Steward, 2002; Montagnino & Mauricio, 2004). Protective factors to assist mothers of TD infants build resilience are talked about in the literature and include developing confidence, nurse-caregiver relationship, being heard, strong family relationships (Glasscock & Hayes; Henry, 2008; Mentro & Steward).

Add to this the dilemma of the informal caregiver probably having to resign from paid employment to be able to fully care for her high needs infant and an already oppressive situation is perpetuated (Glasscock & Hayes, 2000; McKeever 1999; Mentro & Steward, 2002; Thyen, Kuhlthau & Perrin, 1999). Research shows that the employment profiles of this group of mothers differ markedly from mothers of healthy children as most did not work outside the family home (Thyen, et al.). However, most of them wished they could for psychological, social and economic

reasons (McKeever; Thyen, et al). The caregiving mother is potentially losing her identity as a financially productive and therefore valued member of society, in a paternalistic society that places dominant values on paid work, further marginalising her. An analysis of oppression causes me to reflect on the role society plays in the reproduction and maintenance of culturally oppressive practice. Cudd (2006) supports this statement in her definition of oppression as the existence of unequal and unjust institutional constraint.

To complicate matters women as caregivers in the home are now providing specialised care that once was solely the domain of the registered nurse. Gender inequalities are perpetuated as not only is the mothers status lowered as she has become, through necessity, a non-income earning informal caregiver but the fact that many nursing skills can be performed competently by lay women in household settings has diminished the societal value of nursing work (Bjornsdottir, 2002; McKeever, 1999). Visibility of any gender disparities will increase chances of societal support and the exposure becomes the task of both the nurse and the female caregiver. The mothering role is altered as the normally private domain of mothering is transformed into a very public activity, conducted under the gaze of healthcare professionals and other support workers (Kirk et al., 2005). No longer is the home a private place, away from public scrutiny, so the care the mother gives is visible to the health professional. For the mother of a TD infant the meaning of home is transformed.

### **Burden of Care**

Another key theme to emerge from review of the literature is “burden of care”. When we talk about mothering what instantly comes to mind is caring, as this is considered to be the essence of being a woman, however there are boundaries surrounding this ability to care. Nel Noddings an American feminist, educationalist and philosopher is well known for her work on ethics of care. Noddings (1984) states that caring when it is the result of easy obedience to the natural impulse is not burdensome but when we move beyond the natural circles of caring, we may begin to feel burdened. Much of the literature focuses on the fact that women are expected to care about and give care to others (Fisher & Tronto, 1990; Kirk et al., 2005). Literature confirms that the 24-hour caring required by the technology dependent child may generate anger,

frustration and resentment and lead to behaviour that is less than 'maternal' (Kirk et al.). Glasscock and Hayes (2000) exposed this caregiver burden in their phenomenological study where mothers described feeling like you can never give her/him (the child) enough attention, believing your infant will only develop to their maximum growth and development if she (the mother) dedicates a large amount of time to her (the child), or never leaving the child's side. This illustrates the level of dedication and time mothers of TD spend on caregiving. Fisher and Tronto (1990) go so far as to say "too much caring leads to less caring about". Because of their lack of control over the caring process women's responsibility for caring remains ambiguous. How much women are willing to absorb this cost depends on a variety of factors including availability of resources, existence of others who are willing to share responsibility and the degree to which women acquire self-esteem through caring (Fisher & Tronto). Stress and physical exhaustion associated with the 'burden of care' cause higher than average amounts of caregiver physical ailments (Glasscock & Hayes, 2000; Henry, 2008; Montagnino & Mauricio, 2004, Thyen et al., 1999).

To complicate matters social policy literature has identified that caring has dual dimensions as it can mean caring for (carrying out instrumental activities) and caring about a person (ontological care) (Kirk et al., 2005). Parents identify this as being a major factor in influencing the different ways nurses and mothers give care (Kirk et al.). This is of particular consequence when parents perform clinical procedures on their child, what may be a routine procedure for the nurse becomes a task laden with emotional significance when performed by the parent. Mothers consider themselves experts in delivering care to their infant, and that the care they provide far exceeds professionals when it comes to sensitivity (McKeever, 1991).

In addition, to investigate the role of mothering the TD infant in the home one must look closely at what constitutes a "home". Traditionally the home is portrayed by Western society as a place of safety, privacy and freedom - a haven from the outside world where the family is free from the unwanted attention of others (Wang & Barnard, 2004). Usually a home is a place that the occupants can move in and out of at their will but for the mother of the TD infant this freedom is taken from her, due to the inability to leave her high needs infant, and the home may become a prison rather than a castle (Yantzi, Rosenberg & McKeever, 2006). Add to this the need for the

home to become a site for caregiving which involves complex nursing work, bringing with it frequent medical or nursing interference, and “the sanctity” of the home as an escape is removed (McKeever, 1999). The dichotomy of public and private as opposites is reinforced. Homes are transformed by the presence of medical equipment and by the personnel who accompanied this technology (Kirk et al., 2005). Technical equipment is expensive and funded by public funds and the market, which was once confined to the hospital setting, has now expanded into the home (McKeever). McKeever found that mothers camouflaged or hid medical equipment in the home in an attempt to portray normality. Virtually nothing is known about how the equipment intrudes on the work and the subjective experience of mothering (McKeever).

### **Agency and Mothering**

McKeever and Miller (2004) state that it is the overriding world view that the conduct of mothers is inextricably linked to the well-being of children. This encouraged further reading to determine the background of how this perception evolved. Kukla (2005) describes how in the late 18<sup>th</sup> century a dramatic political change took place whereby maternal bodies became public, as up until this time medical advice offered to women pertaining to pregnancy and childbirth had been in total ignorance of female anatomy. This change not only saw mothers’ bodies responsible for the material production of the child but brought with it an added burden that once the infant was born it became the mothers’ caregiving ability that would shape their habits, sentiments and bodily constitution (Kukla, 2005). Ruddick (1989) describes a mother as a person who takes responsibility for a child’s life and for whom the provision of child care is a significant part of his or her life. Therefore, under this definition anyone could do mothering work. However, there is no expectation on anybody, who is not the mother, to do this work. The literature reviewed agrees that mothering is a role that has been socially constructed rather than biologically inscribed and that our culture dictates that it is usually women who are committed to caring for children (Ruddick). It is evident that the mothering role comes under direct scrutiny of the public in ways that male activities do not (Jackson & Mannix, 2004). Not only is this scrutiny politically driven but also medically orientated as a child’s health outcomes too became subject to a mothers caregiving ability and as the parent with the most responsibility for the care of the infant mothers are often implicated in,

and therefore held responsible for the illness (Jackson & Mannix; McKeever, 1991; McKeever & Miller, 2004).

In fact these mothering roles come to play a crucial part in the well-being of the state as they are fostered in the child 'good social principles'. This attempt to produce the citizen best suited to fulfill the community's policies through the process of shaping or molding the child is an example of Foucault's governmentality of populations or as Foucault describes it "the conduct of conduct" (Foucault, 1979). In the case of this inquiry the scrutiny of this woman's childrearing ability is further complicated through the necessity of proving her caregiving/nursing ability also (Kirk, 2001; Kirk et al., 2005; Mentro & Steward, 2002). The woman who is the mother of a TD infant gains agency over her mothering role through developing the confidence and expertise necessary to successfully care for her high needs infant, and through the realisation that there a need for adjustment away from the normal mothering role (Black, Holditch-Davis & Miles, 2009). Much of the literature acknowledged the ability of mothers to become assertive in their new roles once they become aware of their capabilities and expertise (Kirk; McKeever & Miller, 2004; Montagnino & Mauricio, 2004).

The general assumption is that when a TD infant is discharged home from hospital negotiation has taken place between the hospital and the parents agreeing to the transfer of this care (Kirk, 2001). Reviewed literature reports that initially feelings of insecurity are reported by parents about their readiness to assume the care of their infant at home (Jackson, Ternstedt, & Schollin, 2003). However, parents do accept the responsibility of care, not through negotiation but through a lack of other choices for care (Kirk). It is feelings of parental obligation and the professional's expectations (of parents) that render the parents powerless in their decision making and ultimately tips the decision making process (Kirk). Kirk calls this 'naïve' acceptance. McKeever (1991) highlights this fact when she states that "abandoning a child who needs special care is rarely an option for women because they have little 'cultural ammunition' for disclaiming the role of caregiver" (p.45).

McKeever and Miller (2004, p. 1188) discuss the way mothering "always includes managing and mediating social fields in order to protect, nourish and teach children,

and to optimise their physical, psychological and social development". In the situation of a child with complex medical needs these aims are intensified. The authors go on to discuss the conflictual relationships mothers often engage in with medical professionals to obtain the appropriate care and services their infant requires. Mothers recognise the dominant power of the professionals and modify their behaviour to be consistent with the expected maternal role in the field of paediatric medicine and accept their "place" as subordinates (McKeever & Miller). Parents spoke about being disenfranchised by health care professionals with reasons for this ranging from a perceived lack of competence to a need for control on the part of the health professional (Kirk, 2001). Mothers sometimes adapted medical procedures to meet the individualised needs of the child causing conflict with health professionals who disputed the medical care delivery (Kirk et al., 2005). The powerlessness the mothers have within the medical field sometimes sees mothers resorting to seeking the assistance of intermediaries who have the symbolic or cultural capital to fight on their behalf (McKeever & Miller). Examples of this are seen in the threat of initiating legal action on behalf of the child to get the care they (the mothers) perceive they need (McKeever, 1991). This is a desperate situation and one that ultimately runs the high risk of the mother being seen negatively by the health professionals and as such the infant being deprived of necessary care. It is documented that this is a fear so great for these mothers that most acquiesced and played by the rules of the healthcare game (McKeever & Miller). However, over time the knowledge and experience mothers develop allows them to become assertive and subsequently to confidently negotiate what are appropriate roles for them in regard to the care of their infant (McKeever, 1999). Professionals often try to extend or push these boundaries but parents become experts at assessing what the likely costs and benefits of taking on additional roles will be, not only to the infant but to the whole family (Kirk, 2001).

For most people the home is a private place away from the public arena (McKeever, 1999). For the mother of a TD infant the meaning of home is transformed from a private to a public domain by the presence of health professionals and other support workers, placing the mothering role under direct scrutiny of the public gaze. Nurses, social workers and other homecare health visitors enter the private domain of the home where mothers are asked to make their child care practices visible, and to submit to monitoring and modification of their practices (Mayall, 1990). The mother

becomes visible in specific ways only and the professional has the power to judge her mothering practice.

Despite the impact of this public gaze, in general, the reviewed literature shows that mothers of TD infants highly value and respect the input of specialised homecare nurses (Henry, 2008). A key worker with specialised knowledge has a potentially positive effect on relieving maternal oppression (Glasscock & Hayes, 2000; Henry, 2008; Kirk et al., 2005; Mentro & Steward, 2002). Even though the oppression is societal/institutional nurses can remove themselves from this by empowering the mother in her role. The nursing service provides support, teaching and guidance to the mother who provides the day to day, intensive, vigilant hands on care.

### ***Summary***

Chapter Three examined the literature to uncover the mothers experience in the role of caregiver to the TD infant. Key emergent themes were “invisibility/ visibility”, “absolute involvement”, “burden of care” and “agency and mothering”. From the reviewed literature we can see that mothering the TD infant rests on some deeply rooted ideologies, in particular the ideology of patriarchy. These ideologies shape the way these women see their world and shape the way they view themselves. The invisibility of the mothering role and the silence of the mothers voices suggests that ambivalence is present in the lives of these women.

Chapter Four provides discussion of the literature, based on the three identified themes - government policy, gender inequalities and medicalisation. A conclusion and recommendations are made based on these themes.



## CHAPTER 4

Chapter Four summarises the reviewed primary literature, draws overall conclusions, highlights unresolved issues and provides direction for future research

### *Discussion*

The purpose of this research was to critically review the literature to uncover the experiences of mothers caring for their TD infant at home. Since the 1970s there has been an ongoing shift in the location of medical care from the public sphere of health institutions to the private sphere of family homes. With this shift in care came the development of informal caregiving, a role which arguably has been socially constructed and places a moral obligation on women, in particular, to function as carers. Existing government policies, determining support provision, have been developed based on the positioning of the role of the informal caregiver resulting in care that is inadequate and often ineffective. Only by uncovering how it is in reality for these mothers, rather than accepting what we induce them to say, can we truly facilitate opportunities for the mothers voice to be heard and incorporated in policy development. Using a critical lens we can argue current discourses, while they appear to be based on common sense and to be scientifically correct, are in fact socially produced (Hartrick Doane & Varcoe, 2005).

Caring is described as the essence of being a woman but it is this nurturing aspect of motherhood that opens the way to possible exploitation and oppression (Hays, 1996). The invisibility of informal caregiving work coupled with its marginalised status prevents it from receiving the societal recognition it demands. We live in a society that places an enormous value on paid work, and arguably it is paid work that “provides a sense of status and identity, and a place in society” (Cooke & Philpin, 2008, p. 41), and over the last forty years women have adopted the patriarchal values associated with paid work (Else, 1996). If this is true, then for women who have had to resign from paid employment caring for a TD infant at home may seem an inadequate means of maintaining self-esteem. However, positives arise from the fact that boundaries between this unpaid domestic work and paid employment are

beginning to shift, situating informal caregiving in an intermediate domain (McKeever, 1999). Arguably, the visibility of the informal caregiving role improves with this new positioning. Stress and physical exhaustion associated with the 'burden of care' cause higher than average amounts of caregiver physical ailments (Glasscock & Hayes, 2000; Henry, 2008; Montagnino & Mauricio, 2004, Thyen et al., 1999). In response to this Henry states that there is a need to focus beyond the health of the child, particularly to develop strategies to support maternal mental health

Most sources agree that the homecare nurse assumes a large part of the responsibility and accountability for the TD infant's care direction in the home (Henry 2008; McKeever 1991; McKeever & Miller 2004). Henry adds that Maori families value contact with health workers from a similar cultural background and that culturally appropriate health services significantly improve outcomes for families, as they provide care for their infant. While it is the mother who provides the hands on care the experienced nurse brings to the relationship a particular knowledge that assists the mother to achieve best health outcomes. McKeever and Miller discuss how mothers adapt their behavior to fit with what they believe health professionals expect from the maternal role and formulate answers to questions based on what they think are the socially correct and expected right answers. It is the nurse who intentionally incorporates relational theory into everyday practice that is able to truly listen, hear certain things and respond accordingly by advocating for support and care that is meaningful and significant in improving the lives of the family (Hartrick Doane & Varcoe, 2005).

Parents spoke about being disenfranchised by health care professionals with reasons for this ranging from a perceived lack of competence to a need for control on the part of the health professional (Kirk, 2001). In general mothers consider themselves experts in delivering care to their infant, and that the care they provide far exceeds professionals when it comes to sensitivity (McKeever, 1991). Nursing in the homecare environment requires the development of a professional partnership with the mother, one where the combined knowledge of the nurse and the caregiver are used to promote health and healing. Relational nursing practice provides a conceptual framing for care provision that addresses the nursing responsibility while simultaneously acknowledging the mothers' expertise in recognising the unique needs

of her infant (Hartrick Doane & Varcoe, 2005). This parent/professional relationship is critical to the outcomes of the infant (Henry, 2008) and is achieved when the nurse, through reflexive practice and ways of truly being with the family, develops new ways of seeing and being with those she provides care for (Hartrick Doane & Varcoe). The concept of reflexive practice involves critically thinking about the practice the nurse provides – to look deeply at ways of practicing and to think deeply about how this could be improved. While today's current healthcare system limits and shapes the work of nurses there are still opportunities to pursue possibilities for emancipatory change (Hartrick Doane & Varcoe). It is the role of the Homecare nurse to ensure that ideas for change must follow the families lead especially when it involves improving support for invisible caregivers who are currently providing a valuable service that is immeasurable in both financial and social value. The relational partnership strengthens the resolve of nurses to resist the pressure of modern healthcare delivery that focus predominantly on providing a technical form of practice and instead encourages a role that allows nurses to engage in dialogue with those they are providing care for to uncover more meaningful ways of service delivery.

Contemporary health service budgets are scarce and while increasingly sophisticated technology is promoting survival of premature and sick infants so too must the long term care of the survivors be supported. The concept of home care evolved in large part so that governments could divest themselves of more and more healthcare expenditure (McKeever, 1999; Yantzi, Rosenberg & McKeever 2006). Financially the home is burdened by the escalating costs of caring for the TD infant and because of the need for the caregiver to resign from paid employment. Mothers, as informal caregivers, are often expected by professionals to extend or push the boundaries of care that they provide in an attempt to further shorten hospital admissions and length of stay. Only when the mother becomes experienced at assessing what the likely costs and benefits of taking on additional roles will be, not only to the infant but to the whole family, does she gain the power to negotiate such roles (Kirk, 2001). In contrast to this is the 'naïve' acceptance parents assume when they initially accept the responsibility of caring for the TD infant at home due in large part to feelings of obligation and the expectations of health professionals (Kirk).

### ***Recommendations***

It is recommended that the discharge process from the Intensive Care Nursery incorporates the values of relational nursing to enhance dialogue between health professionals and parents to ensure parent readiness to care for the TD infant in the home.

The homecare nurse is integral in providing support for the mother caring for the TD infant at home. Nursing care which incorporates relational theory sees the infant not as an autonomous being but as part of a diverse, complex family and therefore is able to respond accordingly with support that is meaningful and significant for each unique family.

It is recommended that Clinical Supervision, as an avenue to discuss reflection on practice and shared experiences, be utilised to enhance ongoing clinical development of the Homecare nurse. Clinical Supervision provides the channel through which the nurse can consciously become aware of his/her engagement in the family relationship and where necessary foster social and personal change.

Care related policies are currently developed based on the way informal carers are constructed in a contemporary society that places a moral obligation on women to function as carers. Mothers must be involved in developing new policies which promote support provision that is meaningful and relevant. The relational nurse is ideally positioned to facilitate opportunities for the mothers' voice to be heard and represented in policy.

Virtually nothing is known about how technology and equipment intrudes on the work and the subjective experience of mothering. It is recommended that further research is done in this area.

Within the limitations of the study I was unable to capture and portray the experiences of Maori women caring for a TD infant at home. More research, especially by Maori for Maori in this area could assist the development of government policy that accurately reflects their unique support needs.

## *Conclusion*

This inquiry clearly demonstrates that there is inadequate societal support for Technology Dependent infants and that the responsibility for caregiving provision is inequitable, as the extraordinary demands of these children are placed almost entirely on the mother. Women as caregivers to TD infants face incredible constraints on their life circumstances and often struggle to realise and communicate what their own interests are. This is often reinforced by policy and practice norms.

Whilst recognition is shown of the pressure placed on the Homecare Nurse, by healthcare organisations to deliver care that is technically focused, scientifically based and orientated towards achieving specific outcomes, literature suggests that this method of support is currently not meeting the needs of mothers who are providing care at home for a TD infant. More effective, appropriate, and fulfilling care can be delivered when a relational partnership is created between the nurse and the mother that allows the nurse ways of see this family's reality and to truly be with them. Relational practice enables the nurse to engage in dialogue and subsequently uncover certain things that are meaningful and significant in the lives of the family. In addition, culturally appropriate support is highly valued, promotes ongoing communication and further improves outcomes. Care delivery appropriate to each individual family will improve outcomes for the infant, caregiver and family.

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## APPENDIX 1

### *Summary of the data-based literature.*

<b>AUTHOR/ DATE</b>	<b>AIM</b>	<b>METHODS</b>	<b>THEMES/ FINDINGS</b>
Black, Holditch-Davis & Miles 2009.	To examine becoming a mother of a medically fragile preterm infant.	Life course theory, a sociological framework was used to analyse the phenomenon of becoming a mother of a medically fragile preterm infant.	Increased confidence combined with effective agency on behalf of their infants strengthened women's identification of themselves as mother of this child. Maternal role and identity were key issues in navigating the difficulties of mothering in a confusing technological context.
Bjornsdottir 2002.	To discuss the implications of the shift in the location of the provision of healthcare services from healthcare institutions to the home.	Using Foucault's exploration of power, particularly his idea of governmentality, a genealogy of care-giving in the home in Iceland's health-care has been constructed. Study undertaken in Iceland.	Governmentality leading to the emergence of dominant discourses and practices eg. Informal caregiving in the home. Nursing services and governments attempts to withdraw its responsibility for longterm care. Social responsibility. Gender inequality issues – most informal caregivers are women.
Glasscock & Hayes 2000.	To describe the lived experience of being the mother of a child with cerebral palsy.	Using a phenomenological method to analyse transcripts of interviews with 15 mothers who were caring for a child with spastic cerebral palsy. Study undertaken in the United States.	Caregiver burden. Family/social support. Women's/mothers' roles. Socioeconomics. Strong family relationships are counted on during difficult times. Caregiving stressors and day-to-day caregiving is difficult. A positive caregiver role and interest in learning about cerebral palsy improves children's quality of life. Therapy and social services assist them with their children.

			Multiple roles and alterations in activities affect daily living. Families financial status is affected.
Henry 2008.	To gather qualitative information from a selected group of Maori families about their experiences caring for a technology dependent child.	An ethnographic approach using purposive sampling. Participants, who identified as Maori, were selected through the Kidzfirst Homecare Nursing service in Counties Manukau DHB. Semi-structured interviews took place in the parents homes. A New Zealand study.	A New Zealand study analysed – explores experiences of Maori families. Maori Health Strategy – to improve health outcomes for Maori. Acknowledges the Treaty of Waitangi. Being heard. Parents need for information. Parents value honesty. Appreciate health professionals who demonstrate sensitivity. Families value the presence of someone they can identify with, often of a similar cultural background. Parent-professional collegiate relationship.
Jackson, Ternstedt & Schollin 2003.	To study how mothers and fathers of preterm infants describe their experiences of parenthood during the infant's first 18 months of life.	Using a phenomenological method the findings of interviews with 7 sets of parents of preterm infants born <34 weeks gestation were analysed. Study undertaken in Sweden.	An awareness of gender differences in experiences (between mothers and fathers). Mothers had more responsibility for care of the infant. A need to be acknowledged as a “mother”. Reluctant to leave infant with anyone else. Confidence took time to develop.
Kirk 2001.	To assess how the transfer of responsibility from professionals to parents was negotiated.	A grounded theory study of parents caring for medically fragile children in the community. Study undertaken in the United Kingdom.	Complex nursing care being carried out in the home. Does role negotiation occur between parents and health professionals? Parental obligations and the desire to bring their child home were the key factors in their acceptance of responsibility for care.



			<p>The lack of alternatives to parental care-giving.          Difficult for parents (usually the mother) to counter professional expectations because of power asymmetries.</p>
<p>Kirk, Glendinning &amp; Callery 2005.</p>	<p>To report a study exploring parents' experiences of caring for a child who is dependent on medical technology.</p>	<p>A grounded theory method with in-depth interviews with the parents of 24 children.          Study undertaken in the United Kingdom.</p>	<p>Parenting is transformed into a public activity, conducted under the gaze of healthcare professionals.          Transformed meaning of home.          Nature of care-giving.          Dual roles: parent or nurse.          Jobs and lives.          Parental care-giving and emotional significance.          Individualised nature of parents' knowledge.</p>
<p>McKeever 1991.</p>	<p>To investigate the social effects of medical-scientific progress – the extension of chronically-ill childrens</p>	<p>A thesis submitted to the Faculty of Graduate Studies at York University.          Based on critical feminist health sociology.</p>	<p>Contemporary intensive care medicine and its technology preserve lives but increase incidence of chronic morbidity and longterm dependency on life support technology.          Society expects people to look after themselves.          Women – not men or the state – assume the responsibility for this caregiving.          Women live out their lives at the intersection of the conflicting roles of maternal caregiving and technical deliverance.          Women are both defined and oppressed by the expectations inherent in these discourses.          Study examines the institutions and social relations that shape the caregiving experience.          The ways in which mothers themselves understand and speak about the caregiving process were explored.</p>

McKeever 1999.	To identify any negative consequences of the homecare movement.	“The family” as care providers and the household as the primary site for healthcare delivery of long-term care. Study undertaken in Canada.	Nurses and family caregivers are in ambiguous social positions – which are subordinate to those who control household resources and determine policies and practices. Redistributive healthcare practices have perpetuated gender inequalities.
McKeever & Miller 2004.	To interpret the mothering experiences of women whose children have disabilities or chronic illnesses.	A reanalysis of three independent qualitative studies focused on mothers’ accounts of raising children with severe disabling conditions. Study undertaken in Canada.	Social positioning in the medical field: Good mother/bad mother. Strong pressure to conform to traditional ideologies of care in which mothers devote themselves selflessly to the welfare of their children. Mothers are required to adopt, and to adapt to an unfamiliar, relatively low-status position of skilled, unpaid, paraprofessional in fields in which most mothers only engage intermittently.
Mentro & Steward 2002.	To provide a more thorough understanding of the dynamic of caregiving for a medically fragile child.	The inquiry is a review of the literature from an alternative perspective and analysis of the themes using a Sense-Making methodology (which examines the dynamic nature of the human being across the dimensions of time/as opposed to a static time) by consideration of dynamic situations, gaps, bridges and outcomes.	The term “care tasks” or “burdens” negatively labels medically fragile children – consider using caregiving instead. This inquiry considers the larger phenomena of caregiving – looks at caregiving across time rather than static (as in an interview) to address the full range of experiences. Social and family changes – loss of self-identity. Financial concerns. Professionals strains – lack of skill and expertise, lack of privacy. Nurse-caregiver relationship.

		Study undertaken in the United States.	Technological problems. Caregiver assessing child's medical state - unknowing. Accessing social support. Maintaining normalcy. Caregiver poor physical and mental health.
Miller 2008.	To examine the experience of receiving and caring for a technology dependent infant in the home.	An inquiry using van Manen's phenomenological method. Data was collected from interviews with 8 mothers. Study undertaken in the United States.	Moving from learning about the infant to making judgements regarding infant's health. Recognising the need for adjustment in roles, responsibilities and priorities. Navigating constantly changing emotions to achieve near normalcy.
Montagnino & Mauricio 2004.	To define the stressors and coping mechanisms of parents of children who are dependent on a respiratory device (tracheostomy) and a nutritional device (gastrostomy).	The primary caregiver of all patients who met the criteria were asked to participate in the study by a mailed out/ mailed back written questionnaire. Study undertaken in the United States.	Anxiety learning new skills. Anxiety handling emergencies. Psychological burden. Fatigue. Social isolation. Coping. 5 coping mechanisms listed: -Sharing difficulties with the family -Seeking information -Counselling -Help from neighbours -Faith in a higher power.
Thyen, Kuhlthau & Perrin 1999.	The study examines: -the way that children with chronic conditions are cared for at home and assisted by technology affects maternal employment and child care -the social and clinical factors associated with the decision of a mother to quit employment to care for a child at home	A cross-sectional study of employment of mothers 6 months after the child's initial hospitalization leading to technology assistance. The study included a comparison group of families with apparently healthy children matched for age and gender to estimate the effects attributable to the	One third of the mothers of a child assisted by technology reported quitting their job. Family resources are diminished at a time when financial needs increase. The mental health of the mother was less good in those mothers who were caring for a child assisted by technology. The study suggests that employment has a protective effect on mental health. Health policies should address issues especially the issue of financial burdens.

	-the way in which care at home and the decision of a mother to quit a job affects maternal mental health.	technology needs. Study undertaken in the United States.	
Wilson, Morse & Penrod 1998.	To examine the experience of mothering a medically fragile child in the home.	Using grounded theory methods, 16 mothers were interviewed twice to identify the core variable of absolute involvement, describing the provision of a mother's self-determined standard of care for her child. Study undertaken in Canada.	Absolute involvement emerged as the basic social process. Absolute involvement represented the devotion mothers displayed when caring for their child and family. Absolute involvement integrates 3 other major categories identified: -the attributes of mothering -meeting the demands -appraising the impact.
Yantzi, Rosenberg & McKeever 2006.	To illuminate the challenges as they are experienced by mothers of children with longterm care needs of getting out of the house.	A grounded theory analysis of mothers (of children with long-term care needs) accounts of their experiences of getting out of the house. Study undertaken in Canada.	Physical challenges. Social challenges. Service challenges.