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# TO MEDICATE OR NOT TO MEDICATE? Exchange, Identity, and Care in Everyday Household Medication Practices

A thesis submitted in fulfilment of the requirements for the degree of

Master of Applied Psychology at The University of Waikato by

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#### ABSTRACT

In contemporary societies, medications are one of the most commonly used resources for the prevention, treatment, or cure of illness and disease (Shoemaker & de Oliveira, 2008). Despite this, there is a lack of understanding about how medications are used and understood by lay persons in private domestic dwellings. This research explores the medication experiences, understandings, and practices enacted by mothers caring for their chronically ill children. Four households containing children with chronic illness were involved in this qualitative interpretive research. Semi-structured interviews, mapping, diary keeping, and photo-production exercises were utilised to explore the ways in which medications are implicated in caring practices enacted by the mothers. Giddens' (1984) structuration theory and the concept of 'gift exchange' provide the theoretical foundation for this thesis. This research indicates that the medication understandings and beliefs held by the participants are central to the construction of everyday caring medication practices. These beliefs and practices are not fixed or homogeneous, but complex and changeable; reflecting differing contexts, experiences, and forms of knowledge. The agency of parents as they conceptualise 'care' and choose to embrace or resist medication use, challenges the notion of 'passive' medication consumers. As the use of medication impacts many relationships within and outside of the confines of the household, this thesis highlights the social and symbolic nature of medications. The relationship between a parent and child is central to medication use, but medical decisions made by parents also implicate various other individuals, including health professionals and lay persons. The findings point to the need for health policy which acknowledges and is responsive to, the shifting health needs and understandings of the lay population.

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### **CHAPTER ONE: INTRODUCTION**

Medication use plays a prominent part in contemporary health care systems. As the incidence of chronic illness continues to rise, the use of medications allows people to manage ongoing health needs and utilise medical solutions within private domestic dwellings (Prout & Christensen, 1996). In this respect, the home is emerging as a significant space for rest, recovery, care and the enactment of various health practices, including medication use (Dyck, Kontos, Angus, & McKeever, 2005). As the most commonly used health care intervention (World Health Organisation, 2007), medications also comprise a major part of health costs. Global spending on medications increased by thirty times between 1972 and 2005 (Law, 2006). In New Zealand, personal spending on medications reached a total of \$693.8 million between June 2009 and 2010 (PHARMAC, 2010), and it is expected these costs will continue to rise in the near future. During this same period, the quantity of significant investments in medicine by PHARMAC<sup>1</sup> reached a record high since 1999, with \$40 million being dedicated to the funding of new medicines or widening of access to existing medicines in PHARMAC's funding schedule (PHARMAC, 2010). All of these trends point to how medications pervade the daily lives of  $lay^2$  persons. Consequently, there is a need for a greater understanding of how medications are used and understood by lay persons in the context of everyday life.

This thesis examines the medication understandings, practices and experiences of mothers responsible for the daily care of their chronically ill children. It

<sup>&</sup>lt;sup>1</sup> Pharmaceutical Management Agency - a division of the Health Funding Authority (HFA), which manages subsidy expenditure of medications in New Zealand (Braae, McNee, & Moore, 1999).

<sup>&</sup>lt;sup>2</sup> For the purpose of this thesis, the term 'lay people' is used to refer to people who are not health professionals. Lay people in the wider public have understandings and beliefs about medication that are "a product of complex intermixing of personal biography, socio-cultural beliefs and circumstances, and professional ideologies" (Williams & Calnan, 1996, pp. 259-260).

explores the roles enacted throughout the performance of household medication practices, which implicate various social actors including family members, friends and medical professionals. The aim is to expose the connections between the meanings of medications and notions of care, care giving and parental responsibility. The key argument is that the exchange of medications between a parent and child has far reaching social and cultural dimensions. Rather than being merely a biomedical object with physiological effects, this thesis shows that medications are imbued with emotions, knowledge, identity, relationships, routine and care.

This qualitative interpretive research was conducted alongside a wider project— 'The use of medications in everyday life: Understandings and social practices' exploring household medication use in New Zealand. The larger project involves academics located at two universities in the United Kingdom and three in New Zealand, including supervisors of this thesis based at the University of Waikato. The research sought to produce new knowledge about the meanings attributed to medications and the impact of media and other social processes involved in the use (or misuse) of medications. The case study of four households in this thesis contribute to a total of fifty households involved in the larger research project, encompassing households with chronically ill people, children and individuals of various ethnicities. Households containing children with chronic illness constitute an important part of the wider research. Such households provide a context for exploring key topic areas of the larger research project, including recurrent medication use, issues of safety, risk, and vulnerability, and medication practices and meanings in parenting contexts.

Greater understandings about medications come from examining the physical and cultural contexts in which they are applied and exchanged (van der Geest & Whyte, 1998). Medication uses in clinical settings such as hospitals, or in development phases of a laboratory, are common research fields. As well as their existence in these settings, medicines occupy an important space in the homes

of lay persons. The private domain is a central location for medication consumption (Helman, 1981), yet there is limited understanding about what happens to medications once inside the private dwellings of medication users. As a concrete setting, the home is more than just a backdrop against which medication practices are enacted (Dyck et al., 2005; Easthope, 2004; Hodgetts et al., 2010). The home interacts with our experiences and understandings of medications (Carrier, 1995). It is within the home that medicines acquire personal meaning and value in the daily lives of lay persons. From the examination of seemingly trivial and mundane practices in private households, more understanding can be gained about public and lay knowledge of medications (Carrier, 1995).

There has been considerable research about medication use in elderly populations (for example, see Liu & Christensen, 2002; Ray, 1992; Ryan, 1999). Due to the increased life expectancy of populations in Western societies (Department of Economic and Social Affairs, 2007), this has been a particularly important group to study. The elderly are frequent users of medications, and because they are likely to take many medications concurrently, are at high risk for medication complications and side effects (Hajjar, Cafiero, & Hanlon, 2007). However, other populations are also vulnerable to risks of medication use. Children are excluded from safety testing of medications for ethical reasons (Spilker & Cuatrecasas, 1990). Consequently, they are likely to be using medications that have only been tested on adults, whom are known to have vast physiological differences from children (World Health Organisation, 2007). This poses a significant problem, as children cannot be offered the same standard of "safety, quality or efficacy of medicines as adults" (World Health Organisation, 2007, p. 19). Promoting safe medication use for children has become a major focus of the World Health Organisation. This presents the need for a better understanding of medication practices involving children.

The diversity and complexity of medication meanings and practices in daily life is a salient finding from research that explores lay understandings of medications (Adams, Pill, & Jones, 1997; Conrad, 1985; Helman, 1981; Rogers et al., 1998; Shoemaker & de Oliveira, 2008). However, medications are more than just 'used' by lay persons. Currently, accounts of lay understandings offer limited discussion about how personal meanings of medication are negotiated through the way in which medications are bought, given and dispensed in interactions between individuals. In this thesis, gift exchange theory provides a framework for the analysis of medication exchanges between mothers and their children. Mauss' (1950) text on gift exchange in 'archaic' (sic) societies is considered a founding exploration of gift exchange theory. Contemporary applications of this theory are abundant; particularly in business and marketing fields (Arunthanes, Tansuhaj, & Lemak, 1994; Davies, Whelan, Foley, & Walsh, 2010). Applications in the medical field are far fewer, with organ donation being the focus of a significant proportion of these (for example, see Gill & Lowes, 2008). Application of gift exchange theory helps to highlight the significance of 'giving' in caring relationships and to demonstrate that medications are more than simply material objects with physiological effects.

In the remainder of this chapter, I will provide an overview of the biomedical model and the pharmaceutical industry, which are central to the social context in which participants come to understand and enact medical practices. This overview has an important function, as it sets the social stage for contemporary medication use. In examining lay understandings or social practices, there is a complex interface between lay people and medicine that can make it difficult to "separate out different sources of ideas expressed by lay people" (Hodgetts & Chamberlain, 1999, p. 324). As Carrier (1995) explained:

The way that people think of and deal with objects in their private lives are shaped by public structures of meaning . . . . In their turn, these public

structures are regenerated, modified and subverted in part by what people do in their private lives. (pp. 7-8)

This thesis focuses on medications in a broad sense, taking into account conventional, complementary and alternative medicines (CAM), dietary supplements, and enhanced food products. The use and understandings of each of these medicative forms emerge within a medical discourse.

This is followed by an exploration of a range of qualitative literature on lay understandings of medication. Such literature offers a counterbalance to scientific and medical conceptions of contemporary medication use and understandings that dominate documented medical history (Porter, 1985). Thereafter, I explore parental experiences with medications in the context of caring for their chronically ill children. The focus is on how parents decide to medicate their children, with attention paid to caring, care giving tasks, identity and emotion. Such literature serves as a guide for what to expect from the examination of lay beliefs, understandings and practices of mothers caring for their chronically ill children. The chapter concludes with an overview of the current research.

#### Contemporary medication use: An overview

Health and illness are both personal and political issues that affect all of us to a greater or lesser extent throughout our lives (Nettleton, 2006). This means that health issues are connected to a plethora of situations, information sources, constraints and agendas. There can be competing perspectives on diagnoses and treatment options, and dispute about the most legitimate ways to deal with health and illness (for example, see Dew, 1999). Although this thesis explores medication practices and understandings and encourages a healthy scepticism towards responses to illness, no particular stance on medications or illnesses is being advocated.

Medicines have a long standing and turbulent history that could be described as an ongoing rise and fall from stardom and fame (Le Fanu, 1999). While at some moments in history particular medicines were revered as 'magic bullets' or elixirs of life, at other times such medicines were considered the root of widespread distrust in medical intervention and a source of scepticism and fear (Duffin, 2010). These patterns are echoed in the present, where both medical miracles and tragedies saturate the home environment on a daily basis, whether through personal and shared experiences, or 'media worthy' stories disseminated to the wider public.

Medical history indicates that medicines are extremely diverse in their form and use. The earliest of medical treatments involved spiritual therapies such as prayer to purge the soul. Greco-Roman traditions relied heavily on the rebalancing of four bodily humours, which utilised non-drug therapies such as dietary and lifestyle modifications. The medicinal use of metals characterised medical therapy in the 15th century. Mercury, sulphur and antimony were considered the "wonder drugs" of this period (Duffin, 2010, p. 107). It is unlikely that these 'treatments' resemble conventional medicines that members of the public would recognise in the twenty-first century. These few examples demonstrate how medicines have changed, disappeared, and emerged over time.

There are a number of definitive moments which have shaped modern medicine today. For example, the first application of Penicillin in 1941 diminished and healed lethal infections (Le Fanu, 1999). The discovery and use of Penicillin spurred immense interest in the power of antibiotics for fighting chronic disease and infections, leading to the discovery of many other antibiotics. Physicians' observations of the effects of antibiotics reflect the wonderment and excitement of medical discovery at the time. As stated by Le Fanu (1999): "In the public imagination antibiotics came to symbolise the almost limitless beneficent possibilities of science" (p.5). These and other definitive moments created

optimism that there might be 'magic bullets' for every disease and ailment (for more examples, see Duffin, 2010; Le Fanu, 1999).

In recent years, however, this optimism has turned to scepticism for some as we have continued to learn of the consequences of medication use. While the use of metals in the 15<sup>th</sup> century was considered a medical break-through, it is now known that many metals have adverse side effects including "... gastrointestinal disturbances, gum swelling, salivation and neurological toxicity" (Duffin, 2010, p. 107). The thalidomide tragedy is an important marker of diminished confidence in medicine on a global scale (Duffin, 2010). Thalidomide use alleviated morning sickness in pregnant women, but was later linked to birth defects in 10,000 children (Duffin, 2010). The thalidomide tragedy reminds the public that even with the best intentions, medicines may be detrimental to health (Duffin, 2010).

Changes in our knowledge of medicines are evident in both drug advertisements and literature spanning over time. Duffin (2010) documents how older advertisements may feature drugs no longer used because they are deemed dangerous, ineffective, or have been replaced by newer medical technologies. Furthermore, advertisements or literature may feature drugs for health 'issues' no longer considered diseases. For example, in a study of doctors' attitudes towards the repeat prescribing of minor tranquilisers Melville (1980) stated: "... Almost any housewife is well aware that valium can't do her any harm, even if she doesn't altogether approve of it" (p.101). This comment reflects that at this time, drugs may have been targeted at housewives to enable them to cope with the demands of domesticity. It also reflects an inaccurate assumption about the safety of valium use.

While medications undergo testing for negative effects (Spilker & Cuatrecasas, 1990), it can take years for the long-term effects of a particular medicine to develop, and to be isolated and identified. Consequently, it is difficult to ascertain whether current medications considered 'benign' will not at some point become a target of scrutiny and disbelief. Conversely, it is also possible

that past therapeutic rationales will maintain contemporary relevance (Duffin, 2010). For example, despite the secularism of Western societies, spiritual responses to ill health are still notable. Participants from Rogers and colleagues' (1998) research, for example, sometimes turned to prayer when they felt medications did not suffice.

The use of any medicines, however antiquated or unorthodox they may seem now, are at the time a reflection of existing knowledge, technology and therapeutic rationale (Duffin, 2010). Our current responses to illness and disease, and even health practices in the absence of illness, are impacted by these changes. Prayer and trephining<sup>3</sup>, for example, might have seemed adequate responses to ill health when illness and disease were closely aligned to notions of sin, punishment and spiritual wellbeing. Our views on medicine and disease are far more secularised now.

While technology and knowledge have certainly impacted conceptualisations of disease (for more examples, see Duffin, 2010; Le Fanu, 1999), medical histories tend to centralise science and physicians in the progression of medicine (Porter, 1985). Such accounts are incomplete, however, as medical encounters involve not only a physician, but 'patients', families and communities (Porter, 1985). Porter offers a different perspective of medical history, arguing that the "physician-centred account of the rise of medicine may involve a major historical distortion" (p.175). Porter's text is orientated to the 'patients' view', with attention paid to how sufferers or lay persons are frequently those who direct medical care or develop medical initiatives. The history of medicine is not simply a story of science, but also of self-help, community care, and agency in lay persons (Porter, 1985). Nevertheless, the centrality of science in historical accounts speaks volumes of the persistent influence of scientific knowledge.

<sup>&</sup>lt;sup>3</sup> Trephining involved drilling a hole in the head of mentally ill individuals to release 'vapours' or 'spirits' that were thought to cause illness (Szasz, 1987).

#### The biomedical model and the pharmaceutical industry

To understand the social practices of medication use within the households studied requires an examination of wider social processes in which they are entwined. In making sense of the world, individuals commonly draw upon convention, customs and shared knowledge (Hodgetts et al., 2010). The biomedical model, as the dominant conception in Western medicine (Filc, 2004), provides a construct through which participants can make sense of the practices they are engaging in. For many lay persons, taking medication is a routine and normalised everyday practice (for example, see Jerrett, 1994). As Busfield (2006) argued, pill taking has become a standard feature of modernity; this indicates the normalisation of biomedical beliefs, values and responses to ill health, which permeate the political core of a society and have thereby become both moral and ethical understandings (Durst, 2005).

The biomedical model emerged as science and reasoning took precedence over traditional and religious rationalisations of the world (Giddens, 2001). As a supposedly logical, rational and therefore superior form of knowledge (Bondi, Kitchin, & Thrift, 2009), there is a tendency to accept scientific knowledge about disease as truthful or accurate. As outlined in Table 1 on the following page, the biomedical model purports that illness and disease are caused by a specific identifiable agent (Giddens, 2001), and thus tends to legitimate individualised treatments such as surgery or medicine use (Filc, 2004). This is particularly problematic because, as Busfield (2006) explained, such responses "provide an individualised solution to problems that often have social and structural origins" (p.310).

*Table 1* Features of the biomedical model, drawn from Conrad (1992), Filc (2004), Giddens (2001) and White (2002)

Feature	Explanation	Limitations
Doctrine of specific aetiology	Disease is cause of a specific agent (reflected in germ or molecular theories of disease).	"Decontextualises social problems, and collaterally, puts them under medical control" (Conrad, 1992, pp. 223-224). Centralises individual care solutions such as surgery or pharmacological intervention.
Mechanical metaphor	Assumes that in order to obtain health, bodily malfunction or the cause of disease must be isolated and treated.	Induces the 'medical gaze'; viewing patients in a detached and mechanical way.
Reductionism	Focussing on the observable (such as bodily symptoms) to deduce malfunction of the unobservable.	Extraneous factors contributing to ill health are often not taken into consideration. The mind is reduced to 'the brain' and subjectivity to 'brain activity'.
Dualism	The biomedical model contends that the body may be treated in isolation from the mind.	This assumption denies the active subject. Patients' beliefs and experiences regarding treatment and illness impact their overall wellbeing. Psychosomatic illness and placebo effect indicate there is a connection between the mind and body.
Technological imperative	The use of technology to aid diagnosis, treatment and prevention of disease.	Only trained medical professionals are legitimated as experts; excluding alternative forms of knowledge and treatment. Treatments utilising technology are constructed as superior; hospitals are seen as a medical arena for treatment where medical technology "is concentrated and best employed" (Giddens, 2001, p.156).

Despite the widespread assumption that medications are 'proven' to be effective through scientific research (Moynihan, 1998), there are many consequences of medication use. As well as innumerable side effects (Busfield, 2006; Bussing & Gary, 2001; Conrad, 1985, 1992; Hansen & Hansen, 2006; Rogers et al., 1998; Viswanathan & Lambert, 2005) microbes can become resistant to medications. There are now a number of drug resistant illnesses, including Malaria, Gonorrhoea and Staphylococcus (Duffin, 2010). The quest for health through medication use can, paradoxically, also be a threat to the health and wellbeing of individuals (Moynihan, 1998). Despite these downfalls, biomedical understandings continue to hold a substantial amount of power in shaping and legitimating notions of health and illness and thus what constitutes adequate responses to ill health (Filc, 2004; Giddens, 2001). As a scientifically legitimate response to illness and disease, pharmaceutical use continues to be supported in a social context of biomedical dominance.

The legitimacy of the 'science' underpinning medical knowledge continues to be fiercely debated. Beyond the application of science, many drug discoveries can be attributed to accidental, serendipitous or chance events (Le Fanu, 1999). The knowledge gained about the causes of illness and disease was not enough to provide an "intellectual basis for the purposive design of drugs" (Le Fanu, 1999, p. 214). Instead, the 'golden age' of drug discovery spanning between 1940 and 1975 (Duffin, 2010) was, in part, a response to the realisation that applied synthetic chemistry could remedy many ailments, without the need for a comprehensive understanding of what was actually wrong (Le Fanu, 1999). One need not have even been a doctor or understood disease to discover a chemical substance worthy of application in the medical field. It is also known that improved housing, hygiene and water sources contributed largely to the decreased prevalence of infectious disease, which raises questions about the effectiveness of medicines to which these trends are commonly attributed (Dew, 1999; Navarro, 2009). These, and other social determinants, are now recognised as having major impacts on health and wellbeing. We have also come to

understand that many 'diseases' are based on deviations from social, rather than biological, norms (Conrad, 1992; Giddens, 2001; Szasz, 1987; White, 2002).

Criticisms of the biomedical model suggest that, while biomedical models of health pervade modern societies, people are also seeking other ways of dealing with health concerns (for example, see Foote-Ardah, 2003; Sointu, 2006). This is especially the case when patients are unable to access biomedical treatments, or are dissatisfied with the results (Giddens, 2001). The literature on this apparent shift away from biomedicine tends to focus on the limitations and negative impacts of the biomedical model. It is important to retain a balanced perspective and recognise that, despite the limitations identified, many modern medications are useful technologies for the treatment, prevention and management of many ailments. This is also an important consideration when reflecting on the role of the pharmaceutical industry which, similar to the biomedical model, tends to draw critical attention.

Following the 'golden age' of drug development and discovery, there became a need to mass produce medicines so that the wider public could benefit from these products. Now dominating as a "major global industry" (Busfield, 2006, p. 297), medicine revenue of over £7 billion per year in the United Kingdom makes pharmaceuticals the third most profitable economic activity (House of Commons Health Committee, 2005). In 1999, pharmaceuticals were the single most profitable industry in the United States (Conrad & Leiter, 2004). In developing countries such as Brazil, China and India, pharmaceutical companies are beginning to surface as key players in a global supply chain (Busfield, 2006). The ongoing growth of the pharmaceutical industry is also marked by the development of new products and expansion of medical markets offering considerable profit potential. The increasing scale of medication use worldwide means that "medicine is not just about science and compassion: It is also about business" (Moynihan, 1998, p. xii).

The financial costs of health are certainly an important issue to consider, particularly in the wake of excessive consumer spending on medications. Ensuring affordable access to medications for the entire population is the central task of New Zealand's Pharmaceutical Management Agency (PHARMAC) (Braae et al., 1999). This organisation attempts to lessen the out-of pocket financial costs to consumers by managing the government subsidisation of many medications. Drug discovery and development is a costly process, however, and it is often pharmaceutical companies that are responsible for covering these costs (Moran, 2003). According to one estimate, only 21.5 percent of drugs that begin clinical testing ever make it to the medical market in order to generate profits (Moran, 2003). When these marketed drugs are purchased, consumers have numerous expectations about them. Amongst these, it is expected that medications will be safe, efficacious, and reach the medical market in time to prevent further suffering of those in need of medical intervention (Spilker & Cuatrecasas, 1990). In attempts to meet these expectations and regulatory requirements, the profits gained from already marketed medications allows continued investment in research of new and existing medical technologies. While making money from sickness may seem morally objectionable on some levels, and reducing the burden of medication expenditure is a high priority policy agenda, a balanced perspective also takes into consideration that "it is the profit that provides the incentives for innovation and which pays for it in a situation where there are no other sources of funding" (Spilker & Cuatrecasas, 1990, p. 25).

The pharmaceutical industry has also received criticism for the ability to exert control over shaping what is considered 'normal' and 'deviant' through relationships with health consumer groups (see Jones, 2008), manufacturing and marketing of drugs and disorders, and use of direct-to-consumer advertising (DTCA) or political power (Williams, Martin, & Gabe, 2010). The process of medicalisation is a central part of these criticisms, especially as it has intensified in recent decades (Conrad & Leiter, 2008). 'Medicalisation' literally means to

classify and treat non-medical phenomena as medical conditions (Conrad, 1992). This construction intends only to denote a description of the transformative process between non-medical and medically defined 'issues' (Williams, Gabe, & Davis, 2008). However, as society has become increasingly medicalised, this term has come to invoke negative connotations (Conrad, 1992, 2005; Williams et al., 2008), and mark the social dominance of medicine (Zola, 1972).

In recent decades, there have been notable changes in the driving forces of medicalisation (Conrad, 2005; Fox & Ward, 2008). Where medical professionals, for their power and prestige as gate keepers of medical treatment, once played a central role in the medicalisation process (Conrad, 1992; Payer, 1992), it is now apparent that medicalisation is more sustained "by commercial and market interests, than professional claims makers" (Conrad, 2005, p. 3). Moynihan and colleagues (1998; 2002) are especially vocal critics in this regard, arguing that as well as marketing medications, the pharmaceutical industry is equally responsible for 'selling' sicknesses to mass populations. They perceive this 'disease mongering' as inappropriate and commercially motivated creation of illnesses in order to expand the pharmaceutical market. Such claims mark a significant departure from the 'social construction' of disease associated with the medicalisation process, to the 'corporate construction' of disease attributed to the pharmaceutical industry (Payer, 1992; Williams et al., 2010).

Research documents the medicalisation of natural life events (such as menopause, ageing and childbirth) and deviant behaviour (Conrad, 1992). More recently, the literature directs attention to the emergence of a range of medical treatments aimed at enhancing quality of life, as opposed to offering treatments for 'disease'. Non-medical use of medication for lifestyle and enhancement purposes marks the envelopment of the 'healthy', as opposed to just 'ill' persons, in pharmaceutical intervention (Fox & Ward, 2008; Williams et al., 2010). The tendency to view medicines as a solutions to a diverse range of problems is a significant cultural shift whereby individuals engage in pill taking in response to

'problems' as if they "will be solved by magic" (Busfield, 2006, p. 130). This process of 'pharmaceuticalisation' denotes the "widespread use and uptake of pharmaceuticals . . . for purposes which extend far beyond the realms of medicine or strictly medical" (Williams et al., 2008, p. 816). It is a complex and dynamic part of the "long-term and ongoing construction of the pharmaceutical regime" (Williams et al., 2010, p. 20).

Direct-to-consumer advertising of prescription medication further implicates the pharmaceutical industry in processes of medicalisation and pharmaceuticalisation. Whether through the radio, television or print media, DTCA provides the pharmaceutical industry direct access to potential consumers, infiltrating private home environments and bypassing medical professionals. Currently, DTCA is only allowed in the United States of America and New Zealand (Mintzes, Barer, Kravitz, & Kazanjian, 2002a). Before DTCA was legalised and regulated, representatives from the pharmaceutical industry were worried about the effect advertising would have on doctor-patient relationships (Conrad & Leiter, 2008). It was anticipated that DTCA might increase self-diagnosis, prescribing rates and consumer requests for specific medications. Ensuing studies suggest this is indeed the case. For instance, Mintzes and colleagues (2002a) have found that patients' requests are a "powerful driver of prescribing" decisions" (p.279), even when doctors may be ambivalent about patients' medication choices. Such research contributes to understandings of the central role 'consumers' may play in contemporary medication practices.

Generally, it is acknowledged that the impacts of DTCA on the medicalisation process are complex. Some argue that DTCA has an essential function in educating consumers about disease and potential (pharmaceutical) solutions. Whether or not the information presented is balanced is another issue all together (Conrad & Leiter, 2008). Others voice the concern that, as a major resource for the expansion of medical markets and direct engagement with potential medication consumers (Conrad & Leiter, 2008), DTCA fuels the process

of medicalisation (Conrad, 1992; Conrad & Leiter, 2008; Mintzes, Bonaccorso, & Sturchio, 2002; Vuckovic & Nichter, 1997; Williams et al., 2010). These arguments are ongoing and not readily resolvable but will become increasingly important as attempts to deregulate advertising restrictions continue in Europe.

The issues raised by critics of medicalisation are certainly worth attention, but like many social issues, sustained medicalisation and pharmaceuticalisation are extremely complex and multi-layered. The above literature constructs lay people as victims of 'disease-mongering' by the pharmaceutical industry. But rather than being passive consumers of medical treatments, other literature shows that lay people are increasingly exerting their own agency around medical intervention (see 'Lay perspectives'). The collective actions of consumers, for example, may result in gaining early access to medication still in the licensing processes, or conversely, lead to the removal of unsafe medications from the market (Williams et al., 2010). Nineteenth century advertising of patent drugs were often targeted at physicians, but health consumers are the major target audience of advertising today, particularly in the US and New Zealand (Conrad & Leiter, 2008; Mintzes et al., 2002). Conrad and Leiter's (2008) research documents a shift from professionally dictated treatment (by doctors and the like), to lay persons playing a more active role in their treatment choices and health needs; "opening the door to increased medicalisation by health 'consumers'" (p.830). Similar to other objects, medications:

... Are not things that spring into existence unbidden or, manna-like, fall out of the sky for us to pick up and parade up and down with in front of some anonymous mass . . . Instead, objects exist concretely in practical relations with concrete individuals. (Carrier, 1995, p. 7)

Carrier highlights that medications are not simply imposed on a naive public, but have functional utilities that may reflect and/or satisfy the needs and demands of consumers to a lesser or greater extent. The extensive influence of the pharmaceutical industry cannot be overlooked (Williams et al., 2010). However, there is also a tendency to apportion blame too narrowly for the medicalisation of human experiences. Medicalisation is not simply the result of medical imperialism, as it is also a product of multiple social forces (Conrad & Leiter, 2004).

### Lay perspectives

Lay understandings of medications are shaped through lived and shared experiences of medication use (Conrad, 1985; Shoemaker & de Oliveira, 2008; Viswanathan & Lambert, 2005), and drawn from various sources of information (Bajcar, 2006; Hansen & Hansen, 2006). In this way, medication meanings are largely diverse and idiosyncratic (Cohen, McCubbin, Collin, & Perodeau, 2001), reflecting a unique history of individuals' interactions with medications. Making sense of medication is an emotional and cognitive process that is dynamic and ongoing (Bajcar, 2006). Thus, understandings of medications shape and change over time as they are continually rendered by the experiences of lay people. The fluidity and diversity of understandings is well reflected in the literature, where both positive and negative symbolic meanings of medications are a key point of discussion.

Medications are used in many ways: as preventatives, treatments, and cures of illness and disease, as diagnosis tools, health promoters, enhancers and beyond (Spilker & Cuatrecasas, 1990; Williams et al., 2010). These diverse 'transformative powers' (van der Geest, Whyte, & Hardon, 1996) of medications form a central part of lay persons' medication understandings. The ability to heal, transform and cure various ailments and complaints underpins a common incentive to utilise medications. It is in these effects that the caring capacity of medication lies. In private households, the concrete presence of medication provides a sense of preparedness and ability to deal with illness as it arises in everyday life (Hodgetts et al., 2011). Furthermore, it is the tangible form of medications that allows patients and others to physically address and measure

their care giving efforts (van der Geest et al., 1996). Medications make care real and tangible (Hodgetts et al., 2011; van der Geest et al., 1996), they may be "swallowed, smeared on the skin or inserted into orifices - activities that hold the promise of a physical effect" (van der Geest et al., 1996, p. 154).

Pharmaceutical benefits have far reaching impacts on the enactment of the dayto-day life of medication users. Medications may minimise the disruption of illness (Adams et al., 1997; Helman, 1981; Viswanathan & Lambert, 2005), allowing individuals to successfully carry out various social roles that might otherwise be hindered by illness. Participants in Conrad's (1985) research, for example, described the ability to prevent or reduce the onset of seizures through the use of medication. Likewise, medication may be used to reduce the frequency of asthma attacks (Adams et al., 1997), help control symptoms associated with schizophrenia such as hallucinations and delusions (Rogers et al., 1998), or keep blood pressure at a safer level for those experiencing hypertension (Viswanathan & Lambert, 2005). In this way, medications are implicated not only in processes of care, recovery and survival, but also in identity construction, relationships and routine (Doran, Robertson, & Henry, 2005; Hodgetts et al., 2011; Pound et al., 2005). Medication use may be described as 'life defining' (Hodgetts et al., 2011) in that it becomes embedded in daily routines, punctuating daily life and weaving into the very sense of 'self' of medication users (Hodgetts et al., 2011; Viswanathan & Lambert, 2005). These findings demonstrate that medications function in ways which "exceed their medicinal purposes" (Helman, 1981; Hodgetts et al., 2011, p. 353).

Despite the benefits medications might entail, the onset of chronic illness can be highly disruptive, particularly when illness and medication use is not reconcilable with existing social identities (Adams et al., 1997). Having to accommodate for illness and medication use in daily life can change plans, meanings of day-to-day life, and appraisals of self (Viswanathan & Lambert, 2005). Coming to terms with medication use is a largely conflicted process. Medications offer hope and

certainty that illness may be cured or controlled to some degree (Doran et al., 2005; Pound et al., 2005), but in the same instance, are laden with negative connotations (see Shoemaker & de Oliveira, 2008), and may symbolise a decrease in dependency or autonomy (Pound et al., 2005). Furthermore, the real and potential risk of experiencing long or short-term side effects instils "fear and distrust of medicines" in lay persons (Pound et al., 2005, p. 138). Some medications are readily accessible and so routinely used that they are considered largely benign (Vuckovic & Nichter, 1997). However, there are striking contrasts between interpretations of some medications as 'magic bullets', 'life savers' or 'wonder drugs' and others as 'dangerous', 'toxic' or 'poisonous' (Rogers et al., 1998). These differences and complexities in understandings reflect an awareness that medications have the capacity to do harm as well as good.

In a review of the literature of lay understandings of medications, Pound and colleagues (2005) conclude that the term 'resistance' best reflects many lay persons' responses to medication use. Indeed, there is a widespread belief amongst lay persons that being dependent on a chemical substance is not a 'good thing' (Conrad, 1985), and many chronic users of medications hope that they will one day be able to cope without ongoing pharmaceutical intervention (Barter & Cormack, 1996). 'Resistance' is, however, a problematic term. While lay persons may strongly dislike or fear taking medications, these attitudinal responses are not always translated into action. The capacity to 'resist' medications may be somewhat limited, especially for those who suffer from severe and chronic illnesses. In many cases, medication use constitutes a matter of 'life and death' (Foote-Ardah, 2003; Viswanathan & Lambert, 2005), and is therefore a mandatory element of daily life; offering security, certainty, and control in the face of illness (Adams et al., 1997; Conrad, 1985; Hodgetts et al., 2011; Rogers et al., 1998; Viswanathan & Lambert, 2005). By attempting to stop using medications, lay persons may come to realise that they are in fact highly dependent on medications to manage their symptoms. This was apparent for some of Barter and Cormack's (1996) participants, who after stopping their

medication regimen, were forced to resume the same night so that they were able to sleep. The term 'resistance' also fails to capture how consumer demand for medication plays a pivotal role in sustaining medical markets, and influences doctors' prescribing patterns (Conrad, 2005; Conrad & Leiter, 2004; Mintzes et al., 2002a; Vuckovic & Nichter, 1997). Clearly, lay persons may resist as well as embrace medication use.

It is also of value to highlight that 'resistance' may be conceptualised differently over time or by different groups of people. Traditionally, health professionals dominated perspectives on non-compliance or non-adherence to medication regimens (Adams et al., 1997), deeming such resistance as problematic, deviant or irrational behaviour. This perspective of health professionals reflects a widespread (but increasingly challenged) assumption that medication adherence is 'good' for one's health, and that non-adherence is detrimental to health. Such views impede discussion about the suitability of medication use in response to illness, the risks involved, the potential to utilise CAM, or resist medication use altogether. In some cases non-adherence to medication regimens is certainly a factor leading to poor health outcomes (Sorensen, Stokes, Purdie, Woodward, & Roberts, 2005; Viswanathan & Lambert, 2005). However, iatrogenic<sup>4</sup> illnesses, negative impacts on self-identity and other complications arising from medication use suggest that this is not a simple or directly causal relationship. There are variable views, amongst lay persons and medical professionals, on whether medications 'help' or 'hinder' health (Helman, 1981).

Medications are not always used as intended, as they may be shared, discontinued, stored for later use, or not taken at all (National Health Committee, 2007). Rather than viewing these behaviours as direct resistance to medications, there is growing recognition that lay persons play an active role in their medication use (for example, see Conrad, 1985; Donovan & Blake, 1992; Johnson,

<sup>&</sup>lt;sup>4</sup> An iatrogenic illness is an illness caused by medical treatment (Nettleton, 2006).

Williams, & Marshall, 1999; Kalijee & Beardsley, 1992; Roberson, 1992). Conrad's (1985) research on medication compliance with individuals suffering from epilepsy shows that medication regimens often deviate from prescribed practices recommended by medical professionals. This does not mean that the expertise of medical professionals is not valued by lay persons (Jerrett, 1994), but that patients' own interpretations of medications, the circumstances of their everyday lives and their preferences for personal management are central to the construction of their unique medication regimens. Such research highlights the agency of medication users and their prominent role in medical encounters. Conrad (1985) demonstrated that individuals are active agents in the management of their medication, rather than passive recipients of doctor advice and instructions. Conrad also made an important link between understandings of medications and medication practices, arguing that "variations in medication practice by and large seem to depend on what medication and self-regulation mean to our respondents" (p.34).

Researching the lay understandings of medications is important as it is peoples' beliefs about medications and illness which inform their responses to medication use (Bajcar, 2006; Conrad, 1985; Shoemaker & de Oliveira, 2008). By examining lay understandings, insights may be gained into the practices of medication users enacted inside domestic dwellings. The link between medication understandings and practices has been the focus of a number of qualitative studies. For instance, Helman (1981) and Adams and colleagues (1997) offer classifications of chronic medication users based on the ways they use and interpret illness and the role of medications in daily life. Helman (1981) classified long term psychotropic drugs users into three symbolic groups - 'food', 'tonic' and 'fuel'. Those who considered their medication, instead stressing the importance self-control, autonomy and choice in responding to illness. These participants were described as more 'anti-drug' than others and did not engage in regular psychotropic drug use, instead preferring to self-medicate as they saw necessary. At the opposite end of this

continuum, participants that were classified in the 'food' category were likely to perceive medication use as a necessity for survival. These participants felt that medication was essential to achieving and maintaining their personality and social relationships; thus, they were more likely to engage in regular and routine psychotropic use.

In their study of medication use amongst sufferers of asthma, Adams and colleagues (1997) identified two main groups of medication users - 'accepters' and 'deniers'. 'Accepters' described 'asthma sufferer' as being an integral part of their personal identity. For these participants, the need to take daily medication was accepted and incorporated into existing daily routines and social roles. Those who denied the identity of asthma sufferer, however, were less likely to take medication in the prescribed manner, deeming medication use 'unnecessary' and concealing it from others. Whether medications are accepted, denied, perceived as 'tonic', 'fuel' or 'food', these classifications generalise perspectives in order to communicate fundamental differences in the ways people understand illness and medication use. Such classifications offer insights into how people may respond to medication use which may be useful information for health professionals. Such research should not, however, undermine the fluidity and idiosyncrasy of medication understandings.

Research by Helman (1981) and Adams and colleagues (1997), amongst others, highlights that medications have both symbolic and social dimensions. The readiness or reluctance to accept medication use reflects the ongoing stigmatisation of illness and disease, and demonstrates how socially constructed meanings of medication, illness, and disease, continually pervade lay persons experiences with medications. The connection between objects and identity has been the subject of examination for many years (Veblen, 1899). Without undermining the practical functions of material items, it is necessary to recognise that there is more than mere utility involved in the relationships between people and objects (Carrier, 1995). The consumption and display of objects, for example,

can enable people to position themselves in a hierarchy of individuals and maintain distinction from those in "lower ranks" (Carrier, 1995, p. 2). Such knowledge opens the way for analysis of the relations between medications, individuals and wider society.

The literature explored in this section provides an important foundation for understanding medications as social and symbolic objects. In the development phase, use in clinical settings, shelf-life in a pharmacy or existence in a private relationship, the life cycle of medications engage numerous social actors over time, each of whom hold distinct understandings of medications (Cohen et al., 2001). By acknowledging their social lives, medications may be described as continually evolving "socially embedded phenomena" that shape social relations in their interactions between micro, meso and macro structures (Cohen et al., 2001, p. 442). This conceptualisation of medications offered by Cohen and colleagues (2001) extends vastly upon the interpretation of medications as mere material objects, which is a pivotal theme underlying this thesis. Also of particular relevance to this thesis, this section shows that 'patients' or lay persons are very much a part of medical history, and are active agents in medication use.

### Caring for chronically ill children

The notion of 'care' has come to the fore in this research due to the focus on medication practices parents enact throughout the care of their chronically ill children. Despite being a common and familiar term used in everyday life, 'care' is not a straightforward or simple concept. Care is perceived and experienced differently between those delivering and receiving it (Bondi, 2008), which means that there are many possible interpretations of 'care' and 'care giving'. Furthermore, there are many types of care. Care may be emotionally and mentally grounded, or concerned with physical acts of care (Tronto, 2001). Care can be directed at another or directed at self. While care may be carried out as a

moral duty toward family or friends (Evans & Thomas, 2009), many forms of care are performed by persons in paid positions. The commodification of care in industrialised societies (Ungerson, 1997) requires that any definition of care should capture the variety of power differentials in various care relationships (Tronto, 2001). There is also considerable debate about how care needs and responses should best be determined. In the context of health and medical related behaviours, these are relevant considerations. In many instances, there is ongoing deliberation to determine whether medications are 'needed' for physiological reasons (Moynihan, 1998), or dispute about whether medications constitute a caring response to ill health (Dew, 1999).

In some cases, care requirements may be obvious (Tronto, 2001). Those with physical disabilities, for instance, may require support with physical tasks such as moving around the home or carrying out household duties or personal care. It is widely known that infant children require support with fundamental survival needs such as food and shelter. Not all individuals are quite so vulnerable or have the same level of dependence, however, and identifying care needs is not always a transparent or straightforward process. There are likely to be more than one possible way to care for individuals in any given community (Tronto, 2001). Similarly, there are multiple ways to respond to ill health. Caring for chronically ill persons might be communicated through the delivery of a 'get well' card, supporting the individual to live independently at home, visiting them in hospital or ensuring that they take their medication. There are differing cultural and individual perspectives regarding whether or not such actions constitute 'care'. Thus, defining care is a difficult and problematic task. Nonetheless, the lack of a standard definition of care is to some extent advantageous for the foundation of this thesis. It centralises lay people's perspectives on care and care giving, and accommodates for competing or conflicting constructions of caring medication practices.

It is necessary to provide an explanation of how and why medications might constitute care. Neglecting to do so would involve making a major assumption that underpins most literature on medication taking. The idea that medications are good for health or should be taken in response to illness has a sound basis. After all, fighting illness and disease and reducing suffering are fundamental purposes of medication development and use. However, caring through medications is a deeply paradoxical concept. As the few historical examples provided earlier illustrate, medication use may have negative impacts on health that are profoundly incongruent with notions of 'care'. Despite the potential for negative impacts of medication use, research offers many examples where the provision of medication is indeed aligned with 'care'.

There is intense pressure on parents to adequately care for their ill children. On a personal level, it can be difficult for parents to witness their children suffering from illness (Vuckovic & Nichter, 1997), as this goes against parents' moral and emotional instincts (Jerrett, 1994). The promise of medication to reduce pain and suffering, or enhance health, make them a powerful tool for care in many relationships. Between parents and their children, medications offer a modern solution to parental caring pressures (Vuckovic & Nichter, 1997). In the context of the modern lifestyle, many parents may have little time to care for their sick children (Vuckovic & Nichter, 1997). Medications are a quick, highly accessible, and effective response that allows parents to more easily accommodate for illness in their hectic daily schedules (Vuckovic & Nichter, 1997). As highlighted earlier, medications have various physiological and psychological effects that are an integral part of the caring capacity of medications (see 'Lay perspectives').

Caring for the ill is often enacted by ensuring adherence with medication regimens. In households with chronic medication users, there is an emphasis on 'remembering' and 'reminding' to take medications. Other household members frequently assume responsibility for ensuring that their family members adhere to their medication regimens. This is carried out in various ways, from simple

verbal or written reminders (Marhefka et al., 2008), to the more elaborate use of devices such as electronic beepers, calendars or timers (Marhefka et al., 2008). Reminding and remembering also includes more discrete methods, such as the pairing of medications with other household activities (for example, meal times), and the placement of medications in shared household spaces where their visual presence aids remembering for both medication users and other household members (Hodgetts et al., 2011; Marhefka et al., 2008). Similarly, for Milliken and Northcott's (2003) participants, parents expressed care through the constant observation of their children's treatment, and ensuring compliance with medication regimens. Such practices subtly reflect the connection between medications and care.

The connection between medications and care is expressed on a more explicit level in health policy. For example, in their study of neuroleptic medication use amongst sufferers of Schizophrenia, Rogers and colleagues (1998) highlight how the success of mental health policy 'care in the community' is assessed by the level of medication compliance. While a high level of medication compliance is equivalent to successful care, medication non-compliance is considered problematic (a theme emerging from many 'compliance studies'). Rogers and colleague's research shows that medication use and compliance may be adopted as a key indicator of the success or failure of community based care for mental health patients. The idea that medications constitute a form of care is also evident in human rights laws. Access to "essential medications" is an integral part of health rights outlined in the 1946 constitution of the World Health Organisation (World Health Organisation, 1946). In 1948, this right to medications was also recognised in the Universal Declaration of Human Rights (United Nations General Assembly, 1948). Similarly, in New Zealand, PHARMAC's role is underpinned by the notion that all New Zealanders should be able to access medication in their responses to ill health. These formal acknowledgments of the 'right' to access medications indicate that using medications as a mechanism for care is a pervasive cultural idea. The quest for

health and wellbeing has become somewhat of a cultural project, moral endeavour, and societal obsession (Illich, 1986; Vuckovic & Nichter, 1997) that is commonly sought through medication use.

There have been significant social changes in responses to health and the management of illnesses that have centralised the family as a primary source of care for chronically ill children. The process of deinstitutionalisation saw the transfer of care for many ill individuals from professionals in institutional spaces, to community sites of care and private dwellings with (sometimes ill prepared) lay persons (Lauver, 2008; Milliken & Northcott, 2003). In many developed countries, national health policy (such as cut-backs in health spending) have centralised the home as a space of care and have placed greater responsibility on family members to perform care giving duties (Evans & Thomas, 2009). Pharmaceuticalisation is also enmeshed in these changes, with easy access and widespread use of medications simplifying the ability to enact medical care within the home (Fox & Ward, 2008; Prout & Christensen, 1996). Thus, the family has emerged as the "primary source of care for a chronically ill child, and it is the parents who must manage the child's illness on a day-to-day basis" (Jerrett, 1994, p. 1050).

Caring practices carried out by family members are hidden in the private space of the home, isolating many carers from support networks in the wider community (Evans & Thomas, 2009) and rendering many care sacrifices, efforts and practices invisible. For this reason, it is important to pay attention to health practices occurring within the home. Due to concerns about the impact of the aforementioned social changes on the family unit, there is a tendency for research to focus on the 'care burden' inherent in caring for the chronically ill. From such research, we have learnt that providing care is a physically, mentally, emotionally and sometimes financially demanding task (Blum, 2007; Bussing & Gary, 2001; Evans & Thomas, 2009; Lauver, 2008; Singh, 2004).

Although the provision of medication is an important part of caring for the chronically ill, there are multiple tasks entailed in this process. Research suggests that a significant effort exerted by care givers involves them utilising their research skills in efforts to make the best medication decisions for their children (Bussing & Gary, 2001; Hansen & Hansen, 2006; Jackson & Peters, 2008). By acquiring more information, seeking additional advice, and challenging or questioning medical direction, parents are able to make sense of medications and reduce uncertainties surrounding their use (Bajcar, 2006). Blum (2007), for instance, noted that her participants used the internet as a source of information about medications, drawing on both professional websites concerning paediatric psychopharmacology, as well as social forums where the wider public are able to discuss and share their lay knowledge or experiences with others. Jackson and Peters' (2008) participants disclosed that they rely on media, scientific journals, "health and education professionals" for information and support (p.2728). Researching medications before deciding on a direction of care is part of an assessment process whereby parents consider both benefits and risks of using a medication.

Care givers commonly assume sole responsibility for their young or dependent children's adherence to medication regimens (Marhefka et al., 2008; Milliken & Northcott, 2003). As earlier highlighted, this includes implementing various strategies for remembering to take medications. Such strategies point to how medication use has come to be ingrained in other daily practices and routines (Hodgetts et al., 2011). Taking responsibility for medication adherence is a task that also involves administering medications, controlling dosage (Blum, 2007; Marhefka et al., 2008), and obtaining medications from the doctor or pharmacy as they are required (Marhefka et al., 2008). The perception of children as relatively dependent on adults (Prout & Christensen, 1996), and vulnerable to medication effects (Blum, 2007; World Health Organisation, 2007), means that parents are unlikely to allow their children to enact medication regimens

independently. In Bush and colleagues research (1996), not a single participant viewed their child as autonomous in this respect.

Observation practices are also common amongst parents and have various practical implications. Through the observation of physical symptoms and behavioural patterns (such as a child's typical eating and sleeping patterns), parents are able to identify subtle changes in their children's wellbeing (Blum, 2007; Callery, 1997; Gunnarsson & Hydén, 2009; Jerrett, 1994; Lauver, 2008; Milliken & Northcott, 2003). Observation allows parents or care givers to identify any medication side effects and judge when symptoms require medical attention (Blum, 2007; Gunnarsson & Hydén, 2009; Lauver, 2008; Milliken & Northcott, 2003). An integral part of caring is coming to know these unique patterns of behaviour (Lauver, 2008), as conducting these assessments requires an awareness and familiarity with behavioural cues (Lauver, 2008). Blum (2007) employs the term 'vigilante' to capture the intensity of parents monitoring of their ill children. Parents are likely to challenge medical authority if they believe they have a basis for it (Blum, 2007; Jerrett, 1994). This advocacy is informed by parents' intimate knowledge of their children. Constant surveillance positions parents as well informed experts of their children's needs and wellbeing (Callery, 1997).

In caring for chronically ill children, parents' actions reveal that medications are not seen as the only possible solution to health needs. Nutrition is a key concern for care givers and ensuring a healthy balanced diet is an integral part of caring (Evans & Thomas, 2009; Gunnarsson & Hydén, 2009), especially for children who suffer from food allergies. Food allergies highlight how food and health are highly enmeshed. By altering diet to avoid particular foods, parents may reduce the likelihood of inducing allergic reactions. Alongside diet, breast feeding is also thought to be a good source of nutritional value (Malacrida, 2002). Parents sometimes partake in prolonged breast feeding as a preventative against illness and disease (Gunnarsson & Hydén, 2009). Rather than simply focussing on the

treatment of illness, these preventative actions and attempts to strengthen immunity indicate ecological thinking (Gunnarsson & Hydén, 2009), and consideration of lifestyle factors on health and wellbeing.

Literature documenting the significant effort exerted by parents who carry out these numerous tasks points to how caring for chronically ill children is above and beyond a perfunctory administration of medication or completion of various tasks. As Lauver (2008) argued, caring is "more than a set of care giving tasks to be performed at set intervals. Caring for [a] child required listening to one's intuition [and] gaining an understanding of the child's personality and behavioural characteristics" (p. 86). Caring is: making lifestyle adjustments to accommodate for the complexities of caring for chronically ill children (Evans & Thomas, 2009); dedicating a significant amount of time and energy to ensuring safe and effective responses to ill health; and making sure that ill persons do not feel like a burden on other family members (Evans & Thomas, 2009). Importantly, part of caring is also managing and withstanding the many conflicting emotions that are stirred up by care giving (Bondi, 2008; Evans & Thomas, 2009).

#### Deciding for or against medication use

As will be shown in this research, the decisions made by the parents on whether to use or not use medication are not straightforward or consistent, but often involves steering a path through a range of challenging and/or conflicting information sources. The literature surrounding attention deficit hyperactivity disorder (ADHD) diagnosis and treatment is particularly useful for gaining an insight into the difficulties parents may face when making medical decisions on behalf of children. For care givers of children suffering from ADHD, the decision to medicate or resist medication aligns with the notion of a 'dilemma' or 'balancing act' (Hansen & Hansen, 2006), and is impacted by various social, individual, ethical, and emotional factors. There remains dispute around the safety and efficacy of medication use in response to ADHD amongst children. While some argue that ADHD is a legitimate neuro-developmental condition requiring medical intervention, opposing perspectives assert that ADHD is a behavioural problem. Consequently, the rising diagnosis and treatment of ADHD has received a substantial amount criticism. Such debates highlight that there can be competing perspectives regarding the nature of illness and what constitutes 'best care'.

There are multiple social pressures acting on parents' decisions to resist or choose to medicate their children suffering from ADHD. Although obvious social actors include parents and medical professionals, non-medical people also play a significant role (Malacrida, 2004). Educators, for example, are often involved in the identification of behavioural problems, diagnosis, and administration of medications in the school environment (Jackson & Peters, 2008; Malacrida, 2004). In addition, family members and friends are also likely to pressure care givers (Jackson & Peters, 2008). Pressure and information received from these sources can be highly polarised. While many parents feel pressure from educators to medicate their children (Jackson & Peters, 2008; Malacrida, 2004), they may simultaneously receive opposing demands from family or friends not to medicate (Jackson & Peters, 2008). Clearly, parents must manage a range of conflicts when attempting to care for their chronically ill children.

For those parents who do choose to medicate their children suffering from ADHD, responses are mixed. Some accounts reveal relief and confidence in the decision to medicate children; care givers were able to identity benefits in home, schooling and other social environments (Hansen & Hansen, 2006). Conversely, other care givers report negative changes in their child's wellbeing, such as a 'flatness' in personality and mood, or chronic tiredness (Hansen & Hansen, 2006). Regardless of the choice made by parents, care givers tend to have "a deep commitment to doing the best by their child" (Jackson & Peters, 2008, p. 2727). Ongoing dispute about the 'right' way to treat ADHD means that parents often find themselves having to repetitively justify, explain, or defend decisions

regarding their response to their child's ADHD diagnosis (Bussing & Gary, 2001; Jackson & Peters, 2008). In deciding to medicate their children, parents become the subject of intense scrutiny from those individuals whom perceive the decision as a dangerous and even negligent action.

It has been well established in this thesis that symbolic meanings of medication impact the identity of users. The social approval or disapproval of parents' decisions regarding ADHD treatment reveals how the identity of parents is also central to medical practices. Parents' competence as 'responsible care givers' is measured according to their ability to respond quickly, adequately and responsibly to their children's health needs (Gunnarsson & Hydén, 2009). Parents attempt to affirm their identity as 'responsible care givers' through the enactment of multiple care giving tasks. Most parents are highly motivated to provide care and are sensitive to the possibility of being ascribed with the 'inadequate care giver' label (Malacrida, 2002). Care givers are likely to feel inadequate when they are unable to solve or effectively manage their children's health problems (Singh, 2004).

From wider literature it becomes apparent that care giving is a relatively gendered role. Many studies concerning parental experiences of caring for their ill children tend to involve only the mothers of children (Bush et al., 1996; Jerrett, 1994). Jerrett's (1994) research is no exception. When attempting to include fathers of children in her research, she was often referred back to the mother of the children on the account that they are more responsible for and involved in the child's daily care. Since mothers are commonly seen as "the natural source of physical and emotional nurture" (Malacrida, 2002, p. 372) in Western societies, they are commonly held personally responsible for the physical and emotional development of their children (Blum, 2007; Malacrida, 2002).

It is important to understand that gender relations are a "powerful socialising force" (Singh, 2004, p.1195) pivotal to parents care giving actions and experiences. In a culture that "valorises maternal self-sacrifice" (Singh, 2004, p.

1194), mothers experience social and personal pressure to be a 'good mother' (Blum, 2007; Gunnarsson & Hydén, 2009; Singh, 2004). This pressure may be exerted in the form of 'blame' for children's emerging health problems. The childhood diagnosis of ADHD is a powerful example in which to ground these claims. Where the cause of ADHD is attributed to inadequate maternal practice, interventions are targeted at home-care strategies such as dietary changes or increased attention devoted to the child (Bussing & Gary, 2001), which centralise maternal care solutions (Malacrida, 2002). Mother-blame is perpetuated by mothers themselves, who experience feelings of guilt and inadequacy over their children's health issues (Blum, 2007; Bussing & Gary, 2001; Singh, 2004). Even when a medical explanation of ADHD is accepted, "whereby the focus of blame is moved from the mother to the child's brain" (Hansen & Hansen, 2006, p. 1281), a mothers' sense of personal responsibility or liability for her child's diagnosis and health issues does not dissolve (Blum, 2007). This mother-blame, whether individual or societal, marks the ongoing pervasiveness of gender roles.

Milliken and Northcott's (2003) research shows that being unable to accomplish the everyday care of their children is an extremely painful experience for parents. For participants in Milliken and Northcott's study, the desire to assume responsibility for the care and protection of their ill adult-child invoked feelings of powerlessness as they came to learn that the authority to direct care resided with health professionals, rather than themselves. Parents described feeling 'disenfranchised' from their role, and sought to challenge their marginalisation by continuing to watch over the psychiatric treatment of the child and ensuring medication compliance. This research, along with others, provides ample insights into what drive parent's care giving tasks and why they desire to play such a major role in the treatment and care of their ill children. As explained earlier, individuals may gain a sense of control and certainty through medication use (Conrad, 1985; Hodgetts et al., 2011). While 'certainty' and 'control' are recurring themes in medication literature, the need of parents to care for their children is more complex than what can be captured in these words.

Parents and their children may share close emotional bonds which, among other emotional experiences, are an important driving force for care giving tasks. Female care givers in Evans and Thomas' (2009) research perceived their care giving tasks as a reflection of love, affection, responsibility and "moral duty" towards their family (p. 114). When care giving reflects such fundamental dimensions of parent-child relationships, is becomes paramount that parents do everything they can to care for their ill child (Gunnarsson & Hydén, 2009). Evans and Thomas' (2009) research indicates that assuming responsibility for care giving is more than just a matter of children's dependence and vulnerability, but also of parent-child relations, identity and morality.

The ADHD literature shows that care giving is highly emotionally charged. It is common for parents to experience fears about 'ruining' or 'hurting' their children through medication use (Bussing & Gary, 2001). Some parents worry that drug therapy may change a child's personality or stunt their emotional development (Hansen & Hansen, 2006; Jackson & Peters, 2008), while others note actual changes in sleeping and eating patterns of their medicated children (Hansen & Hansen, 2006). Exploration of lay understandings of medications has shown that real and potential side effects are a major concern for medication users, and these findings certainly apply to those care givers making decisions on behalf of children (Bussing & Gary, 2001; Hansen & Hansen, 2006). The conflicting perspectives of Ritalin as a 'miracle drug' (Bussing & Gary, 2001), or a 'quick fix' (Singh, 2004) for behavioural deviancy and 'bad parenting' induces fear, stress, anger and confusion for parents attempting to make the best decision for their child (Blum, 2007; Bussing & Gary, 2001; Hansen & Hansen, 2006; Singh, 2004). Stimulant medication use is often seen as a 'last resort' (Jackson & Peters, 2008) following various other interventions such as family counselling, dietary changes, behavioural modification therapy, increased attention and so forth (Bussing & Gary, 2001; Jackson & Peters, 2008). This tendency to try multiple alternative therapies reflects a tacit understanding amongst parents that they should do

everything they can to obtain and maintain their children's health and wellbeing (Gunnarsson & Hydén, 2009; Jackson & Peters, 2008).

Worry and fear about medication side effects are emotional hallmarks of many parental experiences surrounding medication use and not just specific to Ritalin (Lauver, 2008). It is likely that care givers will experience an array of emotions such as ongoing worry, anxiety, uncertainty, and concern for the ill child (Evans & Thomas, 2009; Lauver, 2008). Care givers of chronically ill children also revealed that they often feel overwhelmed at the constant need to adapt to the ongoing needs of a chronically ill child (Lauver, 2008). Aside from sheer volume of information and competing knowledge (Vuckovic & Nichter, 1997), grasping complex medical terminology and processes is a highly demanding task. While the health of ill persons is certainly a central concern, these emotional experiences also have a direct impact on the wellbeing of care givers (Evans & Thomas, 2009). For instance, participants in Evans and Thomas' (2009) research recall a loss of appetite and weight due to the worry and concern for an ill person. Physical and emotional exhaustion were common experiences amongst their participants. When ill persons were in better health, participants described feeling better, more energetic and hopeful themselves. Such connections reflect the close emotional bonds developed between ill persons and their carers.

Within the literature, there is a tendency to emphasise the emotional angst felt by parents throughout the care of their ill children. Care giving is, however, also saturated by positive emotional experiences. Receiving a diagnosis for a child's chronic illness may evoke feelings of shock, sadness and anger (Jerrett, 1994). Yet many care givers feel relieved when a diagnosis is finally provided (Hansen & Hansen, 2006). In many cases, receiving a diagnosis is a positive step towards finding solutions or additional support and care givers welcome this phase (Hansen & Hansen, 2006). The social processes whereby a particular family came to be a primary source of care for chronically ill individuals conjure the image of family members begrudgingly assuming the care giving role. Although the 'care burden' and emotional, physical, and financial hardship of caring for the ill is well acknowledged in available literature, it is important to note that many individuals embrace the role (Evans & Thomas, 2009), and derive a sense of pride and satisfaction from their care giving tasks (Evans & Thomas, 2009; Jerrett, 1994; Singh, 2004).

#### The present research

As explained earlier, this thesis explores lay understandings of medications, and the everyday practices and experiences of mothers caring for their chronically ill children. A key idea that underpins the argument of this thesis is that medications are much more than simply material objects or pharmaceutical products with physiological effects. Medications have symbolic meanings which impact how they are perceived and used in everyday life. This thesis documents the role of medications in transactions between parents and their children, exploring the various roles parents enact around medication use, and the impact of these transactions on identity and relationships. This research extends current knowledge regarding the symbolic nature of medications, and the way in which parents enact care for their chronically ill children inside private domestic dwellings.

Chapter two outlines the methodology employed within this research. To begin, this chapter explains the theoretical assumptions—from Giddens' (1984) structuration theory and gift exchange theory—which underpin this research. Following this, the research design, process, and setting are documented. Rendering unfamiliar the practices and beliefs associated with daily life in order to enable examination can be difficult for participants and researchers (Chaney, 2002). The methodology employed within this research intends to support participants to examine the taken-for-granted medication practices performed in everyday life. As detailed in chapter two, this is achieved through the case study of four households, employing the use of multiple participatory data elicitation methods. Finally, this chapter provides an account of how the data was analysed.

Chapter three presents an analysis of participants' understandings of medications. This analysis is divided into two parts. The first examines some complexities of medication understandings arising from participants' accounts. In the second part, physical and social dimensions of participants' conceptualisations of medications are identified and discussed. This chapter also explores the links between the understandings of lay persons and the medication practices enacted inside private domestic dwellings, as well as between public and private structures of meaning. Finally, a summary of the medication preferences of each participant involved in this research is provided.

Chapter four examines how medications are utilised in processes of care giving for chronically ill children in the households studied. This chapter highlights the efforts exerted by parents in the administration, preparation and selection of medications for their ill children. I will explore the emotional dimensions of gift exchanges involving medications, with particular emphasis paid to routine and automatic medication use in everyday life. Attention is then directed to alternative gift exchanges entailed in caring and health maintenance. In particular, participants' resistance to medication use is central to this discussion.

Chapter five documents how medications are implicated in the generation (or degeneration) of participants' care giving identity and their relationships with their children, family, friends, and health professionals. This chapter highlights the role that maternal and intuitive knowledge plays in informing participants' medication practices and other social actions. Finally, I identify and examine the various roles participants perform throughout the daily enactment of medication practices. Examining these roles includes consideration of the many tasks parents undertake in efforts to obtain and maintain the health and wellbeing of their children - employing a broader conception of 'the gift' (see 'Theoretical perspective').

Chapter six presents a discussion of significant overarching themes which emerge throughout chapters three to five. This chapter draws on gift exchange theory, and Giddens' (1984) structuration theory (1984), to help illuminate and summarise what the participants' experiences reveal about the ways in which people interact with medications in the household environment. This chapter also addresses what the findings from this thesis mean in the context of future qualitative research on the understandings, experiences and practices of lay people. It concludes with broader social implications.

#### **CHAPTER TWO: METHOD**

The research design and methodology employed in this research were aimed towards gaining in-depth accounts of participants' everyday 'worlds of medications'. The methods of data collection described below involve visual imagery, written records and spoken accounts: the combination of which support participants to assess their taken-for-granted assumptions about everyday interactions with medications. To begin, Giddens' (1984) structuration theory and gift exchange theory are outlined, and links made to how these theories assist in the examination of participants' medication practices explored in subsequent chapters of this thesis. Then, an outline of the research methodology and process describes the case study of four households, which entailed two phases of semi-structured interviewing, mapping, photo-production and diary keeping exercises. The data collection methods sought to allow participants to take the role as the creators of knowledge (Carlson, Engebretson, & Chamberlain, 2006), facilitating a participatory research process in which participants may experience both enjoyment and ownership in the research process (Hodgetts, Radley, Chamberlain, & Hodgetts, 2007a). The scope of the research will be described, and finally, the analysis process.

## **Theoretical perspective**

This thesis draws on both structuration theory and gift exchange theory in the analysis of participants' medication experiences. Structuration theory provides a perspective on broad societal processes that is central to understanding the public dimension of private medication practices. This theory delineates Giddens' (1984) attempt "to formulate a coherent account of human agency and of structure demands" (p.xxi). Gift exchange theory provides a theoretical foundation for the analysis of the exchange of medications between a parent and their child.

There are two important components in Giddens' (1984) structuration theory that make it a suitable philosophical perspective for this particular research. Firstly is Giddens' outlook on the nature of human subjects as active agents in day-to-day social activities. Giddens veers away from a mechanistic view of humans as docile bodies and highlights the capacity of human agents to 'act otherwise'. Giddens explains agency as the ability for individuals to "intervene in the world" (p.14) with their actions, such as when they resist, modify, or subvert institutionalised practices. This interpretation of humans as having agency is well attuned to the literature explored in chapter one that examines how medication users construct their medication practices.

A second component of structuration theory provides some understanding of the impact of social structures on human actions. Structure is commonly understood as a form of 'patterning' of social actions, relations and phenomena, and also akin to physical constructions like the human skeleton or building foundations (Giddens, 1984). For Giddens, 'structure' "refers not only to rules implicated in the production and reproduction of social systems but also to resources" (p.23). A main proposition of structuration theory is that, rather than existing external to human action, day-to-day activities "draw upon and reproduce structural features of wider social systems" (p.24). Giddens highlights the duality of structure and two faces of power (individual power and institutional power) in day-to-day social practices. In chapter one, acknowledging these two faces of power was an important balance. While individuals may exert their agency in daily medication use, this may be either constrained or enabled by wider social structures such as biomedical hegemony.

Gift exchange theory enlightened three important components of medication practices and understandings that are central to this thesis. Firstly, this framework asserts that material items are not merely "abstract bundles of utilities and value" (Carrier, 1995, p. 28), but they also acquire meaning from relationships between individuals. Secondly, the theory highlights the way in

which the transaction of objects can communicate a variance of sentiments such as care, affection or aggression. Finally, gift exchange theory also denotes how the transaction of objects can reinforce, modify or weaken relationships between the recipient and giver (Carrier, 1995; Mauss, 1950). Gift exchanges are central to the establishment and maintenance of hierarchies and personal relationships (Carrier, 1993, 1995; Mauss, 1950; Schwartz, 1967).

In chapter one I introduced the way in which medicalisation and pharmaceuticalisation literature reinforces the construction of medications as 'commodities' subject to passive transactions between consumers and sellers. However, individuals do not interact with medications as simple or inert material objects. Instead, individuals engage with medications in a way that "reveals ambivalence, desire, antipathy, faith and suspicion about medicines" (Doran et al., 2005; Hodgetts et al., 2011, p. 353). Gift exchange theory accounts for the way in which commodities are transformed from 'mass products' to gifts or personal possessions<sup>5</sup>.

Drawing from the Maussian model of gift exchange theory (Mauss, 1950), gift and commodity transactions are distinguished by the nature of the relationship between the giver and recipient. Many everyday commodity transactions(such as buying groceries from a supermarket) involve relationships and objects that are not especially enduring or associated with each other, "nor do they speak of any past or future relationships with transactors" (Carrier, 1995, p.20). Carrier described the individuals and objects involved in commodity transactions as 'fungible', that is, they may be replaced with items of the same utility and value. In contrast, gift exchanges are typified by relationships and objects that are "unique and inalienably linked to each other" (Carrier, 1995, p.28). For example, 'the vase from Mum' carries the essence of the relationship between transactors that could not be matched by a replacement item in the event the vase was

<sup>&</sup>lt;sup>5</sup> The term 'possessions' is used synonymously with 'gifts' to draw attention to the way in which such objects are bound with personal meanings and social identities unique to the individual.

smashed. Even if it might look the same and function the same way, it could not legitimately replace the original vase gifted by Mum.

Modern Christmas celebrations are a particularly familiar setting for gift transactions in western societies. Research has revealed how Christmas gift giving is a mechanism for communicating care and affection within and outside kin networks (Caplow, 1984; Carrier, 1993). Gift giving from adults to children is an especially important part of the Christmas ritual, and while this action is purported to be contingent on the good behaviour of children, Caplow (1984) was not able to identify any instances where gifts were withheld from children as a disciplinary consequence: "Those to whom the possibility was suggested seem to be shocked, perhaps because such an action would be incongruent with the unqualified love of parents for children that the festival celebrates" (p.389). Accepting a gift is an important part of maintaining the relationship between transactors (Carrier, 1995). Conversely, the refusal to accept a gift symbolises the rejection of the bond between giver and recipient (Carrier, 1995; Mauss, 1950): "To refuse to give, to fail to invite, just as to refuse to accept, is tantamount to declaring war; it is to reject the bond of alliance and commonality" (Mauss, 1950, p. 13).

The links made between objects and individuals that are explored in gift exchange theory make it a suitable orientating framework for the examination of relationships between individuals and medication. These links are not new, nor are they unapparent to individuals or advertisers. The effort involved in the selection of Christmas gifts, in order to find one particularly suited to the recipient, encompasses an understanding that objects reaffirm the social identities of transactors. Similarly, objects are marketed in ways that make the connection between objects, identities, relationships and personal desires. Examination of modern Christmas gift giving rituals illustrates how gift exchanges can communicate various sentiments and impact social relationships. Such insights might seem somewhat removed from medication use, so it is important

to recall that medications are also objects subject to exchange between individuals.

# **Research design and methodology**

This research is part of a larger project entitled 'Medications in everyday life: Understandings and social practices' involving the collaborative efforts of academics from the University of Waikato, Massey University, University of Otago, Victoria University of Wellington, Loughborough University and Royal Holloway. As a student member of this research team, I benefited immensely from the knowledge and support of senior researchers. The research design and methods were already developed and trialled by the wider research team. Developing my methodology in this context involved a negotiation between existing research methods and focus, and my particular interests and research direction. As part of a larger research team, I sought to ensure that the research aims of the wider project were met throughout my data collection phases, but I also attempted to create a novel focus within the project domain.

My research involved the case study of four households containing children under the age of twelve experiencing chronic illness. The case study is an appropriate approach for revealing unique features of household medication use (Bryman, 2004; Small, 2009). As Small (2009) asserted, a single case study "can justifiably state that a particular process, phenomenon, mechanism, tendency, type, relationship, dynamic, or practice exists" (p. 24).The exemplifying case refers to those cases that are chosen because they provide a suitable context for particular phenomena to be analysed (Bryman, 2004). The illnesses experienced in the households studied are provided in the demographic information presented in Table 2 on the following page:

Pseudony m	Age and sex	Occupation	Household type	Age of children	Chronic illness
Natalie	34, Female	Mother	Single parent	14, 11, 10 and 6 years	Immune deficiency Hay fever
Sarah	33 <i>,</i> Female	Mother and teacher aid	Two parents	8, 5 and 5 years	Trigonocep- haly Hay fever
Maddison	23, Female	Mother	Two parents	4.5 and 2.5 years, 7 months	Asthma Hay fever Lactose intolerance
Olivia	23, Female	Mother	Single parent	6 months	Strawberry birthmarks

In each case, four methods of data collection were used, including semistructured interviewing, a mapping exercise, a photo-production task and diary keeping.

#### Interviews

Semi-structured interviews were used to encourage participants to talk at length about their medication practices and experiences. Semi-structured interviewing may be described as both flexible and responsive, in that the conversational style permits interviewees to direct conversation topics and concerns depending on their own opinions and experiences (Flick, 2009). This flexibility allows for unanticipated but relevant topics to arise. Deviating from research questions or topics is often encouraged in qualitative interviewing, as this provides an indication of those things most personally salient or important to the interviewee (Bryman, 2004). Such flexibility also increases the responsiveness of the interviewer, who is able to use probing questions, follow-up questions, or 44 interpreting questions to help further elucidate participants' responses (Bryman, 2004).

There are also practical benefits implicated in using semi-structured interviewing as a data collection method. The recording and transcribing of interviews is a technological advance which reduces reliance on the interviewer's memory and also allows them to focus on being responsive to the interviewee (Bryman, 2004). Audio recordings of interviews allows for thorough and repeated inspection of participants' responses (Bryman, 2004), and allows attention to be directed not only to what participants say, but *how* they say it (Silverman, 2010).

The current research involved two phases of semi-structured interviews for each participant. Interview protocols were developed with consideration of set themes determined by the wider research team, as well areas I wished to explore relevant to this thesis. These protocols provided a guide as to what should be discussed during the interviews. But, as Silverman (2010) noted, "interview protocols, while helpful, only take you so far" (p.195). Preconceived interview questions used to initiate conversation were open-ended in nature and oriented towards exploring values, beliefs, behaviour, experiences, relationships, emotions, roles and locales around medication use. The initial interview also functioned well as a medium for rapport building between the researcher and participants, while the final interviews involved diary and photo elicitation discussions described in the subsequent sections.

### Mapping exercise

The use of spatial analysis is commonly applied to the examination of illness and disease epidemiology in medical geography (Gesler, 1986). Gesler asserts that geographical mapping helps to reveal underlying processes determining spatial arrangements, which can aid the assessment of health care delivery methods and accessibility. In the current research, maps helped to identify where

medications were stored within the home and determine how medications flow in, out, and within the boundaries of the home.

The mapping exercise formed part of the initial interview with participants, and involved them drawing a map of their home to indicate where medications are stored (Appendix A). These locations were photographed with the permission of participants so that these photos could be referenced to the map and provide further visual representation about the locale of medications. In accordance with Gesler's (1986) assertion regarding the revelation of underlying processes, this exercise helped participants reflect on and talk about their practices, such as the rationale for why medications are stored in particular locations, how they get there, who can access them and how they leave the home.

#### Diary keeping

The use of diaries in qualitative research have proved invaluable for providing access to private events that would otherwise remain unobserved in the researcher's absence (Elliott, 1997; Johnson & Bytheway, 2001; Lewis & Massey, 2004, September; Milligan, Bingley, & Gatrell, 2005). Diaries provide a record of events occurring in daily life developed solely by the participants, giving them an opportunity to "actively participate in both recording and reflecting on their own behaviour" (Milligan et al., 2005, p. 1882). The type of data elicited through the diary method is described as going beyond the mere collection of participants' interpretations, to incorporating a descriptive and reflective process of examining practices commonly taken for granted (Lewis & Massey, 2004, September). Participants in Johnson and Bytheway's (2001) research made repeated references to their 'usual tablets' in diary records, emphasising the routine and trivial nature of many medical practices and prompting the researcher to request further clarification on these practices: "Many of our diarists were convinced that they lead highly routine lives" (Johnson & Bytheway, 2001, p. 195). Milligan and colleagues (2005) argued that the use of diaries

negates the vagaries of the mind, allowing participants to record easily forgotten daily routines. Diaries are medium through which the flow of daily events may be recorded in close temporal proximity to the events themselves, creating a "series of first-hand images of the 'lived-through' day" (Johnson & Bytheway, 2001, p. 203). Diaries also allow writers to divulge personal, private or even embarrassing experiences that may otherwise remain unshared (Elliott, 1997; Johnson & Bytheway, 2001; Milligan et al., 2005).

Aside from the advantages relating to the form and depth of data elicited from participants, the diary also has some practical benefits that further support its use in qualitative research. As identified by Lewis and Massey (2004), the use of diaries evades typical time, cost, and geographical limitations by providing a record of events that would be both time and cost intensive for a researcher to collect. This observation is especially applicable to the current research, where the participants resided in three different geographic locations. In addition, the diary is more familiar and is comparatively less complex than data collection systems based online or in audio or visual formats (Lewis & Massey, 2004). Such features may contribute to the ease of diary writing.

In the current research, diaries acted as a 'log' for 'observations' and everyday medication use and were relatively unstructured, giving participants the opportunity to record events and observations of most significance to them personally (Elliott, 1997; Milligan et al., 2005). Following the diary keeping process with interviewing is a complementary combination of data elicitation techniques (Zimmerman & Wieder, 1977) that aids further scrutiny of seemingly routine or trivial health behaviours or medication practices.

#### Photo-production

Photo-production is a qualitative method whereby participants are provided an opportunity to photograph artefacts in their world to communicate meanings, understandings, relationships or events in a visual rather than verbal manner (Hodgetts, Chamberlain, & Radley, 2007). In their study of homelessness on the streets of London, Hodgetts and colleagues (2007a) utilised photo-production in researching taken for granted events, meanings or practices associated with 'everyday life'. They asserted that the technique "[orientates] participants to see their world from a different perspective, with a focus on things worth picturing, including the mundane" (p. 266). The process of picturing their world encourages participants to engage in a meaning-making process whereby they deconstruct their own assumptions and world views (Harper, 2002; Hodgetts et al., 2007a).

Similarly, the photovoice research conducted by Carlson and colleagues (2006) details how photos were used to identify things in the community that participants were proud of, and things they wanted to change. This was one way in which participants constructed a 'story' or 'narrative' about their realities living in this community. Harper (2002) argued that photo-elicitation interviewing is more successful at generating information, memories or emotions than words are alone. Likewise, Hodgetts and colleagues (2007) asserted that photo-elicitation interviews invite people to show as well as tell researchers about their own perspective or 'lifeworlds'.

Practical constraints entailed in photo-production such as printing, lighting, quality or framing issues can mean that resulting photos may not turn out the way that participants intended them to (Hodgetts, et al., 2007). The photoelicitation interview provides an opportunity to explore the intended meanings of photos. While photographs themselves are rich with meaning, a verbal account of what is captured (or not captured) within photos, as well as consideration of photos not taken, helps to further elucidate participants' understandings (Hodgetts et al., 2007).

In the current research, participants used photo-production to describe their 'worlds of medications'. Capturing these meanings in visual form allowed participants to extend from what could be verbally articulated in interviews. In the final interview, participant and researcher explored both photos and diary

entries. Following Hodgetts and colleagues (2007), participants were asked to describe photos that they were unable to take but would have liked to, and also asked whether the photos provided had turned out as intended.

#### Ethical statement

Before beginning data collection for the masters research, a University of Waikato Ethics Review for Human Research was submitted (in December 2009). The application outlines matters of ethical conduct and confidentiality to ensure the anonymity of participants. In some of the photographs taken, it was necessary to remove identifiable persons or settings. In diary records and interview quotes, names or any other personal features were altered and the use of pseudonyms employed at all times. All data, inclusive of transcripts, audio files, diaries, photos, demographic information, and field notes generated by this masters research are held by the principle investigator of the medication project at Auckland's Massey University, and myself. They are stored in a secure archive only accessible to those authorised members of the research team. This research was granted ethical approval by the University of Waikato on 17<sup>th</sup> December 2009 (#09:42).

### The research setting and process

As I gained confidence in the direction of my own project, some revisions were made to existing research methods and interview protocols applied by the wider research team. For example, the broader project design was for each household member using medications to complete a diary. In my experiences of interviewing only households with children, however, it was less appropriate for children to be writing diary entries. Additionally, the broader project design also entailed the use of a second diary, to be completed by another household member with a focus on documenting encounters with medications in daily life. Parents are busy people, however, which meant the complexity and demands of the research tasks needed to be reduced. Hence, the two diary keeping tasks were condensed to one record of medication experiences. The interview protocols provided by the wider research team (Appendix B) were also adapted to address my own research focus. My own interview protocols (Appendix C) incorporated a focus on parental roles and concerns around medication use involving children, which was absent in existing interview protocols.

The participants were recruited through the snowball technique. This process began by informing a known kindergarten teacher about the research, who then passed an information sheet (Appendix D) on to parents of children attending the kindergarten who met the appropriate criteria. This in-network selection raises the likelihood that participants will know each other (Small, 2009), which was the case for the current research. A parent provided with the information sheet contacted the researcher and was able to provide contact details for another participant. In turn, this participant recommended another individual who suggested her friend was contacted as a potential participant for the research. Each of these participants committed to the research. Such receptivity is perhaps supported by the fact that the researcher was referred to participants by a known friend or family member (Small, 2009).

Initial contact was made with participants through email or phone to answer any questions regarding the research and determine whether they were willing to participate in the research. An initial interview time was then set. Prior to this interview, some time was dedicated to phone or email contact with participants to ensure their clarity around research aims and to build rapport. Before the initial interview was conducted, the researcher obtained two forms of written consent (Appendices E and F); one relating to the larger research project and one pertaining to the individual masters research. The researcher took an interview protocol (Appendix C), demographics information sheet (Appendix G), a researcher checklist (Appendix H), a camera, diary, audio recorder, and stationery for the mapping exercise. With the permission of interviewees, all

interviews were recorded to obtain an accurate data source and enable the detailed analysis of interview transcripts.

All of the interviews were conducted over a six week period spanning January and February 2010. Interviews were conducted in the homes of the participants (a casual setting in the lounge or dining room), with the exception of one participant who travelled into Hamilton from a rural community to attend her initial and final interviews. These were conducted in the home of her close friend who also participated in the research. The initial interviews involved discussion around the participants' understandings of the meanings and uses of medication, medication practices and risks within the home, parenting roles and interactions with media (Appendix C). The mapping exercise was conducted during the initial interview and involved the participant drawing a simple bird's eye view map of their home and indicating where medications were stored (Appendix A). With the interviewee's permission, photos were taken of these locations and used as a prompt for further discussion about the rationale for where medications were stored, what medications were used within the household and why these substances were considered a 'medication'. In cases where multiple locations were identified, discussion was also oriented around similarities or differences of medications in different locations and their placement within the home.

The first interview that was conducted only took thirty minutes. Post-interview notes (see template in Appendix I) about this participant indicate they were quite nervous and made many brief answers. Nevertheless, the interview protocol was modified to better utilise open-ended questions to encourage more elaborate responses from participants. One example of the modifications made to the interview protocol involved the development of further questions following "What role do you play in your children's medication use?" Other questions were added, including: "What do you teach your children about medication?" and "How do you teach them?" It was acknowledged that I was a relatively inexperienced interviewer, but the changes had positive implications, with initial

interviews after these changes ranging from one to one and a half hours. Postinterview notes (Appendix I), or field notes, were taken following each interview and involved recording details such as initial impressions of the interviewee, how the interview went, main points made, potential revisions to the interview protocol, personal reflection on interview technique and points to follow up in the next interview.

After the completion of initial interviews the remaining tasks (diary and photoproduction) were explained to each of the participants in detail and a time line set for their completion. Participants recorded the dates in a personal diary indicating the period that the diary should be kept, the time frame for taking photos and the date for the final interview. They were also advised to contact the researcher regarding any further questions or alterations to the agreed time line. Participants were asked to keep a diary for a total of one week, with one diary entry per day. In particular, participants were asked to record any recognition of medication related media items throughout the day (or other encounters such as purchasing medications), and detail any medication practices occurring within the home. For mothers, this often involved providing an account of their own medication use and experiences of administering it to other household members. Few constraints were set around diary content in efforts to produce a record of medication experiences and observations in the home and the wider community that were personally salient to the participant.

A fictitious diary entry (Appendix J) was provided to participants who expressed apprehension over the writing task. Typical concerns included the quality of writing (such as grammar, spelling and clarity of writing) and content of entries. Participants were reassured that spelling and grammar were not crucial and that any possible misunderstandings could be discussed at the next interview. Participants were provided a diary and pens to complete the task and advised that, on average, the task may take around fifteen minutes to complete each day. Participants were contacted on at least one occasion during this week to ensure that the task was being carried out without difficulty.

Discussion around the photo-production task revealed that participants held similar concerns about 'getting the task right'. The task was explained to the participants as a method for describing their own subjective interpretations of medications (hence emphasising the inability to 'do the task wrong'). Participants were provided with a disposable camera to carry out the photo-production task over a period of two weeks. One week into this task, the participants were reminded by phone or email. When the participants advised that photoproduction was completed, cameras were collected by the researcher and converted to CD and hard copy prints for use in the final interviews. The total number of photos taken during the task varied from six to twelve photos. At times, participants expressed some dissatisfaction concerning the quality of photos produced. In the current research, such problems were reduced through discussion around both photos not taken and unclear photos.

The researcher took the interview protocol (Appendix C), researcher check list (Appendix H), printed photos and CD, post-interview reflection notes from the initial interview, and an audio recorder to the final interview. These interviews involved exploration of photos (for example, why it was taken, what it shows, what it means to the participant) and diary entries. Conversation concerning diary entries focused on media items identified throughout the week, parenting roles, medication uses, understandings and risks. The interview provided an opportunity for the researcher to clarify anything recorded in the diary, and the participant to further elaborate on entries or unrecorded events. This discussion also allowed participants to share their experience of the photo taking and diary keeping processes including how they got started, any difficulties encountered and what they might do differently if they had an opportunity to do the task again. Similar to the process employed in Elliott's (1997) study employing the use of diaries, this diary-interview approach could have been further strengthened if

the researcher had an opportunity to read the diary prior to the final interview. Elliott (1997) achieved this by the participant returning completed diaries through the post before the interview. Post interview notes were recorded following these interviews.

Following the completion of final interviews, participants were sent a voucher in the post in recognition of their time and effort. These vouchers were \$100.00 in value for one of the following five options as chosen by the participant: Pak 'n' Save, Countdown, Foodtown, 'The Warehouse'<sup>6</sup>, or Petrol voucher. Voucher preference was indicated on the 'Medications in everyday life: Understandings and social practices' consent form and was provided through the project funding from the Health Research Council and Marsden Fund.

It is acknowledged that the time period during which data was gathered (the school holidays between January and February 2010) would have impacted on the experiences of participants. Having children in the home over this time period may have contributed to heightened awareness of medication risks, or increased incidences of medication use. While this may be considered advantageous for obtaining a greater variety of medication practices and experiences with children due to them being home more often, it may have simultaneously reduced the participants' interactions with medications in the wider community. For example, one mother described how she avoided leaving the house while the kids were on school holiday; reducing her exposure to advertising or other medication related phenomena outside the home. Having children in the home throughout the interview process also served as a distraction for participants. Some expressed embarrassment at interruptions to the interview, while others became frustrated at not being able to concentrate on the task at hand. However, regardless of distractions and despite being given

<sup>&</sup>lt;sup>6</sup> 'The Warehouse' is a New Zealand owned bargain shopping retailer. This retailer is also mentioned in chapter three.

the opportunity to take a break or stop the interview to care for the children, each participant was happy to continue with the interview process.

As well as children being present, during five of the eight interviews some participants also had their partner or friends present within the household. These individuals contributed to the discussion to varying degrees. Partners tended not to become involved in discussion unless specifically addressed by the researcher or the participant, but friends were more likely to engage in dialogue around medications and occasional conversation concerning unrelated concepts. Consequently, interactions between friends sometimes resulted in deviations from discussion around medications. Nonetheless, when focused on medications, input from friends often acted as a challenge to participants' responses, resulting in a useful elaboration or clarification of participants' perspectives.

By focusing on households containing members with chronic illness, it was assumed that medication use would be frequent. This assumption is informed by previous research, which shows that people with chronic conditions are likely to be actively engaged in medication use (National Health Committee, 2007), but also reflects my own understandings of chronic illness. Such understandings are perhaps indicative of the widespread normalisation of medication use in response to illness. However, this assumption was also challenged by the current research where medication use within households was not necessarily as extensive as expected.

### Scope of the research

This research was focused on mothers' accounts of caring for their chronically ill children. Focusing on the perspectives of mothers in the absence of a fatherly perspective was not a conscious research decision, as only mothers emerged as respondents in the recruitment process. Not all of the households studied contain a male parental figure, and for those that did, mothers' were more involved with their children's care on a day-to-day basis. All mothers identified themselves as the 'gatekeeper' and 'dispenser' of medications, and the primary carer of children. As such, mothers are an appropriate informant of medication use within the home. Certainly, a male perspective may have further enlightened how household roles were developed and delegated or provided novel insights into medication meanings, uses and risks within the home. However, this does not minimise the importance or relevance of the experiences and understandings described by female participants. Furthermore, it is predominantly mothers who are implicated in the shaping of medication practices and understandings in their young children that are carried with them to adulthood (Bush et al., 1996).

This research was also focused on medication meanings and uses in the context of physical illnesses (see Table 2). Understandings of medication use, risk and meanings in response to mental illness, however, were beyond the scope of this research. Parents' beliefs about medications for mental illness might be distinct, and warrants further research.

### Analysis

The analysis process began with producing transcripts from each of the eight semi-structured interviews that were conducted. Once transcripts were completed, the data was analysed thematically using gift exchange theory as an orientating framework. This theory highlighted the connections between medications as objects, identity and relationships. The transcripts were coded into sections -medication beliefs, medication practices, participants' rationale and roles in medication use- which loosely reflect the results chapters that have emerged. Following Radley, Hodgetts, and Cullen (2005), I spent time viewing each participant's photographs, transcripts and diary entries, documenting any connection between participants' verbal and written anecdotes and what had been captured in their photos. Initially, this process allowed for the researcher to identify significant, overarching, common or unique themes within and across participants' accounts. Any contrasting, conflicting or ambiguous themes or participant accounts were discussed with others on the research team.

A separate table for each participant was constructed (Appendix K) so that their descriptions, explanations, and beliefs about medication use could be visually presented alongside their written diary entries and photographic portrayals of their worlds. This allowed for links between different forms of data to be visually perceptible. The resulting tables provided an amalgamation of written responses, spoken dialogue and scenes captured in photographs, from which many themes emerged. Data analysis was an ongoing process of re-reading and re-visiting the transcripts, diary entries and photographs produced by each participant. This exercise allowed a more narrow focus to emerge from the many themes present in participants' accounts.

## **CHAPTER THREE: CONCEPTUALISING MEDICATIONS**

Previous research has highlighted that lay health beliefs and medication understandings are variable and diverse (Bush et al., 1996; Helman, 1981; Pound et al., 2005; Shoemaker & de Oliveira, 2008). Cultural diversity in the way that people perceive and utilise medications is well recognised (Bush et al., 1996), as well as variance arising from personal factors (Conrad, 1985). This diversity can pose a challenge for researchers attempting to grasp lay understandings of medication. Various efforts have been made by researchers to categorise participants on the basis of commonalities in the ways that they perceive or use medications. For example, Adams and colleagues (1997) discuss 'deniers' and 'accepters' of illness identity and medication use. Helman (1981) categorised long term psychotropic drugs users into three symbolic groups—'tonic', 'fuel' or 'food'—based on how participants conceptualised and used psychotropic drugs (see chapter one). Despite such analyses, researchers identify many overlaps between groups and acknowledge that groups of medication users are not homogenous (Helman, 1981). Health practices and understandings can deviate from theoretic categorisations to varying degrees, and are fluid and changing (Bajcar, 2006).

Exploring how medications are variously defined and interpreted in everyday settings by those using and dispensing them is essential for making sense of medication practices occurring within the home (Hodgetts et al., 2011; Shoemaker & de Oliveira, 2008). In documenting and deciphering medication understandings, researchers have highlighted the links between understandings and practices. For instance, Conrad's (1985) research concerning medication compliance demonstrated how individuals' compliance or resistance to medication regimens varied in accordance with their personal and subjective understandings of medications. Whether individuals perceived medication as a symbol of dependency, or a mechanism for control, impacted how they engaged in medication use (Conrad, 1985). These findings emphasise the importance of 59

grasping what medications mean to individuals, or how medications are interpreted, as essential precursors to elucidating medication practices. This chapter explores how the participants in the current study, as mothers and main caregivers of their children, conceptualise medications and subsequently, how they apply medications in everyday contexts.

As a key feature of contemporary societies, the biomedical model provides an interpretation of medications that is particularly familiar to participants. As this chapter will show, the prevalence of biomedical knowledge impacts how medications are perceived and used in everyday life. Nonetheless, many household practices and medication understandings described in this chapter are not a straightforward application of biomedical knowledge. Corresponding to research by Helman (1981) and Adams and colleagues (1997), participants' understandings of medications are not adequately captured inside clearly defined categorisations or models of health. In their daily lives, people form understandings of medications that are complex, and lack a simple distinction between public and private structures of meaning (Carrier, 1995; Hodgetts & Chamberlain, 1999). The participants' medication understandings reveal both adherence and resistance to biomedical interpretations of medications and disease. Such findings highlight how individuals may modify, reinforce, or subvert publicly or socially defined meanings in their private understandings and use of medications (Carrier, 1995).

This chapter begins by outlining some complexities in participants' medication understandings, before going on to explore their medication conceptualisations. The participants identified both physical and social features of medications, reinforcing the notion that medications have meanings transcending their material form (as explored in Cohen et al., 2001). The chapter also provides a summary of the medication preferences of each participant. These preferences are found to be inextricably linked to the medication understandings that participants hold, and are an important foundation for the medication practices discussed in subsequent chapters.

# **Complexities in medication understandings**

The photographs generated by participants as part of the photo-production exercise (see chapter two) provide some insights about how participants perceive medications and their use in everyday life. The photographs in Figure 1 on the following page are taken by different participants, and represent multiple facets of their 'worlds of medication'. The top row, from left to right, captures medications in public spaces (a location for the provision of professional medical care and advice), private spaces (storage location in the home), and the amalgamation of these two dimensions (the transit of medications from public to private through media). The next row, which includes a pharmacy sign, the Countdown supermarket entrance, and a local 'superette' sign, depict various locations of convenient access to medications in participants' local communities. In the bottom row, a range of different medication types are presented. The first photo shows a child's liquid form antibiotics. The second displays Anthisan<sup>7</sup> cream and finally, Lion-shaped vitamin C tablets. These are all 'medications' utilised in the households studied.

<sup>&</sup>lt;sup>7</sup> Anthisan is an antihistamine most commonly used to relieve inflammation of the skin caused by insect bites or rashes (Netdoctor, 1998-2010a).



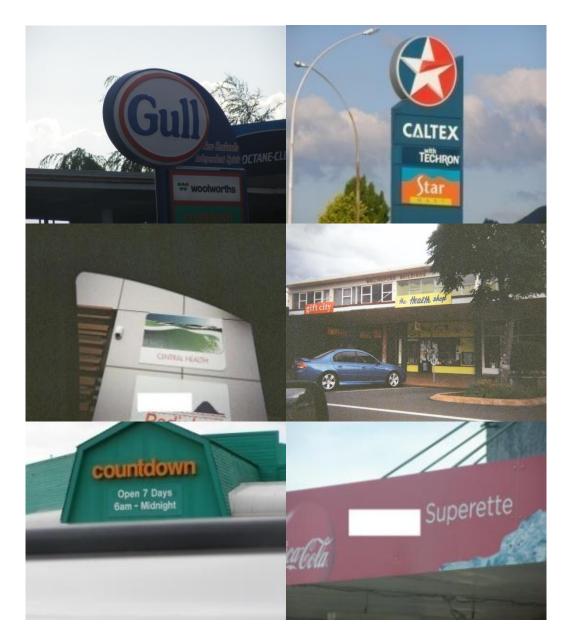
Figure 1 An array of photos from participants' photo-production task.

For each participant, their individual photos provided a focal point for discussion that raised many questions. For example, when examining photographs of various locations, participants were encouraged to express how they feel about accessibility to medications in their local communities. In photographing their own medications, participants sought to explain what it was about these substances that constituted a medication. For instance, are vitamins a medication? How might vitamins differ from antibiotics? In describing how such photographs represent their 'worlds of medication', participants were more likely to pay attention to taken-for-granted assumptions underpinning their understandings of medication. In doing so, a number of complexities in participants' understandings of medications emerged. Firstly, participants perceived medication accessibility as being both dangerous and convenient. While ease of access to medication is identified as a major risk, simultaneously, inaccessibility was thought to be problematic. The need for medication to be both accessible (but not overly accessible), reflects two conflicting desires that are difficult to reconcile. Secondly, the boundaries between medications and other goods are indistinct, and this makes conceptualising medications a difficult task. Finally, there are many diverse uses of medications in the households studied.

## Medication accessibility: Convenience and risk

Participants' photographs in Figure 2 on the following page indicate that individuals do not have to venture far to access medications in their local communities. Participants identified pharmacies, medical clinics, health shops, supermarkets, petrol stations, 'The Warehouse', and hospitals as sites where medications may be obtained. Existing research has also identified other locations yet to be encountered by these participants, including online clinics ('e-clinics') (Fox & Ward, 2008), "mail order and catalogue sales" (Sanz et al., 1996, p. 97), "discount outlets . . . and vending machines" (Vuckovic & Nichter, 1997, p. 1288).

*Figure 2* Participants' photos of physical locations where medications may be accessed.



The photographs of physical locations were most often selected by participants to reflect their 'worlds of medications':

Interviewer: So out of all your photos, what one do you think best describes your world of medications? Sarah: Probably the doctors and the chemist [Figure 1]. Interviewer: Why those ones? Sarah: . . . You go to the doctor to get your prescription, and you go to the chemist to get your drugs. That's medicine. The people that give it to you and the people you get it from (female, 33 years, relief teacher aid and mother of three children).

This excerpt demonstrates that the physical places of medication access and provision of professional medical care or advice are central to participants' conceptualisations of medications. The significance of physical places is noted by Williams (2002), who stated that "places, together with the health care services which characterise them, are increasingly seen as a context for the development and maintenance of the health of populations" (p.148). Sarah's excerpt also emphasises that it is not merely the physical structures themselves that are associated with medications, but the people within them, and the subsequent social interactions that occur in these dwellings. These locations provide a physical context for the enactment of various roles and social interactions between parents and medical professionals. The locations identified are not merely "backdrops" for social interaction, but provide a context of "physical, social, relational or cultural processes" (Hodgetts et al., 2010, p. 157) that impact social actions and sense of self (Hodgetts et al., 2010).

The photographs in Figure 2 point to the ways in which medications pervade the daily lives of lay people, and how their presence is somewhat normalised in community environments. During their engagement in the photo production task, participants described a growing awareness of the omnipresence of medications in their everyday life. For instance, Natalie (female, 34 years, full time mother of four children) was able to identify locations associated with medications that she simply would not have considered before:

Natalie: [I learnt] just more places that they are used. Interviewer: For example? Natalie: Well I guess at high schools they have to administer them . . . and old peoples' homes . . . I was going to take a photo of the old people's home [laughter].

Interviewer: There are probably a lot of medications there! Natalie: Yeah, it sort of just makes you more aware. You'd be driving past and you'd be like 'oh, there would have medications!'

Consequently, the multitude of locations in which medications may be accessed informs participants' understanding of medications as highly accessible goods, which is concurrently perceived as a major parental concern. Natalie, for example, worries about medications "falling into the wrong hands". She feels anxious that her son can go to the local convenience store and buy Panadol<sup>8</sup>. Natalie highlighted the irony of her son not being of legal age to purchase restricted items, some of which she considered as less harmful than a packet of Panadol: "They can't buy lotto or cigarettes but they can go buy Panadol? Awesome!" In the following comment, Natalie conveys her perspective that it is unnecessary to supply medication in so many places:

Natalie: . . . Farmers and 'The Warehouse' you sort of consider to be on a similar par. Farmers is probably a little bit more up-market, but yet Farmers don't sell medicines. They don't sell Panadol. Well not that I've ever seen. They don't sell medicines Interviewer: Do you think there's an expectation for them to now? Natalie: Hopefully not. [Laughter] I don't think we need any more.

The long opening hours of various sites where medications may be purchased also promotes the accessibility of medications. Many petrol stations, for example, are open twenty-four hours per day. The front entrance of Countdown supermarket (as shown in Figure 2) reads, "Open 7 days, 6am - midnight". This sign boasts long opening hours and convenience to the public. The participants' concerns about easy access to medications also stems from the manner in which

<sup>&</sup>lt;sup>8</sup> Panadol contains the active ingredient paracetamol and is used to relieve mild pain and fever (Netdoctor, 1998-2010g).

medications are displayed conspicuously on shelves. At her local supermarket, Maddison (female, 23 years, full time mother of three children) noted that medications are within direct sight and reach of children:

They talk about child safety and all that everywhere but look at all these pills that are at the supermarket where a kid can grab it off the shelf, if their mother is not looking, open the box and pop them . . . Did they ever think of safety in supermarkets? Obviously not! Because they're all accessible at the supermarket! Panadol, Nurofen<sup>9</sup>, Ibuprofen<sup>10</sup>, everything! They didn't think about that did they?

Participants had their own suggestions about reducing the risks associated with medication accessibility. In supermarkets, for example, both Natalie and Maddison suggested that medications could be kept behind the counter, or locked in glass cabinets. As Maddison stated: "I think it should be behind the counter stuff". Maddison's quote highlights that participants expect physical boundaries such as doors, counters or locked cabinets between medications and other consumer goods. While there are some similarities to be drawn between medications and other consumables (see 'Blurring boundaries of medications'), Maddison's perspective demonstrates an implicit awareness that medications are intrinsically different from other consumer goods. Doran and colleagues (2005) asserted similar findings, arguing that people "treat medicines, especially prescription medicines, as particularly distinct from common goods" (p.1441), despite medications being 'common' in terms of availability and accessibility. boundaries address Although physical may not wider issues of pharmaceuticalisation, such safety measures may reduce the likelihood of

<sup>&</sup>lt;sup>9</sup> Nurofen contains the active ingredient ibuprofen and is also used to relieve mild pain and fever (Netdoctor, 1998-2010f).

<sup>&</sup>lt;sup>10</sup> Ibuprofen is a brand name given to a pain relief medication, but is also the generic name of the active ingredient present in many medications (such as Nurofen or Brufen) (Netdoctor, 1998-2010b).

unsupervised children accessing medications and may also heighten awareness of medications as 'dangerous' goods.

Although participants are critical about medications being so readily accessible, they still appreciate accessibility and convenience in everyday practices with medications. For instance, of the four chemists available in Olivia's (female, 23 years, full time mother of one child) local area, the one most geographically convenient became her regular pharmacist: "Well you don't have to get back in the car and drive somewhere else and hop back out again". Likewise, Natalie keeps her personal asthma inhalers on her bedside table to ensure easy access: "Often I have to get up in the middle of the night and take them and I don't want to have to walk down the hallway". Pharmaceuticals are increasingly accessed directly from the home computer (Fox & Ward, 2008), domesticating and streamlining processes for obtaining medications. Participants in Fox and Ward's (2008) research claimed that obtaining pharmaceuticals via online consultation is faster, easier and cheaper than going to a general practitioner and a pharmacy. These examples show that convenience is a consideration as lay persons construct their medication practices.

The participants in the current research highlight that increased medication accessibility is problematic, but inaccessibility can also be an issue. The equilibrium between risk and convenience of medication access is difficult to ascertain, especially in a population such as New Zealand, where medical services are required to meet the needs of a population with an increasing diversity of backgrounds and health needs. As outlined in chapter one, ensuring access to medications is a matter of human rights. Being able to access medications as they are required for health needs is clearly an important policy consideration. At what point this accessibility becomes dangerous to the wider community, however, requires further investigation.

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#### Blurring boundaries of medications

In their examination of various locations in which medications are sold, the participants have drawn attention to the blurring boundaries between what they class as 'medications', and other consumer goods. 'The Warehouse' is an environment that invokes heightened concern from participants. Natalie claimed she would not go to 'The Warehouse' to obtain medications, as this site was not typically associated with medication supply: "I wouldn't go to 'The Warehouse' to get medicines . . . I know that they're there but I wouldn't sort of think 'oh we'll go to 'The Warehouse' and get Panadol'". Similarly, Maddison considers it inappropriate for medications to be sold in 'The Warehouse', not simply because of the lack of physical barriers between medications and other goods, but because she perceives that pharmaceuticals do not 'belong' in this consumer environment: "You wouldn't think that a pharmaceutical place would be inside like a clothing shop. Because I [understand] 'The Warehouse' as a clothing shop". As noted in participants' responses, pharmaceuticals are now sold in a diverse range of consumer environments that have traditionally not been associated with medications. Conversely, locations that are typically related to medications (such as pharmacies) have an ever-increasing product range. In reference to her local pharmacy, Sarah noted the presence of many goods unrelated to medication: "You walk past there and you'd think it was a gift shop if you didn't look. Because that's all [that is] in the window. You wouldn't know it was a chemist". This diversity is reflected in the following photo (Figure 3) of an advertisement in a pharmacy window taken by Natalie:

*Figure 3* A summary of the many products and services available at Natalie's local pharmacy



Such diversification can be viewed in business terms, as the growth of product range and (potentially) income, but also marks the blurring boundaries between medications and other consumer goods.

The distinction between medication and food is becoming harder to navigate (Chamberlain, 2004). Medications are becoming increasingly diverse through the expansion of existing medicines, such as the development of liquid or spray forms (Spilker & Cuatrecasas, 1990), and the increasing availability of CAM. Simultaneously, food available on supermarket shelves has changed substantially over recent decades. Pollan (2007) claims there is a broadening range of 'imitation-food' products available that do not actually resemble whole or 'real' foods. Like medications, foods are increasingly marketed according to what health benefits they induce (Chamberlain, 2004). For example, many foods have added vitamins or nutrients that may appeal to consumers (Pollan, 2007). Presently in some New Zealand cities, fluoride is added to water supplies in efforts to minimise dental decay (Docherty, 2010). This initiative constitutes the mass (and sometimes unknown) medication of individuals through what we ingest, raising ethical concerns on a societal level and highlighting the lack of a simple distinction between foods and medications. Similarly, the New Zealand 70 government continues to debate whether or not folic acid should be added to bread to encourage healthy foetal development in pregnant women (NZPA, 2009).

Participants' attempts to explain what medications mean to them often encapsulate goods such as food. For example, Sarah's assertion that medicine is "something that makes you better" could apply to a diverse range of phenomena, from fresh air or lemonade, to a healthy diet or exercise regimen. Using foods as medicine is a very common and time honoured practice. Consider, for example, the use of hot lemon juice for colds, oranges against scurvy, cucumber slices for puffy eyes, honey on burns, and vinegar on wasp stings. Olivia made her son a cough medicine consisting of carrot juice and raw sugar. While the content of this 'medication' was purely derived from food, it served a medicinal purpose. These practices highlight how foods can also be ascribed with medicative functions.

Participants' perspectives on whether or not vitamins constitute a medication are a pertinent example of the lack of distinction between medications and other goods. Natalie was not inclined to draw any such distinctions in her appraisal of vitamins, stating that "vitamins . . . they're still kind of a more natural thing, but they're still kind of a medicine". Instead of fixed categories, Natalie's excerpt reveals the ongoing shifting of medication conceptualisations as she comes to understand and make sense of her medication beliefs and practices. Such processes are complex and ongoing (Bajcar, 2006). Maddison offers a different perspective from Natalie. She asserted that "to me a vitamin is a vitamin, it's not a medication". Maddison also has a similar perspective about the essential oils she used during the labour of her son to help her maintain consciousness, stating that "I guess an oil is an oil to me and medications are something that help you when you're sick and vitamins boost your energy level".

Despite the connections between food and medications, Maddison and Olivia noted that there are many substances (such as vitamins or food) that have a medicinal value yet they would not classify as medications. Olivia considers that pain relief, homeopathic medicines, and vitamins are not medications:

Olivia: In my eyes I don't see Panadol and Nurofen and stuff like that as actual medication. I see medication as something that you take for an illness or a disease. Interviewer: So what would you call it then? Olivia: I'd just call it pain relief, but I wouldn't call it medication.

Olivia categorises homeopathic medications as 'remedies' and vitamins simply just that, 'vitamins'. According to Olivia, medications are pharmaceuticals such as antibiotics that are obtained through a doctor (hence access is determined by a medical professional) and are taken on a regular basis. The following quotes demonstrate how Olivia conceptualises medications: "[Domperidone is] something I got from the doctor so I class it as medication"; "Something that I have to take regularly, that's what I class as medication". Olivia's perspective suggests that understandings about medications may be drawn from idealised conceptions of conventional medications, such as antibiotics or steroids: "... [An] antibiotic, in my eyes, is medication". Similarly, Maddison asserted: "I think when you have something like a steroid in it, or a hydrocortisone or something in it [then it becomes a medication]". These quotes illustrate how participants may draw on 'stereotypical' medications. Indeed, other substances used for health are less consistently defined.

#### Treatment, prevention and beyond

In the households studied, medications are commonly used for the prevention and treatment of illness and disease. Taking preventative measures before winter in efforts to prevent winter colds and flu is a customary approach for maintaining health in each of the households. In the following quote, for example, Maddison describes how she intends to care for her children in the coming winter: "I will be looking for vitamins for the kids just to boost their immune system". Similarly, Sarah relayed how she purchases vitamins for her kids, and explained to them that ". . . They're going to help you get big and stronger and help you through the winter so you don't get so many colds". Medicines are also commonly utilised in response to sicknesses, such as when antibiotics, pain relief, hay fever medications, or asthma inhalers are used to treat symptoms of infection or illness.

Olivia and Natalie discussed medication use that moves beyond the treatment and prevention of illness and disease. Domperidone is typically used to treat nausea and vomiting (Netdoctor, 1998-2010e). However, a side effect of this medication is an increase in breast milk, and it was hence recommended for Olivia by a midwife: "Every day I take Domperidone. I take this to help me produce more breast milk" (diary entry). It is generally more common for the side effects of medications to be experienced or perceived negatively (Shoemaker & de Oliveira, 2008). In Olivia's case, however, the side effects of Domperidone are viewed positively. The use of Domperidone in this manner is distinct from prevention or treatment in that "they are definitely taken in a maintenance type of way, not for illness at all". This example reflects that medications can be used in unintended and unforeseeable ways (Spilker & Cuatrecasas, 1990).

Natalie's use of Rescue Remedy Sleep<sup>11</sup> to aid undisrupted sleep also extends boundaries of treatment and prevention. Whilst trying to recall why she gave one of her sons Rescue Remedy Sleep during the course of her diary exercise, Natalie concluded "he must've been upset" and went on to describe the circumstances in which she would usually administer Rescue Remedy Sleep: "[I would administer Rescue Remedy] if they're really over tired and grumpy or if I want them to really just calm down and chill out and go to sleep quite quickly".

<sup>&</sup>lt;sup>11</sup> A homeopathic remedy containing five original Bach flower essences that claims to prevent sleepless nights by helping to reduce repetitive thoughts (A Nelson & Co. Ltd, 2009).

Natalie's use of Rescue Remedy Sleep demonstrates the way in which medications may be used as a calming mechanism to treat emotional distress. Such use is one way in which Natalie enacts care for her children in the context of a recent emotional trauma experienced by the family. Vuckovic and Nichter (1997) argue that the treatment of emotional distress reflects wider issues of medicalisation and a decreased ability for individuals to cope with daily stresses and emotional angst. They refer to this as "lowered thresholds of discomfort" (p.1285). While this purpose of medication use may be interpreted by some as superfluous, this thesis does not have the objective of determining whether the use of medications for emotional or physical suffering reflects any weakness or loss of ability in the user. Regardless, the desire to seek relief from suffering is fairly universal and historically constant. The means of seeking relief, however, has varied considerably with relief being sought from pills, potions, herbs, prayer, rituals, talismans or even magical powers (Duffin, 2010).

The central point to be taken from Natalie and Olivia's anecdotes is that medications are used for diverse purposes, despite the fact that medications are, at a fundamental level, understood by the participants primarily as treatments and preventatives for illness and disease. Regardless of variance from conventional uses of medication, the participants still define a wide range of substances as 'medications', demonstrating how medication use and understandings remain complex, sometimes unclear, and shifting as differing needs arise.

# Medications as material objects

The term 'pill' is often employed as a term of reference to medications and draws attention to a familiar physical form of medications (Busfield, 2006). This physical form is a common way in which participants in the current research recognise medications and differentiate them from other goods such as foods, despite the blurring boundaries between these consumer goods. As stated by Sarah: "[You] know it's medication because it comes like a pill. It's like a tablet isn't it?" Sarah's quote emphasises that medications have material dimensions that influence how they are perceived, understood and used. A number of the defining features of medications identified by the participants are founded on tangible dimensions of medications. These include those things that we can perceive in the material manifestation of a medication, or a physical bodily response to medication. This section pays attention to the embodied experiences or physiological effects of medication, which provides an important foundation for understanding medications in the context of parenting and caring.

Dividing physical and social features of medications into distinct sections in this chapter is an attempt to order the findings. Nonetheless, I do not intend to communicate that the physical and social features of medications are easily distinguishable, or that physical features are isolated from social influence or existence. For example, existing research has documented that even the physical perception of pharmaceutical effects may be socially influenced: "Diffuse bodily sensations [are] embedded in, give significance to, and take meaning from, wider social processes" (Prout & Christensen, 1996, p. 38). Such research illustrates that medications have social lives as well as a material existence (Cohen et al., 2001).

At a fundamental level, the participants in the current research perceive medications primarily as treatments for infection, illness, or disease; or as a catalyst to 'better health'. A common thread in the medication experiences shared by each participant is one that reflects the physical transformation from a biological state of ill health to good health. Natalie describes this transformation in the following quote: "They make you better, by getting rid of infection and stuff like that". It is such physiological effects of medications which underpin a basic rationale for engaging in medication use (Conrad, 1985). Embodied experiences influence the way that people perceive medications. For example, many medication users endow medicines with 'life saving' qualities, on account

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that they provide a degree of control and autonomy in the face of illness in dayto-day life (Conrad, 1985; Rogers et al., 1998; Shoemaker & de Oliveira, 2008; Viswanathan & Lambert, 2005). Similarly, the participants in the current research hold belief and hope in medications to transform the body into a 'better' state of health.

There is substantial variance between participants regarding whether beneficial physiological effects are characteristic of all medications, or only apply to some. The hope vested in medications to improve the health of an individual applies to both pharmaceutical use and CAM, although perspectives on the efficacy of the latter vary significantly. Natalie described a point of differentiation between CAM and pharmaceuticals in the following way:

Well they [CAM] might take a little bit longer to work but they make you better as well but using your own body's natural defences. Because biomedicine obviously, they break down some of your natural ones. Like your gut lining or blood cells...

This account reflects Natalie's conviction that different bodily processes result from the use of CAM or pharmaceuticals. Based on this understanding, Natalie concluded that CAM is safer, which informs her preference to use homeopathic medications. While participants who prefer to use homeopathic or herbal medications explain that they may take longer to work than pharmaceuticals, Sarah questions whether they work at all, and uses this reasoning to justify her preference for pharmaceuticals: "I just haven't found any natural ones that have worked". Sarah's (lack of) embodied experience with CAM demonstrates how individuals learn about medications through their own lived experiences (Shoemaker & de Oliveira, 2008). Similarly, Sarah also stated: "Well I just know that if one particular antibiotic works really good, then I'll ask for that over anything else". Sarah's quotes highlight how experiences and beliefs are connected to people's everyday medication practices and choices enacted inside domestic dwellings. Although there are conflicting ideas around the efficacy of CAM, belief in pharmaceuticals to quickly remedy illness and infection is shared even by those who prefer to rely on more 'natural' means for treatment. Both Natalie and Olivia described instances, such as when an infection is fast spreading, highly acute, unstable, or thought to be 'in the chest', when biomedicines would be considered a more appropriate treatment option. In these cases, the severity of the illness influences the decision to immediately treat their children with conventional medicines. Vuckovic and Nichter (1997) attribute this decision to a caring practice and avoidance of child suffering: "When illness becomes more acute, rather than watch their children 'suffer needlessly', [parents] administer fast acting OTC<sup>12</sup> and prescription medications" (p.1298).

Previous research has also identified "expected pharmacological benefits" as a common medication experience (Shoemaker & de Oliveira, 2008, p. 89). However, the expected, wanted and beneficial hallmark of medications (getting better), coexists alongside the potential to experience adverse side effects (Shoemaker & de Oliveira, 2008). Concerns for side effects are common across both medication users as well as parents administering medications to children (Adams et al., 1997; Bussing & Gary, 2001; Conrad, 1985; Hansen & Hansen, 2006; Rogers et al., 1998; Viswanathan & Lambert, 2005). In a costs and benefits analysis of medication use, people compare the potential for side effects against positive outcomes of medication use (Rogers et al., 1998). This process is an important step towards parents' ultimate decision regarding whether or not to medicate their children (Hansen & Hansen, 2006).

In the current research, participants were quick to identify side effects from the misuse of medications<sup>13</sup>, becoming immune to medications, or synergistic effects

<sup>&</sup>lt;sup>12</sup> OTC refers to over-the-counter

<sup>&</sup>lt;sup>13</sup> The misuse of medications was defined by participants as administration errors such as giving the wrong dosage or taking the wrong medication, or resulting from the unsupervised consumption of medication by children.

resulting from polypharmacy<sup>14</sup> as major risks of medication use. Participants voiced their concerns about short and long term side effects of medications, ranging from immediate allergic reactions such as vomiting or swelling, to long-term damage to internal organs and immunity. For example, Natalie stated: "I guess a big risk is not knowing what it does to their organs or the insides of their bodies". Similarly, Maddison, who experiences severe allergies from many antibiotics, described her reluctance to give antibiotics to her child in case he reacted in the same way:

I was real iffy to give him that antibiotic because he was so little and because I didn't know whether it would affect him or not. And because I'm allergic to a lot of stuff I didn't know whether he would react to it as well. So it was really hard. But I had to, I had to give it to him.

Maddison's son was ill with the flu and experiencing trouble breathing at the time she decided to medicate him. Administering the antibiotic held the potential for both risks and benefits. In her above quote, Maddison acknowledged the apparent efficacy of pharmaceuticals and demonstrates the process of evaluating both positive and negative medication effects. In addition, Maddison also referred to how "little" her son is; drawing attention to the way in which children may appear vulnerable to the effects of medication.

In a report compiling the risks entailed in medication use amongst young children, The World Health Organisation (2007) highlights children's vulnerability to medications. Due to ethical concerns, medications are not tested on children or pregnant women (Spilker & Cuatrecasas, 1990), and physical differences between children and adults make the consumption of adult tested drugs potentially dangerous for other populations (World Health Organisation, 2007). Concern about the vulnerability of children was shared by each participant involved in this research, and is illustrated in the following point made by Natalie:

<sup>&</sup>lt;sup>14</sup> The use of multiple medications at one time (Hajjar et al., 2007).

[Nurofen is] really, really hard on your organs, especially your kidneys and liver! [My doctor] said there is all this controversy over giving it to adults, but yet everyone is handing it out to kids willy nilly. And he reckons there's just going to be so many repercussions of it.

In the context of parenting, the potential risk of side effects and those experienced in the past contribute largely to medication choices made by participants. The perception (albeit varying) that CAM are 'less risky' underpins two participants' preference to use homeopathic medications over pharmaceuticals. In reference to pharmaceuticals, Natalie stated: "I don't like to overuse stuff like that . . . [Homeopathy is preferred because] hopefully it's still not hurting their organs". The perception that CAM are somewhat safer in comparison to pharmaceuticals is an important factor impacting the decision to utilise CAM (Foote-Ardah, 2003; Sointu, 2006).

Despite widespread beliefs about the comparative safety of CAM, Sarah asserted that CAM may be just as risky as pharmaceuticals: "Well [homeopathic medications] could have side effects as well. Like with Arnica cream and things like that . . . You have to really look into it, because that is actually a thing that can thin your blood". Many New Zealand physicians share a similar perspective (Poynton, Dowell, Dew, & Egan, 2006), perceiving that some CAM may be dangerous or cause adverse side effects. Drawing on such information and her personal experiences regarding the lack of efficacy of CAM, Sarah prefers the use of biomedicines and acknowledges there are risks entailed in the use of any medications, regardless of their form and content.

Unlike the other participants, Maddison remains undecided on her preference between biomedicines and CAM. This emphasises the way in which medical choices need not be made exclusively in one domain, and highlights that participants adopt shifting models of health in accordance with their day-to-day medical experiences and needs. It is also important to note that, despite the distinctions participants have drawn between CAM and biomedicines, this is a largely fluid boundary, and many CAM are now considered part of the dominant health care system (Poynton et al., 2006). Dew (2001) argued that:

To divide medical practices into orthodox and unorthodox or alternative practices is a gross simplification of a very complex situation. The boundary between alternative medicine and orthodox medicine is not clear cut, and what gets labelled 'alternative' at any particular time is dependent on prevailing medical ideologies, cultural norms and the social organisation and political power of the medical profession and other health practitioners. (p.98)

The medication preferences of participants are summarised in Table 3:

Participant	Medication preference	Justification
Natalie	Prefers to use homeopathic or 'natural' medicines for preventative care and in response to illness.	Hopes to avoid (or at least reduce) short and long term side effects associated with biomedicines (under the assumption that the 'natural' content of CAM is safer than synthetic medicines). She hopes to utilise the body's natural defences and reduce medication dependency.
Sarah	Prefers to rely on pharmaceuticals or 'biomedicines' for treatment and preventative measures, but also uses vitamins to prevent winter illnesses.	Considers side effects a risk with any medication type, whether synthetic or natural based. Pharmaceuticals perceived as more effective in comparison to CAM.
Maddison	Undeclared: Does not report any preference between biomedicine and CAM.	Reports a lack of experience with CAM but claims she is open to trying them. Believes that pharmaceuticals/ biomedicines can be both useful and harmful to the health of her children.

Table 3 A summary of participants' medication preferences

Olivia	Prefers to use homeopathic medicines and organic products for both preventative care and as treatments.	Homeopathic medicines are utilised to avoid short and long term side effects of medications. She goes so far as to make her own 'natural' medicines and relies on many organic products in daily life
		in daily life.

Despite differing beliefs and experiences regarding which medications may generate positive or negative physiological effects, a consistent theme underlies each perspective: Side effects are closely bound with conceptualisations of medications and considered to be an inevitable part of medication use. Consequently, side effects from medication use are an integral part of constructing medications as dangerous goods: ". . . [Medications are] not a toy. They're not something that you should be really be mucking around with. You use them because you need them and that's pretty much all".

# Socially embedded features of medications

The previous section highlighted how medications have a material existence which impacts how they are perceived by lay persons. Yet, medications are more than simply material objects (Cohen et al., 2001). Maddison's discussion about marijuana use in different cultural contexts demonstrates how social norms and medical discourses pervade lay understandings about medications:

Maddison: If you're really in pain and you take something to fix that pain, that's a medicine. You know. So is marijuana a medicine? Because that helps you relieve that pain? Interviewer: It is in some states in America! Maddison: [Laughter] And in Holland it's just called a good night out . . . Because like, some people take it because they've got cancer and that aye? Or real bad, bad, like because they've had accidents and they've got back pains so they take it for that.

This dialogue aptly reflects the interaction between physical and social meanings of medications. In contemplating whether marijuana constitutes a medication, Maddison considers the physiological effect of marijuana, as well as prevailing social norms. There are two major social dimensions to participants' conceptualisations of medications. Firstly, medical professionals are found to play a central role in shaping understandings of medications, as interactions with medical professionals are a key part of participants' 'worlds of medication'. Secondly, the way participants construct medications as 'hard' (used synonymously with dangerous or risky) or 'soft' (benign or safe) indicates the complex ways in which medication understandings are formed; drawing from both private and public structures of meaning. Distinctions between 'hard' and 'soft' medications, medication experiences, how medications are accessed, doctor-patient interactions, and medication content.

#### Medical professionals

Medical professionals, such as doctors or pharmacists, regulate access to various medications. The idea that 'real' medications are administered or dispensed by doctors is a recurring theme in participant accounts. Such interpretations of medications are limited, however, due to the way in which they exclude many medications (such as gifted or over-the-counter medications accessible in local supermarkets, convenience stores or petrol stations). Nonetheless, the perspective of 'real' medications as being regulated by medical professionals captures an important part of the medication experience.

Each participant in this research has encountered numerous interactions with pharmacists, hospital staff and their Family General Practitioner (GP) in efforts to obtain suitable medications for their children. As the gatekeepers of many

medications, as well as trusted informants of medication uses, risks, and benefits, medical professionals play an integral role in shaping the perception of medications held by participants. Generally, a doctor recommended medication gains a degree of legitimacy that is not always provided through other sources such as direct-to-consumer advertising. For example, Maddison and her partner<sup>15</sup> agree that: "If it's not recommended by a doctor it's no bloody good".

Existing research has documented the historically privileged status that doctors have held due to their medical power and hegemonic position within health systems. Foucault (1963), for example, draws attention to the power embodied in the medical gaze; an observational practice applied by medical professionals to view their patients and ascertain medical truths about their physical wellbeing (Foucault, 1963). More recently, Flick (2004) has criticised the unequal power relations emanating from the hegemony of biomedicine and physicians' occupation in the "highest echelon of [this] health-care hierarchy" (p.1276). This positioning of medical professionals was also reflected by the participants in the current research, who often accept doctors' recommendations without doubt.

On the other hand, research suggests that this status and privilege is declining, particularly as resources such as the internet provide larger proportions of the population access to information which bypasses medical professionals (Fox & Ward, 2008; Giddens, 2001; Vuckovic & Nichter, 1997). Nonetheless, participants in this research still considered doctors worthy gatekeepers of medications and each trusted them with medication recommendations. This is highlighted by Maddison, who said:

Being young myself I haven't really had much input on medications and bits and pieces like that from other people. I've just really gone with the

<sup>&</sup>lt;sup>15</sup> Maddison's partner was at home during the interview process and at times contributed to discussions.

flow and I trust the doctors to do their job properly and give my child what is best for their needs.

Despite the high degree of trust in recommendations made by their GP, each participant has had negative experiences with medications recommended by doctors. Most commonly, such experiences involved their children suffering from medication side effects, including immediate allergic reactions. Iatrogenic illnesses are identified as a major contributor to the decline in doctor's privileged status (Vuckovic & Nichter, 1997). However, participants in this study tended to attribute such reactions to a medication-person mismatch. For instance, when Sarah experienced drowsiness from a doctor recommended medication she attributed this to a natural variance between people:

Sarah: [The doctor] said 'oh you can't get Zyrtec<sup>16</sup> on script anymore, we'll give you Razene<sup>17</sup>, it's got exactly the same stuff in it'. Well it can't have! If it does that! Interviewer: So do you still trust the doctor then? Sarah: Oh yeah. I don't know why I reacted different.

Similarly, Maddison had a frightening experience when her daughter reacted to an immunisation and antihistamines were required to control the swelling. Maddison rationalised that the adverse reaction was due to individual differences and asserted that it was obviously not the 'right medication' for her daughter: "It's different in every person. Sometimes this medication will work for this person; this one might not work for the other".

Participants' beliefs about the idiosyncratic nature of medication experiences enable them to preserve a trusting relationship between themselves and medical professionals. There is confidence amongst participants that doctors have their

<sup>&</sup>lt;sup>16</sup> Zyrtec is an antihistamine used to treat symptoms of hay fever or allergy (Drug Information Online, 2000-2011b).

<sup>&</sup>lt;sup>17</sup> Razene is also an antihistamine used for allergy relief (Strand Arcade Pharmacy, 2011).

children's best interests at heart: "If it was going to be that bad for [them], surely your doctor wouldn't recommend it". These findings suggest that doctors remain highly valued for their medical knowledge, and are instrumental in conceptualising and understanding medications.

## Hard and soft distinction of medications

Participants made numerous references to a perceived distinction between 'hard' and 'soft' medications. The term 'soft' is employed to described how participants were likely to view some medications as largely safe to use, but does not mean to imply that such medications are literally harmless. Instead, the term stresses how some medications have come to be classified as common household items, used in automatic ways for a range of ailments. Routine use of medications is extremely complex, and is explored in more detail in the following chapter.

While this research was being conducted, there were two media controversies noted in participant diary records. These include the recall of both Reductil<sup>18</sup> and Warfarin<sup>19</sup> from the market. For participants, these media items reinforced the notion of 'hard' medications. Retracting a medication from the market is an action that confirms a medication has been unsafe for human consumption, and thereby legitimises public concerns around medication use. Assessing the function of media in participants' everyday medication worlds is a complex task, in part due to the myriad of media forms. Newspapers, magazines, internet sites, social forums, advertising brochures, billboards, television advertisements, and news broadcasts on radio or television are all media that address medications. Internet sites and social forums are particularly fascinating, as they enable the

<sup>&</sup>lt;sup>18</sup> Reductil is an 'anti-obesity' drug that affects neurotransmitters in the brain and was discontinued in the UK in January 2010 (Netdoctor, 1998-2010i).

<sup>&</sup>lt;sup>19</sup> Warfarin is an anticoagulant or blood thinner (Netdoctor, 1998-2010d).

dissemination of lay perspectives and experiences (Hodgetts et al., 2010), which may complement or contradict information relayed from a medical perspective.

Hodgetts and colleagues (2010) propose that media "can operate to reaffirm our trust or distrust of people and institutions and to highlight developments and uncertainties about our daily world" (p.330). The media certainly served this purpose regarding immunisations. Maddison, in particular, noted that:

They couldn't decide whether it was good or not. And then they said it was good, and then 'oh yeah we're fully covered if there is, you know, if you have three shots' and then 'oh no you need four shots' and 'oh no'. Mmm. So I kind of backed off that and didn't give my kids that.

Alongside media controversies of 'hard' medications, media are also at the forefront of relaying positively framed information regarding medical technologies and break-throughs. Spilker and Cuatrecasas (1990) discussed how there are scientific "fads" that attract substantial media attention, often resulting in increased availability of funding. Examples include the "War on Cancer", AIDS research and focus on "specific methodologies, such as those of recombinant DNA technology" (Spilker & Cuatrecasas, 1990, pp. 22-23).

Conceptualisations of medications as 'hard' or 'soft' are also shaped through interactions with medical professionals. Natalie, for example, found alternative pain relief after her doctor discussed with her his concerns about children using Nurofen. Likewise, Olivia's decision not to give her child steroid treatment emerged from a conversation in which a specialist described steroid treatment as "potent". Aside from the knowledge shared between patient and doctor, health professionals' role as gatekeepers of prescription medications also constructs these medications as 'hard', while the easy access of over-the-counter medications shapes them as comparatively 'soft' (Vuckovic & Nichter, 1997).

The physiological effects of medications have been a key point of exploration in this chapter. Negative experiences, such as when children experience adverse

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side effects, are pivotal to the construction of medications as 'hard' or 'dangerous'. For example, following her son's reaction to the Meningitis vaccine, Natalie made the decision not to immunise her children in the future:

He had a big tennis ball sized lump under his arm on his shoulder for about three months, but then a 50 cent sort of size piece under there for a long time. He was so sick . . . [After that] I didn't think it was necessarily a good thing, vaccinating them.

Each of the participants disclosed 'horror' stories regarding side effects their children have experienced that at times resulted in the need to seek medical intervention, and in all instances resulted in the discontinuation of using the particular medication. This consequence is perhaps the most direct illustration of how lived experiences with medications shape medication practices.

Knowledge about the content of medications is also an important factor in decisions about whether or not to use or administer a medication. Existing research revealed that distinctions between 'hard' and 'soft' medications may be related to their milligram content (Vuckovic & Nichter, 1997). Those medications containing a higher dosage of the active ingredient were considered 'harder' than those with smaller dosages (Vuckovic & Nichter, 1997). Similarly, in discussing her reluctance around using Phenergan<sup>20</sup> on her child, Natalie relayed how she under-dosed him because she was concerned about how strong the medication might be: "Oh like ones that are a bit stronger than Panadol and things like that that make them drowsy . . . Just a bit more in them I guess". In this quote Natalie makes a connection between medication strength and increased risk of side effects, and possible danger.

<sup>&</sup>lt;sup>20</sup> Phenergan can be used (on a short-term basis) as a sedative for children (Netdoctor, 1998-2010h)

## **Chapter discussion**

This chapter began with an exploration of complexities in participants' conceptualisations of medications. Participants' photographs in Figure 2 show that medications are widely and easily accessible in their local communities. Furthermore, some locations that stock medications have long opening hours and may display medications in conspicuous ways. This was identified as a major concern, as accessibility of medications normalises their presence in communities and presents risks to children. Despite such concerns, participants prefer to have medications readily available in times of need. For these participants, pharmaceuticals are still the preferred approach to 'fix' severe infection and disease. More serious and acute health situations increase the perceived necessity of pharmaceuticals. Even for those who prefer the use of CAM, acceptance of pharmaceutical use in health crises was largely justified by the notion pharmaceuticals can make a person "better", despite the risks entailed. Thus, there are some tensions between the risk and convenience of access to medications. While accessibility to medications in private households may be regarded as convenient, it was deemed more dangerous for medications to be too easily accessible in local communities.

Participants' accounts also point to the blurring boundaries between medications and other consumer goods. This is illustrated in the lack of physical boundaries between medications and other goods in consumer environments, the diversification of product range, and the way in which many goods may offer medicinal effects. It is apparent that the simple notion that medications are "something that you take to make you better" encompasses a wide range of substances. The lack of a simple distinction between medications and other consumer goods raises differences amongst participants regarding what actually constitutes a medication. Such complexities reflect how making sense of medication is an ongoing process (Bajcar, 2006), and also how people do not attach single meanings to their medication experiences (Silverman, 2010).

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In discussing their medication understandings and preferences, the participants sometimes drew distinctions between biomedicine and CAM, and also had different interpretations about what did and did not constitute a medication. The tendency to perceive 'man-made' (sic) pharmaceuticals as 'actual' medicines reflects the ongoing construction of CAM as the deviant or 'other' of biomedicines. It is tempting to create a binary between CAM and biomedicine, or even between medicines and non medicative forms. In everyday practices with 'medications', however, this distinction is more complex (Dew, 2001). The participants use medications for diverse purposes extending far beyond the conventional treatment or prevention of illness and disease. For instance, medications are also used to gain wanted side effects, and as a calming mechanism for emotionally distressed children. Furthermore, medicinal effects may be sought from other material goods, including food items such as the cough syrup Olivia made from carrot juice and raw sugar. Nor do medications always resemble a typical pill form. The images in Figure 1 capture creams and liquid form medications that are utilised within the households studied. To conclude, the meanings attributed to medications are complex and fluid, rather than based on distinct and static models.

This chapter also explored the material and social dimensions of medications as identified by the participants. The physiological effects of medication emerged as a pivotal component of participants' understandings and medication practices. Participants' responses revealed that "getting better" is a common (and expected) embodied experience of medication, though this does exist alongside the potential to experience adverse side effects. These embodied experiences are central to the way in which medications are perceived as having the potential to be simultaneously beneficial and harmful, or as helping and hindering independence and autonomy (Pound et al., 2005). In this respect, medication understandings are found to be deeply paradoxical. The social features of medication identified by the participants point to how medications are more than simply material objects with physiological effects (Cohen et al., 2001). Alongside their material existence, medications have social and symbolic meanings that impact how they are perceived and used in the private practices of lay persons (Helman, 1981; Rogers et al., 1998). Interactions with medical professionals, for instance, emerged as central to the way in which participants construct their understandings of medications, including whether they perceive medications as 'hard' or 'soft'. Despite the declining power and privilege of medical professionals, for these participants, their Family GPs are considered trustworthy sources of medical advice and recommendations.

Knowledge and experience are central to the medication practices enacted by participants in their households. This chapter provides many examples of how lived experiences influence medication practices. For instance, consider Maddison's reluctance to administer her child antibiotics due to her own history of allergic reactions, or parental decisions to stop utilising a medication when their children experience negative effects. Alongside lived and shared experiences, this chapter demonstrates that biomedical knowledge is also an important source that informs participants' conceptualisations of medications. In participants' accounts, we have seen the emergence of a 'stereotypical' medication, which is dominated by biomedical understandings of medications as 'synthetic' and 'pill-like' in form. The photos in Figure 1 also represent links between participants' understandings and biomedical knowledge. Sarah asserts that the photos of the doctor's clinic and the chemist best describe her 'world of medication'. In selecting photographs that best describe their worlds, not a single participant selected a photo of complementary or alternative sites of medical care or advice. Even those participants who question and critique pharmaceutical use still perceive doctors as trusted experts in the medicine field; showing that they have not fully rejected a biomedical model of health. In summary, this chapter has shown that participants draw on many forms of knowledge in their everyday medication practices.

## **CHAPTER FOUR: MEDICATIONS AND CARING**

The notion that medications may be given as an act of caring or compassion in efforts to eliminate and reduce suffering is persuasive in existing literature. Chapter one explored how caring for the ill is often enacted through the provision of medications or ensuring adherence with medication regimens. In the community, the success of mental health policy may be measured by the level of compliance with medication (Rogers et al., 1998). In the household, family members may express care by reminding ill individuals to take medications (Hodgetts et al., 2011; Milliken & Northcott, 2003), assuming responsibility for dispensing medications, or implementing strategies for remembering (Hodgetts et al., 2011; Marhefka et al., 2008).

For parents, giving children medication is an action positioned within a moral context whereby the administration of medication is understood as a way to improve health and minimise suffering (Vuckovic & Nichter, 1997). Jerrett (1994) argued that "to cause their children pain was opposed to parents' natural instincts" (p.1053). This deep seated desire to avoid suffering is also illustrated in Vuckovic and Nichter's (1997) article, where authors claimed that parents are unable to watch their children "suffer needlessly" (p.1298); particularly when administering fast acting pharmaceuticals promise relief from children's various ailments and complaints. There is widespread awareness that medication use is not without risks. However, in the context of pharmaceuticalisation (see chapter one), the administration of medication is both an accessible response, and one that can invoke hope and certainty for parents attempting to care for their ill children. As stated by Singh (2004): "There is nothing very new about a mother's efforts to improve her children" (p.1204), and this frequently involves a turn to science (Singh, 2004).

Gift exchange theory also provides insights into the interpretation of medications as vehicles of care and affection. In exploring the rituals of modern Christmas gift giving, Carrier (1993) examined how the exchange of material gifts can be "... a vehicle of affection that expresses private sentiment within a relationship that is personal and probably familial" (p.55). Carrier (1993, 1995), Mauss (1950), Schwartz (1967), and Caplow (1984) (amongst others) argue that there is more than mere utility involved in the relationships between people and objects. Importantly, such literature highlights the ways in which objects may have concrete practical implications that exist alongside the expression of abstract sentiments (Carrier, 1995). Similarly, as a vital component of caring and gifting practices, medications are likely to have both physiological and psychological effects.

This chapter extends knowledge of how care and affection may be communicated in gift exchanges. The administration of medications by parents to their children is used to exemplify how medication practices, however mundane or trivial in the context of everyday life, can resemble gift exchanges and constitute care. While medications as material objects are central to gift exchanges and the pursuit of health, the chapter also takes into consideration a broader understanding of 'gifts'. This broader understanding accounts for the significant effort participants exert in making their children's medication decisions, and ensuring safe medication use in households. As explored in chapter one, there are many tasks care givers assume responsibility for, not just the physical transaction of medications from care giver to child. Furthermore, this chapter addresses differing perspectives of care. When parents administer medications to their children, this action reflects wider medical discourses and conceptualisations of care. It is apparent, however, that resistance to medications can also constitute care. In efforts to reduce or eliminate medication use in their households, participants rely on alternative gift exchanges to establish and maintain the health and wellbeing of their children.

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## Medications in gift exchanges

Caring for their children is an intense emotional experience for parents. Uncertainty, worry, anxiety, and concern are some of the many emotional hardships experienced by parents caring for an ill child (Bussing & Gary, 2001; Evans & Thomas, 2009; Lauver, 2008). The participants in the current research also described many emotional involvements in their children's medication use. They may feel "pissed off" when medications cause negative side effects, "paranoid" about medication use, or relieved when medication aids a child's recovery. Seeing their children sick is a distressing emotional experience for participants. Maddison highlighted that "when your kids are sick that is the hardest time. When you see your kids sick, all you want to do is make them better". Most profoundly, the participants sense a maternal responsibility to protect their children, keep them in good health, and make the best possible medication decisions on their behalf. This desire is succinctly captured in Maddison's following quote: "I want to protect my kids and I want to try and make the best decisions possible for them". Evidently, caring for ill children is associated with a wide range of emotional experiences and impulses. As care givers invest trust and hope in the restorative functions of medications, the gifting of medication becomes a highly emotionally laden act.

As noted by Carrier (1995), there are clear practical uses for many material items. 'Getting better' or maintaining health are practical implications and embodied experiences of medication use central to participants' understandings of medications (see chapter three). While medications have (diverse and sometimes controversial) practical uses, gift exchange theory also recognises that relationships between objects and people transcend practical utility (Carrier, 1993, 1995; Mauss, 1950; Schwartz, 1967). Modern Christmas gift exchanges are a common illustration of how the transaction of objects can communicate various sentiments. For example, as outlined in Chapter two, parents involved in Caplow's (1984) research view the ritual of Christmas gift giving as an opportunity to communicate the "unqualified love" of their children (p. 389). 93 Similarly, the administration of medication (assuming that it evokes the desired physiological response) allows parents to enact care and affection towards their children. Medications have perceptible physiological effects that make concern and affection real and tangible (Hodgetts et al., 2011; van der Geest et al., 1996). The following examples illustrate how the participants engage in caring for their children through the use of medication.

## Administration and preparation of medications

The administration of medication can comprise a gift exchange where parents act as the givers of medication, and their children as the recipients. Examination of these transactions will focus on the expressions of affection and care entailed in medication transactions, before moving on to explore the social roles involved (see chapter five). During the course of this research, Olivia's infant son was prescribed antibiotics to help him recover from a chest infection. Olivia's diary documents how she routinely administered her son antibiotics twice daily:

Saturday: Today [my son] had his antibiotics at 8am and 6pm. Sunday: [My son] had his antibiotics at 9am and 7pm. Monday: [My son] had his antibiotics at 9am and 6pm. Tuesday: [My son] had his antibiotics at 8am and 6pm. Wednesday: [My son] had his antibiotics at 8am and 7pm. His chest infection seems to be clearing.

Despite Olivia's preference to utilise more natural treatments such as homeopathy (see Table 3), chest infections account for one of the dire health circumstances in which she would resort to using pharmaceuticals. As established in the previous chapter, participants perceive differences in the way that pharmaceutical and homeopathic medications work. Although Olivia believes that pharmaceutical medications present more risks, simultaneously, they are thought to work faster than homeopathic medicines, hence being a more suitable treatment for fast spreading or acute illnesses. For Olivia, the need to utilise fast acting pharmaceuticals conflicted with her personal experiences. She has a family history of allergic reactions to the antibiotic Augmentin, and her own son reacted adversely to Amoxicillin. Olivia stated that "he started vomiting and crapping" the last time that antibiotics were used. Although these experiences validate her concern over pharmaceutical use, the perceived efficacy of pharmaceuticals negated some of her reluctance:

Interviewer: Do you still feel comfortable using it? Olivia: Yeah. I do. Because it is going to heal up his chest infection. Interviewer: So you trust that it will work? Olivia: Yup. And it worked.

Despite her qualms, antibiotics were 'gifted' to Olivia's son with the expectation that they would secure his health. The daily administration of the antibiotics outlined in her diary entries inserted above, illustrate her desire to take care of her infant son. Ensuring that their children get better is a common rationale for medication administration (Malacrida, 2002; Singh, 2004).

Gift exchanges are more complex than the mere administration of medicines. Household medication practices also involve the enactment of various safety precautions. The preparation of medications is a vital component of the capacity of medicines to communicate care and affection. For instance, Natalie noted that the administration of some medications may be particularly traumatic for children. She likened the process of school immunisations to "lambs to the slaughter":

You know, all being walked down to be immunised then walked out . . . I sort of think 'oh what if that nurse dropped that needle and then just washed it'. At the doctors surgery you're there and you're watching. Whereas [at school] they're bloody herded in like sheep to the hall and called alphabetically, and they think if they give them a lollipop it makes it okay. In this dialogue, Natalie illustrates concern regarding her children's experiences of the immunisation process, and also identifies risks involved such as the potential to drop a needle on the floor. In efforts to avoid exposing her children to a traumatic childhood experience, Natalie stated that she would not hesitate to contact her doctor and book an appointment to have them immunised: "I don't let them do it at school. If it is something they've got to have, like when they had the rubella injection, I ring [the doctor] and say 'please can you book in [my children]'". This practice also means that Natalie may be present to support her children while they receive immunisations.

Other preparation efforts include vigilance around checking the dosage of medications before administering them to children. For example, participants commonly use syringes (see Figure 4) to administer medicines to ensure correct dosages are given. As Maddison explained, using a syringe "gives you perfect, perfect measurements" of medication doses.

Figure 4 A photograph of a syringe used to gain accurate doses of medication



On one occasion Maddison had to use her sisters Ibuprofen. But before administering it to her son, she took the precaution of contacting her partner at home to confirm it was the same strength as her son's usual medication. Her diary details this safety precaution as follows: [My son] had a temperature when he woke up. [I] was at my sisters and had to use my nephew's Ibuprofen to give to [my son]. [I] rang my partner to check it was the same strength as [my son's] and same dosage. It was, so I gave [my son] 7mls.

Ensuring the right medication dosage is given is so crucial that, following her son's surgery when he was required to take multiple medications, Maddison kept a written record of medication administration. This record detailed which medication was given, the time it was administered, and the dosage:

... When [my eldest son] had his tonsils out I had to give him three different medications at certain times, so I'd keep a record and write down when I had given it to him and what I had given him. Because otherwise I'd be like 'which one did I give him?' So it was just easier to keep it on the fridge. [Then I would know] 'right, I've given him this at this time'. So that's how I did it when I had to give him a lot of medication at once. I didn't want to stuff it up, he had just come out of surgery.

These medication practices sought to ensure that their children did not suffer negatively from any administration errors. As addressed in the previous chapter and existing literature, medication side effects are a major concern for parents of ill children requiring medications (Adams et al., 1997; Conrad, 1985; Pound et al., 2005; Viswanathan & Lambert, 2005); this is especially so when multiple medications are being used at one time. These preparation efforts draw attention to the fact that gift exchanges are not determined solely by the transaction of material goods. Although the administration of medications involves concrete objects, these medication practices also involve the gifting of time and effort to ensure the safety of medication use within households.

## Selection of medications

While modern Christmas gift giving is a popular cultural feature, it reinforces a limited conceptualisation of 'gifts'. Gifted objects can be more than material, and incorporate things that fall outside of conventional understandings of gifts as neatly wrapped presents given ceremoniously on particular days (Carrier, 1995). As well as these conventional 'gifts', gift exchange theory also includes "all things transacted as part of social, as distinct from purely monetary relations, and it includes labour and immaterial things like names and ideas as well as physical objects" (Carrier, 1995, p.18). It is this broader understanding of the 'gift' that provides the focus and theoretical orientation for this chapter. Carrier (1995) provides many examples of gift exchanges in everyday life that employ this broader conception of the 'gift'. For example, Carrier proposed that when friends go out together for a social occasion, the driver and owner of a vehicle may choose to gift transport to each of his or her friends. Whilst they are out, friends may gift each other rounds of drinks from the bar. These 'gifts' are not neatly wrapped presents, but they represent significant exchanges between individuals that reinforce the bonds or relationships between them (Carrier, 1995).

Gift exchange literature has highlighted how shopping for gifts is a domestic ritual that embodies the sentiment of the gift itself (Carrier, 1993). For instance, Caplow (1984) documented how gift givers thoughtfully considered the recipient's needs and tastes before selecting a gift. The care and affection communicated in gift exchanges is in part captured in the substantial effort exerted by individuals as they search for the 'perfect' or most suitable gift for another. Such effort is analogous to the deliberation, thought, and care parents exert to make medication choices for their children. Previous research revealed that making medical decisions on behalf of their children is a challenging and at times conflicting process for parents (Blum, 2007; Bussing & Gary, 2001; Hansen & Hansen, 2006; Jackson & Peters, 2008). This process has been described as a 'dilemma' or 'balancing act' (Hansen & Hansen, 2006), whereby consideration of risks and benefits of medication use is paramount. The "effort of selection and 98

preparation" (Carrier, 1995, p. 18) entailed in gift exchanges has particular significance in the context of caring for ill children through medications. Such efforts have heightened importance for parents, given the vulnerability of children, the vast variety of possible medication choices, and the emotional dimensions of parent-child relationships.

Selecting medications involves substantial effort. Parents commonly seek information about medications from multiple sources, including media, health professionals, and lay persons (Jackson & Peters, 2008). The participants in the current study regularly engage in research before making the decision to purchase a medication. This might this involve seeking a second opinion about a medication from another health professional, utilising the internet to find out about a specific medication, or attending to medical controversies presented in the media. Research, particularly internet based, provides a wealth of information that parents are able draw on to inform their decisions (Blum, 2007), as well as facilitating individuals participation in the construction of their medication understandings and beliefs (Cohen et al., 2001; Conrad & Leiter, 2004).

In chapter three, the preventative care of children before winter through vitamin supplementation was discussed. In these practices, the gifting of vitamins sought to boost strength and immunity, reflecting the participants' desire to keep their children in good health throughout the winter season. Because of her son's immune deficiency, preventative care assumes particular importance in Natalie's household. Natalie stated she utilises Floradix<sup>21</sup> to help enhance her son's immunity before winter. Choosing this medication for her child was a process that involved consulting the immunologist to ensure she purchased the product that would be most beneficial for his needs. As Natalie stated:

<sup>&</sup>lt;sup>21</sup>Floradix is a liquid form of iron with additional herbs and extracts (Flora Health USA, n.d).

... It was recommended by the Immunologist. Because the immunologist, [my son's] one, reckons that vitamins are just full of sugar . . . You're giving them a tablet that's not readily absorbed into their blood stream, and has sugar and colourings in it. So he reckons that they are really just like lollies. That's what he says a vitamin is. Whereas Floradix is a natural thing, and it's liquid so it's absorbed into their blood stream really fast.

The participants' understanding that medications have various (idiosyncratic) effects prompts the search for medications 'most suited' to children's health and medication needs. As Natalie seeks information from the Immunologist, she demonstrates the effort of "selection and preparation" (Carrier, 1995, p.18) that is such an important dimension of medication gift exchanges.

Just as medications have practical uses, so does the acquisition of information. For example, utilising resources such as medical texts, homeopathic books, or the internet search engine 'google' assists participants to clarify any uncertainties about a particular medication, or to research any unfamiliar symptoms their children may be suffering. Sarah detailed how when her daughter was severely ill with an undiagnosed condition, she made use of her biomedical 'doctor's book' and 'google' in search of a solution:

I was going through all these symptoms. Did all that. I looked in my book before I even googled it . . . . I only googled it because every time I said something to someone they were like 'Oh my god do you realise . . .'.

For Natalie, a primary resource is a homeopathic book that she uses to help her find natural medicines pertaining to symptoms being experienced by her children: "I've got that cool book 'Homeopathic medicines and children'. So, often I'll look up their ailments in there and have a look". By utilising these resources, participants are able to make informed medication decisions on behalf of their children. Given the substantial amount of (sometimes conflicting) information available about medications (Vuckovic & Nichter, 1997), the selection of medications is a task that involves considerable dedication and the gifting of time and effort.

#### Routine medication use

In this chapter thus far, examples of medications in gift exchanges all involved the active engagement of participants in medical decisions and medication administration. However, not all exchanges demonstrate active decisions and agency quite so transparently. Many medication practices occurring within households are routine in nature, as is appreciated with countless everyday life events and interactions. Recognising everyday transactions of care and affection inside households requires intense analysis and scrutiny in comparison to ritualised or ceremonious gift giving (such as Christmas celebrations), as they are often more "ubiquitous and automatic" (Carrier, 1995, p.18). Carrier's assertion has particular significance for the analysis of those medication practices described as trivial or mundane. It is in fact relevant to the analysis of many everyday life practices as ordinary as picking the kids up from school or taking out the rubbish. Daily routines of cooking, for example, entail the 'gifting' of time and money to food selection, purchase, preparation, and cooking by household members (Carrier, 1995). There are emotional dimensions in these routines, such as the expression of love or the desire to care and look after family entailed in cooking for them (Carrier, 1995).

Many medication practices are so ingrained and automated that participants in the current research experienced difficulty in rendering them unfamiliar and describing them in detail. For example, Sarah offered the following description regarding how she obtains medications: "How do I get them? Go to the doctor. Go to the chemist." In relaying the procedure followed when she needs medication, Sarah simply stated: "Just go to the cupboard. Get a pill out. Take it". The short sentence structure and lack of detail illustrates her over-familiarity with these practices. Similarly, Natalie laughed when I asked her how she gets her medications: "In the car! [Laughter] From the pharmacy in the car. In the car and then into the medicine kit". Natalie's diary suggests that familiarity with medication practices applies not only to the adults managing or enacting them, but also to the children receiving medications. Natalie wrote "he knows the drill" in reference to her youngest son's bedtime medication routine, where Rescue Remedy Sleep is often utilised to help him sleep when he is unsettled or ill. This phrase captures her son's awareness of and compliance with the medication routine in which he is a social actor, as well as the way in which this medication has become entwined with wider daily routines.

The way in which medications can become markers in a daily routine (Hodgetts et al., 2011; Marhefka et al., 2008) is evident in Olivia's account of her Domperidone use. Her diary details how she took Domperidone at 9am, 1pm, 5pm and 9pm on most days. Variance in times included two days where she took the medication at 8am, 12pm, 4pm and 8pm, due to changes in her surrounding daily routine. Olivia herself noted how the routine has become quite automatic: "I'm so used to taking it now that it is going to be bizarre when I stop taking it". The administration of Olivia's son's antibiotics also formed a daily pattern that is detailed in her diary records (presented on page 94). Prior to the formation of this administration pattern, however, the participant engaged in conscious deliberation over antibiotic use. The shift between automatic medication use and cognisant medication consideration demonstrates how "illness and medication are conflated and taken-for-granted at some times and brought to the fore and lead to concern at other times" (Hodgetts et al., 2011, p. 12). Bajcar (2006) made a similar conclusion, noting that participants' medication practices could be trivial in the context of everyday life, but at other times they could "reflect more critically on their medication use" (p.66). The research conducted by Hodgetts and colleagues (2011), and Bajcar (2006), were an important consideration during the analysis of 'routine' medication practices. Such research takes into account that medication practices have emerged over time from a unique history of participants' medication experiences and knowledge, rather than being isolated singular events.

In describing how medications are embedded in daily routines and social relationships, Hodgetts and colleagues (2011) likened some medication practices to the simple and familiar task of eating an apple. This analogy is useful in that it attends to the enactment of a familiar practice (eating an apple), as well as an interaction with a material item recognised as commonplace (the apple as a concrete object). Similarly, while medication practices may be described as routinised or familiar, specific household medications may also be constructed as 'ordinary'. These medications are not transacted with the same sense of caution or suspicion associated with the use of 'hard' medications (see chapter three). As Hodgetts and colleagues (2011) claimed, certainty and familiarity are recurring themes when participants permit the presence of medications in their own home.

Some medications were over-familiar and frequently used within households. This was notable in participants' processes for discarding medications and checking expiry dates. Panadol and Nurofen were exempt from these practices because, as Olivia explained, "it never hangs around for that long to go past its expiry". Natalie further emphasises this point in the further dialogue:

Interviewer: Would you check the date before you took them? Natalie: Yes normally . . . . We don't take too many medicines. So generally it's just Panadol and stuff so it's sweet. But if I was going to give them something more, perhaps if it was eye drops or ear drops I would check it. Interviewer: Why would you check those but not Panadol?

Natalie: Because we use Panadol more often so it's less likely to be off. Well I know it's not off.

The use of Panadol in these households aptly reflects Hodgetts and colleagues (2011) analogy of eating an apple. The presence of Panadol is common to every household involved in this research, and the use of this medication is mundane 103

in the context of everyday life. Olivia has little hesitation about the use of Panadol, she "wouldn't think [emphasis added] about walking to the cupboard and taking Panadol" if needed. Maddison itemised Panadol as a necessity to take with her when she leaves the house, highlighting her perception of Panadol as a common household item: "I usually take inhalers, the Pamol<sup>22</sup>, Phenergan for an antihistamine. Sometimes I'll take Ibuprofen, and of course Panadol". Vuckovic and Nichter (1997) argue that routine use of medications leads lay people "to no longer see these products as medicine" (p.1297). This proposition may account for the discord between participants over labelling pain relief as a medication (see chapter three).

It is common for care givers to describe medication taking as simply part of the daily "routine" (Jerrett, 1994). Although medication use may at times appear mundane, routines have important functions. For instance, embedding medication regimes in broader daily routines assists in remembering to take medications (Hodgetts et al., 2011; Marhefka et al., 2008), and contributes to an individual's overall sense of security that 'something' is being done about the disruption and uncertainty of illness (Hodgetts et al., 2011). The presence of commonplace pharmaceuticals can provide a sense of being prepared to deal with and care for those experiencing sickness as it occurs (Hodgetts et al., 2011). Nonetheless, long-term automatic and routine use of medication can have significant health effects. Natalie expressed concern over the "willy nilly" use of Nurofen (see page 79). In addition, she questioned the use of Pamol, suggesting that parents use Pamol to subdue restless children, rather than in response to an ill state of health: "I don't really like giving them Pamol unless they need it. Lots of parents will give their kids Pamol if they're tired, or whingey, or grizzly".

<sup>&</sup>lt;sup>22</sup> Pamol is a form of pain relief used for children containing the active ingredient paracetamol (Johnson & Johnson, 2007-2010)

Natalie's concerns about routine and perhaps needless medication use are not uncommon. For instance, one of the main controversies behind the use of Ritalin as an ADHD treatment arises from the contention that children are medicated in part to make parenting an easier job (Blum, 2007; Malacrida, 2002; Singh, 2004). However, research has also documented the immense pressure placed upon parents to accept a physiological aetiology of ADHD and remedy their child's problematic behaviour through the use of medication (for example, Blum, 2007; Bussing & Gary, 2001; Hansen & Hansen, 2006; Jackson & Peters, 2008; Malacrida, 2002; Singh, 2004). Although this matter is extremely complex and unresolved, it is a useful example to demonstrate conflicting perspectives of care.

## Differing perspectives of care

It is widely understood that social structures impact the actions of lay persons (Giddens, 1984). Mainstream medical knowledge is a key feature in contemporary societies so it informs many social practices (Filc, 2004). Because of this, social actors may construct medication practices as caring because they align with medical understandings or direction. Natalie's rationale for immunising her first two children illustrates this argument:

Well I did [my eldest son] because that's what everyone did fourteen years ago; you just vaccinated your kids. We were all vaccinated, including my brother, so it's just the thing you did. I didn't ever give it a second thought.

Natalie's comments reflect the way in which health practices may be followed simply because they align with the prevailing medical discourse (Gunnarsson & Hydén, 2009). Although medication practices may be carried out fairly automatically, this does not necessary reflect a lack of caring or affection. Instead, such practices indicate that parental constructions of 'care', and the resulting medication decisions and practices, are pervaded by medical knowledge.

Briefly, the focus in this thesis is on the differing, competing and conflicting perspectives of care that form dialectically from both public and private structures of meaning. Such perspectives are apparent in the experiences of participants in the current research and also in existing literature. For example, parents involved in Jackson and Peters' (2008) research reported that there are different representations of medications and discourses of care amongst supporters and critics of stimulant medication use. They were perplexed by the fact that not even experts could agree on "what constitutes best treatment approaches" (p.2729). While some treatments are less controversial than others, biomedical knowledge is not an omnipotent or objective knowledge (Dew & Lloyd, 1997). In chapter three I proposed that participants draw on many forms of knowledge as they construct and justify their medication practices. While private medication practices are influenced by public structures of meaning, they are not determined solely by macro social spheres. Examination of participants' resistance to medication use, as well as their tendency to rely on alternative gift exchanges for obtaining and maintaining health, reflects these competing discourses or constructions of 'care'.

#### Medication resistance

The tendency to respond to ill health with pharmaceutical use has growing opposition in both public and private domains. Increasingly, health professionals seek alternatives to simply prescribing their patients medications (Poynton et al., 2006). Similarly, many medication users search for other ways to manage their illnesses (Rogers et al., 1998). Conrad's (1985) participants expressed a 'hate' for taking medications and revelled in the possibility of one day being "off the drugs" (p.33): "There is widespread belief in our society that drugs create dependence and that being on chemical substances is not a good thing" (Conrad, 1985, p. 34). It is a pleasurable experience for participants in the current research when their children do not require medications: "He hasn't [had medication] for a long time, touch wood. He hasn't had to have anything".

To varying degrees, participants can be both sceptical and hesitant about medication use. Like other lay persons, they express concerns regarding medication side effects and dependency, and seek to reduce unnecessary use of medications through various practices. From Maddison's perspective, visiting the doctor inevitably leads to medication use. As an expression of care and affection toward her children, she will sometimes delay going to the doctor in the hope that her children will get better without medical intervention:

... It's too easy to dish out medication. That's why sometimes I'm like 'right, no'. If my kids are five days into it then I'm like 'right now I have to take them [to the doctor] because they are not getting any better'. But to start with, I always make sure that I leave it a couple of days if it's not life or death. I give it a couple of days to see if their body will correct itself, so that they don't have to take the medication.

Avoiding medication use in this way was not always possible for those children using preventative medication for asthma. While Maddison did make this exception in her household, when it came to treating (rather than preventing) sickness, she was adamant about not using medications unnecessarily. When using hay fever medication, for example, Maddison stated: "I don't give it to them every morning, it's if they've got those symptoms, then I give it to them". Likewise, her emphasis on administering medications on the basis of need is expressed in the following quote: "I would only give it to them if they need it, unless it is working as a preventative like their Flixotide<sup>23</sup>. But other than that, other medications, I would only give it to them until it clears up really".

Natalie has also adopted practices to ensure that medications are not given unnecessarily. When her children complain about headaches, for example, she responds in the following way: "Often I would just make [my children] have a big

<sup>&</sup>lt;sup>23</sup> Flixotide contains the active ingredient fluticasone propionate (from the steroid family) and is used by asthma sufferers to reduce inflammation in the lungs (Netdoctor, 1998-2010c).

drink of water first and a sit down. Half the time a headache can just be from dehydration". Olivia has refused treatment for her son's Strawberry birthmarks unless they begin to cause him additional harm<sup>24</sup>: "For him, the only reason he's going to get [steroid treatment] is if the birth marks are going to cause problems in the future with his eye sight". These examples illustrate how resistance to medications can also constitute care.

Immunisation practices evoked distinct perspectives from participants. While some understand immunisation as a way to 'protect' children, others perceive the practice as dangerous and even damaging to long term health and immunity. Indeed, there is ongoing dispute about the safety and benefits of immunisation practices (Dew, 1999). The contrasts inherent in participants' understandings highlight that there is an array of perspectives on what constitutes 'care'. Both Natalie and Maddison have made a recent decision not to immunise their children, even though this conflicts with their doctor's recommendations and prevailing medical knowledge. Maddison described how her mother (an emergency department nurse) conceptualises immunisations as a way of protecting children:

... She swears by children being [immunised] and all that sort of stuff. There was a big, big discussion about that between her and I and she said, you know, at least my children would be fully covered and I would know that I'd done the best I could. I was like 'but at the end of the day I wish not to give my kids that'.

Maddison's mother overtly constructs immunisations as a form of care and protection of children. From this perspective, the refusal to give medications may be interpreted as uncaring. During visits to the emergency department when her children were injured or severely ill, Natalie often gets this impression

<sup>&</sup>lt;sup>24</sup> As informed by the participant, Strawberry Birthmarks may form in airways, hence obstructing breathing. Strawberry Birthmarks that form on eyelids or around the eye may impact the individual's vision.

from hospital staff. She recalled the tendency of medical professionals to ask if the child's immunisations are up to date, and their apparent disapproval when she informs them that the child is not immunised at all:

Interviewer: Is it frowned upon? Natalie: Yeah, [from] some of them it is. Interviewer: Do they think you're a bad parent? Natalie: Well I guess being a nurse they're pro immunisation, so yeah, probably.

In New Zealand, it is mandatory that parents make a decision about whether or not to vaccinate their children, but vaccination is no longer compulsory (Dew, 1999). Despite this, participants continue to feel pressured to vaccinate their children. Dew (1999) noted that parents must continually justify their decision not to immunise their children, as the choice is often constructed as irrational or selfish.

Natalie made the decision not to immunise her youngest two children after careful consideration of the risks involved. Seeking medical advice and engaging in independent research (typically on the internet) allowed Natalie to make what she considered an 'informed decision' regarding immunisations and her children's health: "Now I wouldn't ever just immunise my kids without ever researching it". In discussing her decision not to immunise some of her children, Natalie stated:

I really did [the second eldest] because [the eldest] was and I hadn't really questioned it . . . And then with [my chronically ill son] I did a lot of research and he hasn't had a lot, well he hasn't had any of them . . . . Then with [the youngest] I'd done a lot of research so I decided against immunising him . . . . So I've got two fully immunised and two not. So we'll see. Out of the four, the two healthiest are one immunised and one not. Following substantial media controversy regarding the safety and efficacy of the Meningococcal B vaccine, Maddison also engaged in research around immunisations. The incongruence of media reports (see page 86) gave the participant further reason to doubt the benefits of immunisation:

Interviewer: So you trusted the media when that was on there? Maddison: Well the media, and then I did some research on that one, on Menz B. I got as much information that I could. And I just made up my decision for myself to not give my kids the Meningococcal [vaccine].

As well as the information they gathered through research practices, personal experiences have impacted Natalie and Maddison's decisions. For example, following an allergic reaction to a 15 month immunisation given to her daughter, Maddison decided against immunising her younger son: "I will give him under the 15 month [immunisations], but I won't give that to him". As previously discussed, Natalie's son suffered from swelling in his arm following a Meningitis immunisation. By refusing to immunise their children, Natalie and Maddison highlight the competing perspectives of care prevalent in everyday life. In addition, their practices reflect how prevailing medical knowledge may be "modified and subverted in part by what people do in their private lives" (Carrier, 1995, p. 8).

### Alternative gift transactions

Although medications are commonly implicated in responses to ill health and the maintenance of health, it is apparent that parents look outside the use of medications altogether in caring for their children (Evans & Thomas, 2009; Gunnarsson & Hydén, 2009). Diet and good nutrition were cited by most participants as one way of maintaining good health for their children. Maddison identified the contents of everyday foods as a substantial risk to her children's health and wellbeing:

I look at all the things, the shows that come on Television, you know, 'What's in our food' and all that sort of stuff. And it tells you all this stuff that's in your food and you're like 'whoa I'm feeding that to my kids'.

In response to this concern, and the diagnosis of her daughter's lactose intolerance, Maddison began to purchase organic food products. By gifting her children these food products, Maddison attempts to maintain her children's health through their diet. In her diary, Maddison expressed interest over an article she came across in a magazine, which claimed that a diet high in vitamin D may assist with weight loss and reducing asthma allergies. Diet was hence perceived as one way for reducing medication use: "I thought it was quite good. Maybe I can reduce their medications and give them more of this [vitamin D] or find it in a pill form or syrup or something like that". Sarah also made efforts to ensure that her children ate "pretty healthily" to help keep them well. In Sarah's household, diet was considered a source of wellbeing as well as a way to hide medications: "I tried to give [chronically ill son] some flaxseed oil like that. He wouldn't take it off the spoon so I put it in his weetbix, but because it is an oil, you could kind of see it".

Some participants hold very strong beliefs regarding the health benefits of breast feeding. Both Olivia and Sarah consider breast feeding as an effective way of minimising the potential health problems arising from the use of formula milk:

It's the right thing to do. You don't get the kids being constipated. You don't get any of the complications you can get with formula . . . You can get allergies, you know, constipation, huge weight gain . . . Babies that are breast fed are a lot slimmer than the babies that are bottled.

Sarah noted that there are "natural antibiotics in breast milk" that are important for an infant's health. While contributing to healthy physical development was a key motive for breast feeding her children, Sarah also argued that the practice aids emotional development: "It's a nurturing thing. I think children are different for it. It becomes a big bond". Sarah explained that breast feeding involves the 111 gifting of a substantial amount of time and effort, which can make this a hard practice for all mothers to engage in, particularly those committed to full or part time work. She also understands that not all mothers are physically capable of breast feeding their children, and feels sympathetic towards those who are unable to: "I feel sorry for people that can't breast feed and they really want to". This was almost a reality for Olivia, who experienced difficulty with breast feeding. The use of Domperidone four times daily in order to produce enough breast milk represents a form of "maternal self-sacrifice" (Singh, 2004, p. 1194). As Olivia said: "The thing is, I know that I may get sick of taking it, but I'm taking it to benefit him".

Since identifying differing discourses, or competing constructions of care, is an important focus in this chapter, it is necessary to highlight the relevance of maternal discourses underlying participants' breast feeding beliefs. Breast feeding is closely tied with notions of 'good' mothering (Malacrida, 2002). The inability to breast-feed, or decision not to breast-feed, are commonly correlated with inadequate mothering, and sometimes the point of blame for children's developmental problems (Malacrida, 2002). Breast-feeding is integral to mothers' adequacy as care givers of their children. Olivia described the first two weeks waiting for the medication to take effect as "pretty rough": "Out of everything with my pregnancy and birth and all of that, the one thing I really wanted to do was breast feed". It appears that the health and wellbeing of mother and child are particularly paramount in post and prenatal periods. When Sarah was pregnant, for example, she refused to take medications herself:

Sarah: I didn't take anything. I wouldn't even take the pills that she gave me for morning sickness.

Interviewer: Why not?

Sarah: I was too scared something would happen to my baby. I just wouldn't. Mmm. I'd just rather put up with vomiting every day than [my child] having some form of defect or something like that.

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Again, this dialogue highlights emotional experiences connected to the health and wellbeing of their children. Sarah refused medication out of fear that this would harm her unborn child in some way.

Keeping her infant chemical free was another effort made by Olivia that she hopes will reduce the risk that he will develop eczema. Although the midwife only recommended it for the first month of her son's life, Olivia has kept the practice up: "[My son] is still chemical free basically. He has no soap. Like if he has a nappy rash that's all organic". She also does not use baby wipes on her son, preferring to utilise natural cloths instead. Alongside refusing medications and eliminating unnecessary medication use, engaging in these practices allowed participants to contribute to the health and wellbeing of their children without relying on medications. As noted in chapter one, parents commonly consider diet and prolonged breastfeeding as caring parental practices (Gunnarsson & Hydén, 2009; Malacrida, 2002). These gift transactions indicate that parents consider lifestyle factors and think ecologically about health maintenance (Gunnarsson & Hydén, 2009), instead of simply relying on medications.

Vuckovic and Nichter (1997) proposed that medications have come to "substitute" care for children, but the findings of the current research do not indicate 'substitution' as such. Participants involved in this research were all full time mothers, so it is difficult to determine how medications may be utilised in households experiencing the pressure of two working parents, assuming that there are differences in medication practices across these population groups. What these mothers demonstrate, is that medications have not come to substitute care and affection, but they have provided another mechanism through which these emotions can be communicated. For children, some of the most pertinent recollections of being cared for when they are sick include their mothers tucking them into bed, giving them a hug, or stroking their forehead (Bush et al., 1996). Such physical actions are also a way in which mothers may care for their children alongside medication use.

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## **Chapter discussion**

Previous research has pointed to the way in which medications have become vehicles of care and affection in parent-child relationships. The current research has contributed to this understanding, demonstrating how the provision of medications may resemble a gift transaction that intends to reduce or eliminate suffering, or prevent future illness and disease. The physiological and psychological effects of medications make caring real and tangible (Hodgetts et al., 2011; van der Geest et al., 1996). Medications may help ill persons to gain a sense of control over their everyday life (Conrad, 1985), achieve academic aspirations or social goals (Malacrida, 2004), or relieve pain. As such, medications are a valuable tool for expressing care and affection towards children. For parents, seeing their children sick is a distressing emotional experience. Participants' described this as the "worst" time and sought to make their children better and reduce their suffering. This was commonly achieved through medication use.

The analysis of participants' medication practices revealed that medication gift exchanges are sometimes the subject of intense scrutiny. In some instances, it is easy to identity the preparation and selection effort exerted by parents. This chapter discussed examples such as Natalie's efforts to protect her children from the trauma of school immunisations, the participants' care in administering medications or documenting medication use, and the time invested in researching medications. At other times, medication practices are mundane in the context of everyday life. Participants sometimes struggled to describe medications (such as Panadol) are particularly familiar in the households studied. With these medications, the usual caution surrounding medication use seems to be largely absent. The mundane use of medications in everyday life reveals that caring may be routine in nature, as well as a conscious and deliberate act. While routine medication use may appear to be automatic or mundane, it can also be complex. Notably, routine medication practices are likely to have arisen over time, reflecting participants' existing medical knowledge and experiences, rather than being novel responses to ill health. Routine medication practices may also reflect participants' confidence in medical knowledge, and belief that benefits entailed in medication use outweigh risks. Constructions of 'care' may be informed by medical knowledge. Nonetheless, it is also apparent that there are differing perspectives concerning what constitutes 'care'.

Participants' expressions of medical resistance demonstrate their ability to challenge medication recommendations and advice. To varying degrees, participants may resist medication use, commonly due to fear of medication side effects and dependency. Participants sought to eliminate or reduce medication use in the following ways: delaying going to the doctor; only administering medications when absolutely necessary; refusing medications; utilising CAM; and considering lifestyle factors such as diet. These practices show that while providing a medication may be constructed as caring, resisting medications can also constitute care. Their refusal to medicate in certain cases also indicates the agency of parents as they navigate complex fields of information concerning medications and health matters for their children and themselves.

When parents refuse a medication this is usually not a straightforward case of active resistance to medical conventions. Deciding whether or not to medicate their children entails a complex process whereby parents carefully consider their own experiences, medication beliefs, and medical expertise; and reflect on the ongoing enactment of familiar and routine medication practices. Whether parents' resulting decisions are beneficial or detrimental to the health and wellbeing of their children is not a conclusion that can be drawn in this thesis. As perspectives in this chapter highlight, there remains dispute around the safety and efficacy of some medical treatments, including, but not limited to, immunisations and stimulant medication use. What is apparent is that parents express the best of intentions in their attempts to care for their children. The desire of parents to make decisions in the child's best interests is a recurring theme in participants' accounts. The decisions made by parents are also an integral part of their identity as responsible care givers. The impact of gift exchanges on parental identity and relationships is the focus of the following final results chapter.

## CHAPTER FIVE: IDENTITY AND RELATIONSHIPS IN MEDICATION USE

Bonds to other people are negotiated, in part, through the exchange of material and social objects (Schwartz, 1967). In his study of so-called 'archaic' Polynesian societies, Mauss (1950) noted that gifts were important for the maintenance of social hierarchies, and documented how the sharing of good fortune between a chief and his tribe helped to preserve his status. Furthermore, gifts were used ceremoniously to mark a number of events such as births, deaths, and marriages. These gifts established or maintained kinship links between various individuals, such as in marriage rituals where "presents put the seal upon marriage and form a link of kinship between the two pairs of parents" (Mauss, 1950, p. 19). Gifts can communicate various sentiments because they are not transacted between isolated individuals; instead, the gifted object is a manifestation of a social relationship where "the object given continues to be identified with the giver and indeed continues to be identified with the transaction itself" (Carrier, 1995, p.20).

Whether modern Christmas giving rituals, or the exchange of goods in preindustrial societies, gift exchange literature provides many insights regarding how exchanges impact the social relationship between transactors (Carrier, 1993, 1995; Mauss, 1950). Acceptance of a gift regenerates the relationship between individuals in gift transactions (Carrier, 1995). While gift giving may reinforce social identities and strengthen a relationship between transactors, it may also challenge or modify social relations (Carrier, 1993, 1995; Mauss, 1950). In the context of health and medical related behaviours, participants have many relationships that are directly impacted through the exchange of concrete objects (medications), as well as the social transacting of knowledge and information.

As primary care givers of their children, parents often feel pressured and assessed (on both individual and societal levels) on the matter of their

competence as carers of ill children. Existing literature documents various ideals and discourses around what constitutes a 'good parent' (for example, Gunnarsson & Hydén, 2009; Malacrida, 2002; Singh, 2004). Briefly, the notion of a 'good parent' aligns with the ability to find solutions to their children's medical problems (Singh, 2004), and respond to health needs quickly, adequately and responsibility (Gunnarsson & Hydén, 2009). Doing so is integral to the maintenance of parents' identity as responsible and informed care givers. The example of mother-blame in chapter one demonstrates how pervasive these discourses are, as on a personal level, the inability to solve their children's health problems is perceived as a reflection of their own inadequacy as a parent and care giver (Blum, 2007; Singh, 2004). As "magic bullets" (Williams, Gabe, & Davis, 2008, p. 816) for innumerable ailments, discomforts, illnesses, and diseases, medications provide parents with a modern solution to these parental caring pressures (Vuckovic & Nichter, 1997).

The participants involved in this research identified numerous roles that they assume throughout medication practices as part of their responsibility as parents and care givers of their children. The roles participants describe include that of the researcher, advocate, observer, dispenser, consumer, and gate keeper of medications. As asserted by Doran and colleagues (2005), individuals "are at the very least consumers and patients, but they also fulfil other roles (eg. parent; employee), and their medicine related behaviours emerge from the interplay of their many roles" (p.1442). Enacting these roles entails innumerable tasks and responsibilities, such as taking children to the doctor or hospital, communicating health needs or concerns, obtaining medications, ensuring safe medication use, dispensing medications, and observing children to determine their health and medication needs. Many of these practices are explored in previous chapters, but here assume particular importance for the way in which they maintain participants' identity as care givers for their children. This chapter explores each of these roles involved in everyday medication practices. Firstly, however, it is

important to discuss the impact of parental knowledge and intuition on these roles.

# Intuition and medication practices

Medical decisions made by care givers on behalf of their children are impacted by parental knowledge and intuition, both of which are becoming recognised as important sources of information regarding the health and wellbeing of children (Callery, 1997). Many of the ensuing descriptions of roles enacted by participants allude to their instinctual feelings about their children's health and medication use. The previous chapter explores how medication practices invoke a vast array of emotional impulses and experiences for participants; "gut feelings" or "maternal knowing" certainly account for some of these. An integral part of participants' overall role as care givers of their children involves listening to and acting on intuitive knowledge (for another example, see Lauver, 2008). As participants' experiences indicate, ignoring intuitive knowledge could in fact be detrimental to the health of their children. Maddison, for example, had misgivings about giving her daughter the 15 month immunisation, which were confirmed when her daughter had an allergic reaction:

I was very sceptical about giving [my daughter] her 15 month immunisation. I was really paranoid [about it] just because I knew quite a few children, even [my sister's] kids, who had reacted to it. And I thought 'oh I, you know, I wonder. I wonder if she will react to it'. And yeah, sure enough she reacted to it. I felt like I should have listened to my gut instinct and not given it to her.

Regardless of the accuracy of intuitive knowledge, participants' experiences reveal that it is sometimes difficult to substantiate intuitive knowledge against prevailing medical knowledge. Previous research has indicated that parents' intuitive knowledge can be met with scepticism from medical professionals (Callery, 1997). Supporting these findings, both Olivia and Sarah have experienced instances where they felt that a doctor thought they were "crazy" or a "neurotic mother" regarding health concerns they held for their children. When Sarah first noticed there was something "wrong" with her son's head she immediately sought medical advice. At first, medical professionals did not share the same concern. Sarah claimed that the doctor "thought I was fucking crazy and there was nothing wrong with his head". Similarly, Olivia described "knowing" something was wrong with her son when his Strawberry birthmarks began developing, despite medical professionals sometimes disregarding this intuited knowledge: "I had a doctor tell me I was a neurotic mother and it was just my hormones. I haven't gone back. I refuse to".

The dismissive remarks of doctors induce a range of emotional reactions including humiliation, frustration, rage, and fear. For both Olivia and Sarah, however, their ongoing persistence with medical professionals that something was "wrong" paid off when it was later confirmed that their intuition and observations were correct. These examples illustrate that there can be value in considering a mother's intuitive knowledge.

For participants, intuitive knowledge is often conveyed as an emotional and embodied event, for example, a "gut feeling" or instinctual "knowing". Examination of these experiences, however, reveals that they are grounded in observation practices and medication understandings. For example, Olivia and Sarah's intuitive experiences stemmed from their identification of physical changes in their son's conditions (such as the development of marks on the skin, or an abnormal skull shape). In addition, Maddison's earlier highlighted concern about her child having the 15-month immunisation was based on her knowledge that many other children had reacted negatively to the medication.

Bajcar's (2006) research indicates that individuals are able to readily accept medication or illness diagnoses when there is "a sense of coherence between his

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or her internal experience and the information that [is] received externally" (p.67). In these instances, corresponding emotional experiences might include feeling "untroubled" or "comfortable" about medical directions (Bajcar, 2006). On the other hand, when information provided by medical professionals conflicts with existing medication understandings, beliefs, or expectations held by lay persons, a heightened need for information is experienced and lay persons are more likely to query or challenge medical professionals (Bajcar, 2006).

Bajcar (2006) asserted that querying or questioning medical direction is simply a process through which individuals make sense of medications and come to terms with their use in daily life. Similarly, challenging medical direction or asserting intuitive or parental knowledge represents the attempts of participants' in the current research to reconcile conflicting medication beliefs or understandings. Again, such actions are closely linked with emotional experiences. For example, it is common for lay persons to feel both anxious and uneasy when conflicts occur (Bajcar, 2006).

Drawing from previous research as well as empirical materials generated for this study, it is important to acknowledge that parents' intuitive assertions are usually bound with publicly observable physical symptoms, and a parent's existing medication understandings. Intuitive assertions are complex and multilayered, and not simply emotional experiences resulting from neuroticism or over-protection.

# Enacting roles in medication use

Exploring the roles participants engage in throughout their medication practices from a gift exchange perspective has been valuable for the analysis of transactions between parents and children, as well as between parents and friends, extended family members, or health professionals. All of these social actors are sources of information utilised by participants whilst forming their medication understandings and making medical decisions. Furthermore, all of these individuals are involved in the ongoing advocacy of children's health and medication needs performed by participants. Consider the following quote in which Sarah recounts her parenting role:

Sarah: I'm the one person that gives them the medication or fixes them up.

Interviewer: Would that change between different places? Like at the doctors there, [name removed], what would your role there be? Sarah: I'm the parent taking the child to the doctor telling him what's wrong. And then he's giving me the advice. Or giving me the medication that I need.

Interviewer: . . . How does your role change then? Sarah: Well I'm not the one that's got the degree. I'm not the doctor. I'm the parent. Interviewer: What about somewhere like the Health Shop? Sarah: I don't take the kids in there. I just go in myself.

Interviewer: So you're a consumer there?

Sarah: Yeah . . . If I'm going in there like for health, like for vitamins and that, for the kids, I'd be going in there as a parenting role.

This excerpt illustrates a number of key themes central to this thesis. Of relevance to chapter three, this excerpt reiterates how biomedical knowledge pervades lay understandings of medications. For example, Sarah perceives doctors as trustworthy experts of the medical field. In comparison, she positions herself as a medical amateur; a parent or care giver of the child educationally distinct from medical professionals (who hold the 'degree'). Thus, she continues to legitimate the authority and knowledge held by medical professionals.

Sarah identifies the home as a space of care for her children; a therapeutic landscape (Gesler, 1992) in which she "fixes them up". But moving beyond this

private space into the public, she also identifies professional spaces of care such as doctors' clinics, which are conventional sites for the provision of medical care and advice. Of particular relevance to the current chapter, the participant demonstrates how parenting or care giving involves the enactment of various roles in both the presence and absence of children. Furthermore, these roles are performed across multiple environments. In this short excerpt Sarah points out the many roles she assumes as a parent: her position as medication gate keeper and dispenser ("I'm the one person that gives them the medication or fixes them up"); observer and advocate ("I'm the parent taking the child to the doctor telling him what's wrong"); and consumer (buying vitamins in the 'Health Shop'). In addition, participants also describe the researcher role, which has already been explored in some detail in the previous chapter.

#### Researcher

There are numerous functions of the researcher role, many of which are highlighted in the previous chapter. These include how research: contributes to parental decisions around medicating children; may help to reduce uncertainty about medication use; and is a fundamental aspect of parents' selection efforts entailed in medication transactions. Bajcar (2006) has also documented that researching is central to how individuals make sense of medications, and claims that individuals have various information needs. As earlier highlighted, this is especially so when individuals are confronted with information that contradicts existing knowledge or experiences. Bajcar (2006) refers to such situations as a 'problematic-mode' that provokes further information gathering in efforts to reduce inconsistencies and "make sense" of medication taking (p.73). These points are all central to understanding participants' engagement in the researching role. In this chapter, there is a focus on how the research process involves social interactions with others, and thus has a direct impact on relationships between participants and other social actors; as well as the participants' own identity as parents and care givers of their children.

The act of research may be understood as a way in which parents maintain their identity as morally responsible and informed care givers, "doing everything they could and should" to care for their ill children (Gunnarsson & Hydén, 2009, p. 170). This role demonstrates participants' active engagement in medication choices, and the desire to make the best possible decisions on behalf of their children. As Maddison highlights, engagement in the researcher role allows parents to manifest care and protection of their children: "... If it was something for the kids I might, I might be a bit sceptical and I'd do a lot of research on it. Mainly because I want to protect them".

There are many sources of information that participants rely on for medication advice and recommendations. Whom the participants choose to interact with, and whom they will accept transacted knowledge from, shapes their relationships with informing social actors. Both Natalie and Maddison, for example, describe how they would not necessarily trust a pharmacist's advice, and would seek a second opinion before purchasing a pharmacist recommended medication:

Natalie: Pharmacists . . . some of them are pretty good. The main one that is normally behind the [counter] doing the drugs up is pretty good. But sometimes I think they're just trying to sell a product.

Maddison: [I would trust a pharmacist] on creams. Nothing orally probably. I would rather leave that up to the doctor. If it was from a pharmacist, I would get a second opinion.

Direct-to-consumer advertising is another source of information about medications that is generally met with scepticism from participants. Participants had diverse opinions on whether DTCA is harmful or useful. Some thought that it

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was unnecessary to have medications infiltrating private home environments through various media, while others do not consider this harmful. Sarah, Maddison, and Olivia agreed that DTCA can serve an educational purpose:

Maddison: . . . It just shows you that there is a variety out there . . . I guess it gives you the benefit of whether you want to try it or not and if it works for you, it works for you, and if it doesn't, it doesn't. But there's that opportunity.

Educating the public is often cited in support of DTCA in broader societal arguments concerning the value and effect of DTCA (Wilkes, Bell, & Kravitz, 2000). Although DTCA may hold some educational value, this does not necessarily infer that participants are likely to head out and buy the medications they have seen advertised. While advertisements or infomercials may spark an interest in a particular product, participants demonstrate their agency and responsibility by seeking additional information. For instance, Olivia stated that she "would have to get somebody else's opinion on it too". Such actions confirm that participants are not simply passive consumers of advertised medications. This is a pivotal finding for interpreting participants' medication experiences and understandings, and a central point for the discussion chapter. Maddison highlights agency and personal choice in the following quote about DTCA:

I can't see the harm in [DTCA]. It's up to personal choice whether you take [a medication] or not. So, what's the problem, you know? It's not like you are being forced to take it.

Although DTCA is a widespread information source in New Zealand, according to these participants, DTCA has not gained the trust and legitimacy attributed to medical professionals and other experts (whether professional or familial). The products advertised on television were thought to entail increased risk in comparison to those recommended by a doctor, who can professionally vouch for medication effects and efficacy. As Maddison stated: You have to think 'right', you know, 'is this the right option to go down?' You've really got to watch . . . . The last thing you want to do is make your kids sick by some cool infomercial on television.

By verifying medication side effects and efficacy with a credible source, participants are able to minimise risks in their children's medication use. Although DTCA and the internet are identified as research resources, these sources do not provide the ongoing personal relationship that can be maintained with doctors, family members, or friends through social interaction. Television advertisements only allow for information to be exchanged in one direction, and hence lack the fundamental reciprocity of exchange that affords personable and meaningful interaction. This point is emphasised by Olivia, who asserted: "I'm not just going to take the TV's opinion. It's a talking box!" Actors or actresses on television advertisements are perceived as both unreliable and inexpert informants. In her diary, Natalie recorded that she viewed a Dimetapp<sup>25</sup> advertisement on television and offered the following opinion on it:

Natalie: [The Dimetapp ad is] with that Bridie whatever her name is. Interviewer: From McLeod's Daughters<sup>26</sup>? Natalie: . . . Endorsement, yeah. People are like 'well she gives it to her kids and she's a famous star off McLeod's'. Interviewer: But would you trust her? Natalie: No because she's getting paid to say it [laughter]. She'd say whatever. If the opposing drug company offered her more money she'd probably go with that one and say that one is better.

Natalie demonstrates an ability to think critically about information presented to her through media, and shows that evaluating which sources are deemed

<sup>&</sup>lt;sup>25</sup> Natalie perceives Dimetapp as a cough medicine. Dimetapp is most commonly used as a decongestant or to treat symptoms of allergy (Drug Information Online, 2000-2011a).

<sup>&</sup>lt;sup>26</sup> An Australian-made television drama series (ninemsn Pty Ltd, 1997-2011).

credible and which are not is an important part of the researcher role. As participants navigate through an overabundance of information about medications, the selection efforts exerted to make the 'right' decision for their children must also entail distinguishing between 'legitimate' and 'illegitimate' sources of information. Vuckovic and Nichter (1997) use an interesting term— "information anxiety"—to describe the anxiety felt by individuals when they are forced "to sort through the huge influx of information delivered by the media" (p.1298). This can be a confusing and daunting process that often leaves the impression that "everything is harmful" (Vuckovic & Nichter, 1997, p. 1298). These insights offered by Vuckovic and Nichter are useful for gaining an understanding of the stress felt by participants as they do their best to research possible medication choices and maintain their position as responsible care givers.

Participants' responses reveal that sources of information vary in their perceived level of credibility. As highlighted in gift exchange theory, gift transactions are characterised by the unique and enduring relationships between transactors (Carrier, 1995). Participants returned to their Family General Practitioner on multiple occasions to convey medical concerns and gain advice. Unlike the information received through DTCA, such exchanges are not carried out in an impersonal way, but rather in the context of trusting and 'close' relationships. Participants have even been known to 'follow' their trusted family GP as they move from clinic to clinic over their medical career. Accordingly, participants were less likely to accept information about medications from non-medical professionals with whom they had little or no connection. As Olivia stated: "... If it was for something for [my son] and somebody who didn't have kids said 'oh you should try this' then I wouldn't. I wouldn't trust somebody I didn't know".

Participants were less likely to question advice or recommendations from a pharmacist if they had a longstanding relationship with that person. Maddison's familiar relationship with her local pharmacist means she feels more comfortable

about purchasing medications from him: "Well we've always gone there since I was a kid. Because our doctors have always been around there and my Nana and Grandad just live down the road. So we've always gone there". In exploring individuals' various informational needs, Bajcar (2006) revealed that:

When participants had a high level of trust in the health care system and their health care provider(s), they tended to require less information for a situation to make sense, and for them to be willing to take their medications. (p.73)

Bajcar's (2006) findings reconcile well with a gift exchange perspective. Her research shows that the type of relationship between patients and health care providers impacts an individual's readiness to accept knowledge or medication recommendations. Similar to gift exchange theory, Bajcar has emphasised that familiar and trusting relationships promotes the acceptance of physical or social objects between transactors.

In their search for information, the participants in the current research sought interactions with familiar and trustworthy people, but also people who were considered to have expertise or experience. For instance, in determining who she would not trust, Maddison stated:

Probably people that don't have children [laughter] . . . And people that haven't had children that have got the same symptoms I guess. I would trust people that do a lot of research on [the medication or illness in question] I guess. And then I would make my decision and I would do research myself.

When social actors are considered by participants to be credible and expert sources of information about medications, relationships are effectively regenerated though the ongoing exchange of information and knowledge. Accepting information serves to reinforce the relationships between participants and medical professionals, or other trusted family members or friends. Of course, it is important to acknowledge that gift exchanges between these individuals are reciprocal. As well as accepting knowledge provided by others, participants have an expectation that their own knowledge will be accepted when it is transacted to others. "Patients' become 'prescribers'" (Helman, 1981, p. 527) when both information and drugs are shared inside social networks. Such role reversals highlight the need for individuals to act as both givers and recipients in exchanges of information and objects between social actors (Helman, 1981). In another relevant example, Callery (1997) explores how mothers transact their maternal knowledge relating to their children to medical professionals, and how the exchange of maternal versus medical knowledge can be the root of conflict or co-operation. In the current research, participants' experiences demonstrate that relationships are more effectively maintained when medical professionals value and accept the maternal knowledge offered by mothers of sick children (see 'Observer').

Seeking second opinions and rejecting knowledge are actions which weaken ties between participants and informants. For the participants, feeling as though their maternal or intuitive knowledge is dismissed by medical professionals impacts the sense of 'trust' participants hold in the medical professionals, effectively resulting in the termination of doctor-patient relationships. While 'trust' and 'intuition' are abstract concepts, they impact relationships in tangible ways. Despite such instances, participants were not inclined to reject biomedicine and the role of health professionals entirely. Instead, they simply sought more engaged and sympathetic health providers.

## Advocate

Acting as an advocate for their children's health needs and ensuring safety around medication use is an important component of participants' role as the main care giver of their children. Participants step into the advocacy role in clinical settings with medical professionals, but also in household settings involving other family members. For example, on one occasion Maddison's daughter acquired some anti-inflammatory cream that had been left in a bedroom. Maddison's diary documents this event, including how she spoke to her sister about leaving medications around the home. Her diary entry reads:

I also had to remind my sister of safety with meds and creams as my two year old found a tube of deep heat used to relieve muscle pain. She was lucky she didn't put it in her mouth as it would have been dangerous . . . My sister was surprised she had found it and was going to be more careful where she hid things in the future.

The placement of medication in the home is a real concern for each participant, particularly when other individuals enter the home carrying unknown medications that are transited through their handbags or vehicles. The household maps (Appendix A) and photographs in Figure 5 indicate that medications are stored in specific sites around the home:

*Figure 5* Photographs of medications stored in the kitchen in high cupboards that are out of reach of children



Sarah described how when her grandparents visit her at home she immediately asks them where their medications are, and takes direct action by moving them to a high location inaccessible to children. Olivia discussed how she intends to address her household members regarding where medications are stored, particularly as her son gets older and becomes more mobile:

Obviously as he starts walking it is definitely going to be something that's going to have to be discussed. We've just had to change around the whole house because he's crawling. My Mum's got bits and pieces everywhere. But it's going to be something that's going to have to change.

Many expressions of advocacy on behalf of the child are also enacted between participants and medical professionals. For example, taking children to the doctor and communicating the health problems they are encountering is one form of advocacy recognisable in participants' accounts. Olivia described how when her son is ill she will "go to the doctor and tell the doctor what's wrong, they work it out and then you go and get your script". This quote denotes the advocacy role in that Olivia communicates health concerns on behalf of her son. The quote also illustrates Olivia's perception that the doctor is responsible for finding out "what's wrong", and expectation that the doctor will offer a solution. Additionally, the quote highlights the tendency to associate doctor-patient interactions with the acquisition of pharmaceuticals in response to health ailments.

The advocacy role is considered especially important for those young children who are unable to accomplish the communication of health concerns independently. As Olivia explained:

[I] tell them what's wrong with [my son], because obviously he can't speak for himself. So there's quite a big parenting role played [in the advocacy role]. Especially when they're this age . . . . All of it is parenting really. Taking a child to the doctor to communicate health concerns or simply to check the progress of previous health complaints is a commonplace and often automatic response to issues considered severe enough to warrant medical attention. As previously highlighted, participants' descriptions of these processes emphasise the routine nature of many household medication practices, including visits to the doctor. As we learn from Filc (2004), physicians occupy a hegemonic role in the health-care system and "their tasks stand at the centre of health care practices" (p.1276). It has long been recognised that doctor-patient interactions involve power dynamics that have historically favoured doctors as individuals of greater authority in determining medical diagnoses and treatment options. Some of the participants' interactions with medical professionals reflect this relationship. For instance, the participants often readily accept medications prescribed by the doctor (see 'Medical professionals'), reinforcing a doctor's position as an expert. Accepting the knowledge and treatment recommendations gifted through doctor-patient interactions also maintains participants' identity as their children's care giver. As explored in the previous chapter, there are competing perspectives of care. Embracing biomedical responses to illness is common, but it is also one of a range of possible actions that constitute care for children.

Taking a child to the doctor, however, is not always as straightforward as participants' descriptions may suggest. Participants' anecdotes reveal that conflict can arise in interactions with health professionals. Such conflict is most common in emergency situations, particularly those contexts in which participants have little or no previous experience to inform care giving decisions regarding their children's health. For instance, in one situation Sarah had no idea what was wrong with her daughter, so she sought medical consultation several times in her effort to find out and seek a solution:

I had been to [the local hospital] twice with her. I couldn't get into our doctor because he was away there was only one doctor on . . . I didn't

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know [what was wrong] . . . They said 'no I don't think it is measles it looks like some kind of virus'. So I said 'I'm sick of you fucking telling me it's a virus! Find out what's wrong with her'.

Sarah's use of explicit language, as well as increases in the volume and pace of her dialogue, reflects the stress, frustration, and desperation she experienced during the medical emergency relayed above. On another occasion, Sarah's son was undergoing a lumber puncture to ascertain what was wrong with him. When her son nearly fell off the bed during the procedure, Sarah recalled yelling at the nurse "what the fuck are you doing?" Again, this dialogue illustrates parental stress in situations of uncertainty.

Typically, medication use or medical advice can provide a sense of security in otherwise uncertain and 'scary' medical crises (Hodgetts et al., 2011). Such findings are certainly applicable to the participants in the current research, who tend to rely on pharmaceuticals to treat illnesses in dire health circumstances regardless of preferred medication practices (see 'Medications as material objects'). In Sarah's case, however, the medical conclusion that 'it is a virus and nothing can be done' is unsatisfactory and does not provide her with a sense of security. The advocacy role hence demonstrates the complex interaction between observation, maternal knowledge and medical knowledge that contributes to and intersects with participants' intuitive experiences.

Participants' interactions with medical professionals are aimed toward finding solutions to their children's health problems. Their repeated demands that medical professionals 'do something' about their child's medical condition, or 'find out' what is wrong provides a sense that they are doing something to help their child. As Sarah's situation suggests, "getting answers" is an integral element of the advocacy role. Likewise, Olivia described a scenario where her sister's son was unresponsive to medication and remained unwell with a urinary tract infection even after two rounds of antibiotics. Olivia explained that under the same circumstances, she would seek additional medical care for her son:

[If it were my son] I'd be taking him back . . . [I would be] asking questions and getting answers. Or I would be taking him to another doctor . . . . If that went on for another couple of days and he was diabolical I would [take him to the hospital].

As shown in the above examples, advocating on their children's behalf sometimes means rejecting medical conclusions. By doing so, participants reinforce their identity as experts of their children's health and wellbeing. While doctors can offer medical knowledge and treatment options, these are not always accepted by participants. Resistance to biomedical knowledge or treatment allows participants to challenge the power dynamic between 'patient' and 'professional', and assert their authority over the medication regimens (or other treatments) of their children.

#### Observer

Observation constitutes an integral part of caring for children. Observation enables parents to ascertain the overall wellbeing of their child, allows them to recognise if their child is experiencing any adverse medication side effects, and helps them to determine when medical intervention might be needed in the event of illness or injury. The ability to deduce a child's wellbeing through observation implies a familiarity with the child's typical or usual behaviour. This familiarity accounts for participants' intuitive insights into 'knowing' what is best for their children, and being able to recognise when something is wrong. Recognising subtle changes in behaviour or other developing symptoms of illness are abilities which demand close physical proximity over long time periods. When Sarah's daughter was hurt, for example, she stated that she "didn't let her go to her friends or anything like that". Maddison also keeps her children nearby to facilitate observation, especially when they are ill: "I usually keep them quite close to us . . . Instead of [them] being away out of my sight".

As documented in Callery's (1997) research, maternal knowledge is invaluable throughout the medical care of ill children. Callery described mothers as experts of their children's wellbeing, and his research involving mothers of children hospitalised in a surgical ward showed that mothers had a highly developed skill "in the assessment of their own children, including observation of subtle changes in their children's appearance and behaviour" (p.27).

The current research also suggests that mothers are competent observers of their children's behaviour. For example, Sarah detailed her daughter's condition after an incident when the garage door was accidentally closed on her head, noting in her diary that there were "no ill effects for the rest of the day":

It wasn't deep enough for stitches, and she didn't get knocked unconscious; she got knocked to her butt. She didn't start vomiting. So I ice packed her head and made sure she didn't go to sleep, basically . . . . I asked her a couple of times [if] her head [was] hurting, she didn't tell me it was sore. She was eating and drinking. She was fine.

This excerpt details Sarah's examination of her daughter's injury, her state of consciousness, and her subsequent eating, drinking, and behavioural patterns for the day. Assessments of these behaviours were central to Sarah's conclusion that her daughter did not require medical care. Maddison also described a scenario when her son was suffering badly from tonsillitis where observation allowed her to deduce that he required medical intervention: ". . . He was so, so hot. He was dripping wet. So [my partner and I] chucked him in the car, grabbed a flannel and a bucket and took him straight through [to the emergency centre]".

The importance of recognising and interpreting physiological and behavioural changes was further accentuated by Olivia. Her infant son is not at a

developmental stage that allows him to express any discomfort through dialogue, so she is particularly aware of physical indications of sickness:

Interviewer: So pulling at ears, is that something that you'd recognise . . . Olivia: Usually, yeah usually. Interviewer: What other things might they do that you're like 'oh there is something not right?' Olivia: [If they are] continuously grumpy. Swallowing as well, or the way they swallow. If they're crying when you give them a feed it's obviously to do with [the mouth or throat] area.

As well as indicating when children are ill or requiring medical care, observation allows participants to ascertain when their child is getting better. Olivia described the changes in her son's coughing patterns as an indication of his improving health and evidence that his antibiotics were taking effect:

... When he started taking [his antibiotics] he started doing real big coughs and then gagging obviously as the phlegm was breaking up and coming up. And he's stopped coughing and you could hear his breathing wasn't as rattily.

Observation affords participants' a comprehensive understanding of when their children's health is improving or deteriorating. Whereas doctors' recommendations and instructions reflect a general medical knowledge (Dew, 2001), participants hold intimate and idiosyncratic knowledge about their children. Such knowledge allows participants to make their own judgements about medication regimens. For instance, after a BMX accident where her son chipped his tooth, Natalie observed that her son was suffering: "Well he was crying so he was in a reasonable amount of pain. I think he was half in shock and half in pain because there was a tiny little bit of nerve exposed". To ensure that the pain remained well managed, Natalie was advised to administer pain relief to her son at regular time intervals for a number of days following the incident. Natalie stopped administering the pain relief prematurely, however, because she was certain her son no longer required it: ". . . He wasn't in pain. I wouldn't have [stopped giving it to him] if he was still in pain. It's just a drug so if it's not necessary then I wouldn't give it to them". This decision may reflect Natalie's concern about medication side effects and dependency, but also demonstrates her finely tuned awareness of her son's pain experience. In addition, the example reflects how "the prescription of medicines to children by their parents is sometimes more correct than the prescription to the same children by their doctors" (Vaskilampi, Garcia, Sanz, & Kalpio, 1996, p. 123).

There are differences between participants' observational experiences which point to how children communicate illness, discomfort or health in an array of ways. Sarah was able to overtly ask her child how her head was feeling, but other participants relied on identifying physical symptoms (such as an exposed nerve), or changes in behaviour (such as excessive swallowing). While these differences are certainly evident across different developmental stages, participants also assert that medication and illness experiences are idiosyncratic and vary from individual to individual (see 'Medical professionals'). In clinical settings such as hospitals or doctors clinics, this specific knowledge is transacted from participants to health professionals, reinforcing parents as experts of their children's wellbeing, and complementing the generalised medical knowledge held by medical professionals.

## Dispenser and gate keeper of medications

Each participant involved in this research assumes the role as gate keeper and dispenser of medications. Maddison, for example, asserted that "I give it to them. I always administer medication to them they don't touch it themselves". Although children in the households studied may occasionally ask their mothers for medication when they feel unwell, participants claim there is an

understanding amongst all their children that medications are only obtained through 'Mum'. As Natalie stated: "In our house I would always administer our medication, even to [the eldest]. He would come and ask for Panadol if he wanted Panadol". Sarah made a similar assertion, claiming that: "They know that is medicine and if you need medicine you must ask Mummy".

As the dispenser and gate keeper of medications, participants took responsibility for many tasks, including: acquiring medications from health professionals; storing medications in the home; determining when medications should be administered and doing so when necessary. These tasks also involve engagement in various other roles described by participants, such as the advocacy and research involved in obtaining medications, or the observation involved in determining when children require medications.

Engagement in the gate keeper and dispenser role is assumed by participants across many different environments, including private households and public sites of professional care. For example, when Sarah is at the hospital with her son, she described how she will still administer medications to him, even though medical staff are available to do this: "Any time that we've been in hospital and the nurses come in with medication in syringes I usually give them to him".

As much as Sarah would like to administer medications to her children under all circumstances, she did acknowledge that many procedures and decisions occurring in the hospital environment fall outside of her expertise as a parent and are hence better handled by medical professionals: "I'm not the professional, I'm the parent". Although participants are often required to relinquish the gate keeper or dispenser roles in medical settings, they continue to maintain their identity as care givers and parents of their children through other means. Maddison, for example, describes 'still being in control' of medication administration as she directs the medical care of her children:

I'm still in control. Because obviously if the doctor is going to give them any medications then they will say to you 'right this is what I think they should have'. [My daughter] reacted to her immunisation and as soon as the needle came out she started swelling already and I said 'oh this looks like a reaction to me' and the nurse said 'oh nah, nah, nah'. And I said 'she's reacting to this, I can tell she's reacting to this'. And [my daughter] was screaming and the nurse said 'oh I think we better go to the doctor' and I said 'yeah that would be a wise idea'. So we went through to the doctor and they said 'right we need to give her some antihistamine' and I said 'yup, nah sweet give her some antihistamine'.

In the event that participants are not with their children when they require medical attention, participants still to maintain jurisdiction over the administration of medications. As Sarah explained:

I'm the only person who gives it to them in the house . . . Even if I'm not here and they need it. Then [my partner] will ring me and say 'what do I need to do?' And then I'll tell him.

As this extract illustrates, other household members are likely to contact the mother to obtain permission or guidance on medication administration practices. This practice also applies, perhaps even more importantly, to individuals outside kin relations. When Sarah's child was injured at school, for instance, she said the school took the precaution of ringing her before administering any medication:

[My eldest son] got smacked in the head at school the other day by the gate. Yes they put an ice pack on his head, but they also called me straight away. Before they did anything else.

In this scenario, Sarah's role as gate keeper and dispenser of medications was affirmed. Participants expressed a sense of taboo or hesitancy around providing medication or any other form of medical care to children who were not their own. The potential risk involved in medicating other people's children may certainly impact this perception, but more so, participants emphasised how it is simply 'not their place'. The participants perceive the role as extremely personal, and an integral part of their duty as a mother. As Maddison stated: "I'm the 'Mum', I do that sort of stuff".

Previous research has indicated the tendency for mothers to enact care giving roles. In the research conducted by Jerrett (1994) and Bush et al. (1996), participants were predominantly the mothers of children. Although the researchers sought fathers to participate in their research, it appeared that mothers were more commonly responsible for the gate keeping and dispensing of children's medication. These findings suggest that medication giving is a particularly gendered role. In the following quote, Olivia's reasoning about her father's tendency to forget to take his medication assumes that the administration of medications is largely a female domain: "He doesn't have a wife to tell him when he has to do it".

Exploration of gender roles has some relevance to participants' accounts. For instance, in describing the rationale behind medication practices, participants sometimes claimed that practices have been learnt from their own mother. For instance, Maddison claimed that "It's what you get taught as you go along I guess". Olivia made a similar attribution, aligning her own medication practices, such as taking antibiotics at meals times, with what she has learnt from her mother:

Interviewer: Was that a direction? Olivia: It wasn't stipulated on there, but that's what I've always been taught, you take antibiotics after food. Interviewer: From? Olivia: From my Mum.

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Interviewer: Oh okay. So that is obviously a learnt behaviour? Olivia: Yup. One mother to another.

Participants feel that their identity as mothers requires them to carry out the numerous tasks and responsibilities discussed herein. On more than one occasion, Maddison described the tasks she completes around medication use as part of her "duty" as a mother. More often than not, however, participants' accounts allude to the practical and emotional grounds for gate keeping and dispensing medications.

Taking sole responsibility for medication gate keeping and dispensing is impacted by the availability of participants. As stay-at-home mothers or single parents, these participants are with their children for large proportions of their daily lives. For instance, Sarah assumes this role in her household partially because she is the one available to do so: "I'm always here anyway. [My partner] is at work". Consequently, this availability impacts participants' assessments of their own competence in this role. Some participants perceived themselves as "more observant" than their partners, or as more skilled at dealing with illnesses, complaints or emergencies arising in everyday circumstances. Given that each participant holds a comprehensive knowledge about their children's health and medication needs, such perceptions have some justification. Alongside competency, skill, and availability, participants' engagement in this role is also emotionally driven.

The previous chapter explored the sometimes negative emotional impulses encountered by participants whilst caring for their children. But as well as adverse emotional experiences, the participants feel an ongoing desire to be a (major) part of their children's medication regimens or other responses to illness. "Wanting" or "needing" to play this role are common emotional experiences amongst participants. Such emotional experiences are illustrated in Sarah's following quote: "I don't just let anybody do just anything . . . . I want to know,

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and I want to be there, and I want to do it". Despite experiences of stress, frustration or fear, by taking sole responsibility for medication gate keeping and administration, participants such as Maddison feel more certain and in control:

I'm very cautious of . . . other people giving them medications . . . . I just know that if I do it myself I know it's done right and if they have repercussions . . . if something happens to them at least I know that it's my fault. Not anybody else's.

Similarly, Sarah explained that she is the only one who dispenses medications in her household because she is a "control freak with stuff like that". Furthermore, Sarah commented that she is likely to experience negative emotions if she is unable to administer medications herself: "Oh I'm just so paranoid about it". It is clear that for these mothers, personally administering medications provides a degree of certainty that the task has been done correctly. These accounts illustrate that caring for children involves complex social, practical and emotional aspects.

#### Consumer

As part of their care giving role, participants are involved in the acquisition of medications for their children. This might involve going to the pharmacy, the health shop, or any number of sources where medications may be obtained, to purchase medications on behalf of their children. Maddison succinctly described this mundane process in the following quote: "Well I took [my eldest son] to the doctor and got some medication for him and then I went to the pharmacy and picked it up". The emotional dimension of supporting their children through health needs is a recurring theme in participants' accounts, but their discussion around the consumer role also points to a financial aspect.

Gift exchange theory provides a distinction between gift and commodity transactions that is useful for understanding participants' consumer role. Where gift transactions occur between individuals with unique and enduring relationships, commodity transactions are characterised by fungible <sup>27</sup> relationships and products. Participants are likely to be present as supporters when their children are receiving medical care, simultaneously however, they are consumers who assume responsibility for the payment of medication and medical services used by their children:

Interviewer: In the home . . . you're controlling [medication use], you're the gate-keeper of medications and you administer them. Natalie: Yup. Interviewer: When you leave the home and go to a doctor or an 'A and  $E'^{28}$ , what is your role then? Natalie: Hand holder! [Laughter]. And payer!

The initial response from Natalie about her role in a medical setting reflects the importance of the emotional and nurturing aspects of caring for her child. However, the economic transaction is also acknowledged, albeit somewhat humorously. The transfer of money is a routine feature in the process of acquiring medications. Nonetheless, viewing parents merely as a 'consumer' is problematic in that it negates the deliberation and thought put into medication purchases. Before making the decision to purchase a medication, commodity transactions are preceded by engagement in many of the roles explored herein. It has been well established in this thesis that participants do not engage with medications as though they are mere 'consumer goods'. Doran and colleagues (2005) claimed that medications are somewhat distinct consumer goods in that

<sup>&</sup>lt;sup>27</sup> Carrier (1995) uses the term 'fungible' to describe objects or individuals involved in exchanges that may be replaced with those of the same utility and value. For example, a fast-food outlet cashier is fungible because any trained and competent cashier can play the role in this transaction (Carrier, 1995).

<sup>&</sup>lt;sup>28</sup> 'A and E' stands for Accident and Emergency.

cost is usually a less important consideration in the decision to purchase a medicine. These findings are supported in the following excerpt:

Interviewer: Do you consider price when you're buying [medications]? Maddison: Not when it comes to my kids.

Participants' responses indicate that their children's health is of utmost importance, regardless of the financial burden required to achieve it. When Natalie was asked if price matters when she purchases medications for her children, she responded: "Not if you're getting a good quality product that does its job". It should be acknowledged that the price of medications or other treatments for illness are a barrier to health for some families (Creese, 1991; Nelson, Thompson, Bland, & Rubinson, 1999). However, the participants in the current study were fortunate enough to have not been in this position. The effect on parents who, because of limited financial means, are unable to provide treatment for their children would be a worthy research endeavour. Drawing from my own research, I can at least conclude that the inability to provide treatment for their ill children would be a very traumatising experience for parents, since providing treatments to reduce or eliminate suffering was clearly intrinsic to these parents' care giving identity.

The price of a medication allows participants to infer judgements about medication quality. In the consumer role at her 'The Warehouse', for example, Sarah relayed how she found some vitamins on special for only \$2.69 (a vast difference in comparison to the \$12.95 she usually pays for them). Due to the unusually low price, Sarah's initial reaction was that the item must be invalid in some way:

... When I saw them I thought 'that must be the wrong price'. So I scanned them [but] they were the right price. I looked at the date [and thought] 'oh they're not expired' ... When you see them like that you

think 'oh they must be expired'. [But] no, they've got a whole year so that's alright!

The association between price and quality was also evident in Natalie's description of Floradix. In comparison to tablet form vitamins she finds Floradix very effective: ". . . It's like, twice the price of vitamins though. So sometimes it's like, you get what you pay for". From a consumer perspective, these quotations show that the price of a medication can convey a sense of quality. Such findings are not new to social theory (see Veblen, 1899). Using price to infer judgements about quality is one way in which participants can cope with the overwhelming number of medications available.

The transfer of monetary value for the counter transfer of consumable goods is a commodity transaction that participants commonly encounter in their daily lives. Typically, people will buy food at the supermarket, pick up a litre of milk at the local dairy and pay for petrol at the service station. Despite familiarity with this role, choosing a medication from the overabundance of products available on the medical market is not simple matter. Other consumer goods often display a symbol or indication on packaging that allows consumers to easily deduce assumptions about quality, safety, or value. As noted by Natalie:

... With medicines you don't get a credence stamp. You know, like with pet food there's a certain symbol you can look for to know that its pet approved and hasn't got ash and all that crap in it. With heaps of things, like there's the heart tick on food, there's, you know, all that sort of stuff. But yet on medicines there is no approved stamp that you can look for. There is no 'okay well we've tested and tried this one and it gets this approval because it met all this'.... And then you could be like 'well yeah I'll pay a little bit extra for it because it's tested and it's supposed to be a bit safer, and it has been through some form of testing'. They have it for bloody pet food but they don't have it for human medication.

Natalie's observation highlights the disconnect between pharmaceutical drug development and testing phases and consumer impressions of shelved medicative products. Spilker and Cuatrecasas (1990) stress that the pharmaceutical industry is in many ways a closed world. Aside from the latest drug or disease 'fad' receiving substantial media attention, drug discovery and development, including clinical testing and regulatory approval of drugs, are phases of pharmaceutical life that are relatively shielded from the public eye. The participants hold a wealth of knowledge about the medications they utilise everyday contexts, but are comparatively uninformed about the in pharmaceutical lives of medications prior to their appearance on consumer shelves. Thus, there remains a sense of unease about standards of safety of medications. These concerns are not unwarranted, especially since "some severe side effects may not be uncovered for many years after a drug is marketed" (Spilker & Cuatrecasas, 1990, p. 54). Nevertheless, Natalie's perspective suggests that safety standards or testing completed on medications could be better communicated to the wider public consuming them.

# **Chapter discussion**

This chapter has explored the many roles participants assume throughout their transactions with medications. As researchers, advocates, observers, dispensers, gate keepers and consumers, participants enact the daily care of their children across multiple contexts with various medical and lay persons. In these many roles, the participants demonstrate agency in the navigation of the healthcare system. This chapter has conveyed that supporting and caring for their children is achieved through emotional, practical, and financial means. Medication practices are formed through a complex combination of parenting expectations, medication beliefs and understandings, and comprehensive parental knowledge and intuition of their own children's health behaviours.

There are many functions of the researcher role. Most importantly, this role enables participants to make sense of medications and reduce uncertainties surrounding their use. Researching aids parental decisions regarding medications for their children, and is an integral part of the selection efforts entailed in medication gift transactions. As researchers, participants gather information and knowledge that may conflict or complement their existing medical knowledge. Because of this, researching is implicated in participants' advocacy role, where they convey their own knowledge or concerns to medical professionals. Most commonly, advocacy involves reporting observations of health issues to medical professionals to gain medical direction or solutions. As care givers of their children, "getting answers" emerged as a significant goal in participants' social interactions (or transactions) with others. At times, this can involve conflict, particularly when maternal views differ from medical knowledge. Advocacy is also enacted in private domestic dwellings, where participants converse with other household members to ensure safety around medication use.

As well as researching, observing their children is central to participants' information gathering. Observation allows participants to draw many conclusions about their children's health and/or wellbeing. It enables them to deduce when a child's health is improving or deteriorating, when medical intervention might be required, or if a child is experiencing negative side effects (or no pharmaceutical effect) from a medication. As such, observation practices directly impact crucial medical decisions made by parents, such as when to obtain professional medical care or stop giving a child medication. These participants have demonstrated that non-compliance with medical direction can be a rational decision. Such decisions are founded on participants' expert knowledge of their own children's physical and behavioural tendencies. This knowledge should be more widely acknowledged and accepted.

As parents and primary care givers, these participants hold substantial control over the administration of medications to their children. This control applies even when participants are absent from their children, such as when children are at school or when participants are away from home. Participants' insistence that they alone should administer their children's medication is influenced by a myriad of factors. Firstly, this practice has practical grounds. In this study, participants were the individuals most available fulfil this role, as typically, they were home with their children on a day-to-day basis. This availability legitimates participants' assertions of their own status as experts of their children's medical needs and wellbeing. Secondly, administering medications to their children has emotional grounds. Participants feel more comfortable, certain or at-ease when they administer medications themselves and ensure this has been done correctly. Thirdly, the participants' 'want' or 'need' to assume the dispenser role is, at times, articulated as part of their duty as 'mothers'. Although this does not infer that participants feel begrudgingly obligated to carry out these medication practices, such feelings reflect the pervasiveness of Western gender relations in household medication practices. Finally, the participants desire to administer their children's medication, as well as their sense of hesitancy and reluctance to administer them to other people's children, reflects their tacit knowledge of how the exchange of medications between parents and their children marks the intimacy of such relationships. It was deemed inappropriate for other individuals to fulfil a role which so clearly communicates the love, affection, and care of children from their parents. Participants described their roles as gate keepers and dispensers of medications as highly personable.

Alongside emotional and practical dimensions of gift exchanges, participants also considered the economics of mediation use. As consumers, participants paid for medications or medical services used by their children. The term 'consumer' is used to describe the commodity transaction occurring between participants and customer service staff who accept monetary payments for medications or medical services. When enacting a consumer role, it is likely that this is preceded by engagement in other roles such as researching or observing. While the consumer role obviously involves a degree of financial constraint, if participants 148 believed that the product would help their children or make them 'better', this was prioritised over medication price. This raises an ethical concern: What price will individuals pay for the cost of health? For these participants, price also allowed them to infer judgements about the quality of medications. The tendency to use price as an indication of quality or safety reflects participants' attempts to simplify the substantial amount of information regarding medications, and their uncertainty about medication safety standards.

During their engagement in these roles, participants draw on their maternal and intuitive knowledge to aid decision making processes regarding medication use. In both the current and previous research (for example, Callery, 1997), it has been shown that this knowledge is invaluable. Both Olivia and Sarah felt that their intuitive knowledge was dismissed on account of their 'neuroticism'. Whilst it is clear that attending to their children's health needs is a deeply emotional experience for parents, this should by no means obscure the legitimacy of parents assertions about the wellbeing of their own children. Rather than a compilation of abstract and irrational emotional experiences, the participants have demonstrated that their intuitive knowledge can be reliable. Their intuitive experiences are grounded in medication beliefs, experiences, and intimate knowledge of their children stemming from observational practices. Transacting this knowledge in the various roles described above impacts the regulation of bonds with medical professionals and lay persons. Participants' experiences indicate that when medical professionals reject intuited or maternal knowledge, this conflict often ceases the ongoing transaction of knowledge between lay persons and this medical professional. Conversely, knowledge is more likely to be accepted in relationships described as close or trusting, and where participants perceive the individual as an expert in the medical field.

Engagement in these various roles has implications for the way in which 'care giving' is understood. The introduction to this chapter acknowledged that medication consumers fulfil many roles (Doran et al., 2005). Similarly, as care givers, participants enact many roles which may not typically be conjured with use of the term 'care giver'. Regardless, participants are researchers, advocates, observers, dispensers, gate keepers and consumers throughout the daily enactment of medication practices. These roles are the basis through which participants enact affectionate caring towards their children, ensure safety around medication use and maintain a parental position as responsible care givers. This identity is reinforced through the gifting of time and effort to research medications, advocate for their children's needs, observe their wellbeing, and administer and purchase their medications. As supported by previous research (for example, Evans & Thomas, 2009; Gunnarsson & Hydén, 2009), accomplishing these tasks are moral duties of 'good parents'.

Consideration of the multiple roles entailed in care giving also draws attention to other individuals involved in the care of children. Rather than being isolated practices between parent and child, medication transactions involve the complex negotiation of relationships between medical professionals, family, friends and various others. Thus, caring is achieved through a social network where knowledge and medications are transacted and exchanged. While specific tasks (such as administration) are carried out by individual care givers, the many relationships involved in the care of children indicates the contribution of an entire social network to caring practices.

### **CHAPTER SIX: THESIS DISCUSSION**

This thesis has documented the medication understandings held by parents caring for their chronically ill (as well as mostly healthy) children. In chapter three, participants drew attention to the physical form and effects of medications, as well as social dimensions. These included how medical professionals are involved in the construction and legitimation of medication meanings and understandings, and the distinction between 'hard' and 'soft' medications. The chapter also acknowledged that cultural contexts (such as social norms or prevailing medical knowledge) are connected to the way in which participants utilise and interpret various medicative forms. In summary, chapter three supports existing knowledge of medications as complex material and social objects.

Exploring how medications are understood by participants in the context of everyday life was pivotal for understanding their interpretation of 'care' and what constitutes an adequate response to ill health. While medication practices themselves are complex and changeable (Bajcar, 2006), caring for children is furthermore complex, as parents face conflicting pressures about caring methods and attempt to maintain a highly idealised identity of 'adequate care giver'. Documenting the lay understandings and rationales behind medication practices challenges the assumption that medication users are 'irrational' or 'inexpert'. Across chapters three to five there are many parallels to be drawn between participants' medication understandings and the practices they enact. Previous experience and knowledge are well known to influence the medication practices of lay persons (Bajcar, 2006; Pound et al., 2005; Shoemaker & de Oliveira, 2008, p. 446), and the accounts from the participants in the current research support these findings.

The act of 'giving' has also been a major focus of discussion in this thesis. Both chapters four and five explore how care may be enacted through medication use

and how the exchange of medications impacts social relationships. Parents' relationships with their children are central to medication use or non-use, but others are also implicated. These include those between care givers and family or friends, as well as medical professionals. This thesis provides a novel application of gift exchange theory. The modern Christmas ritual of gift giving has received a great deal of interest from gift exchange theorists (for example, see Caplow, 1984; Carrier, 1993). This is perhaps because the ritual so transparently illustrates key components of the theory, including how gifts are implicated in the regeneration, modification or weakening of relationships (Caplow, 1984; Carrier, 1993, 1995; Mauss, 1950; Schwartz, 1967), and how the transaction of gifts can communicate various emotions or sentiments (Caplow, 1984; Carrier, 1993, 1995; Mauss, 1950; Schwartz, 1967). Furthermore, modern Christmas gift giving rituals are centred on a familiar and widely recognised conception of the 'gift', hence being easy to relate to and understand.

Applying gift exchange theory to the medication practices enacted within private households has highlighted comparatively unceremonious gift transactions in everyday life. The present research provides many examples of how gift transactions can be automatic and ubiquitous. This thesis demonstrates that even the mundane routines that constitute our day-to-day lives are entrenched with meaning (as supported by Giddens, 1984). In addition, this thesis shows how 'giving' is central to the care of ill children, and how the meanings of medications are entwined in the relationships through which they are exchanged. This thesis has employed a broader conceptualisation of gifts, encapsulating the gifting of time, knowledge, and selection efforts that form many gift transactions in daily medication practices.

# Agency and understandings

The literature outlined in chapter one concerning medicalisation and pharmaceuticalisation is useful for gaining an understanding of the context of medicine use. Many authors continue to criticise the pharmaceutical industry for 'disease mongering' (Moynihan et al., 2002) in pursuit of financial advance. Criticism and suspicion about the pharmaceutical industry and ongoing pharmaceutical use has raised many questions. For instance, some are concerned with the price of health, both physically and financially, if pharmaceutical use continues to pervade contemporary life (Moynihan, 1998; Moynihan et al., 2002). Moynihan (1998) asks whether some ailments and illnesses might remedy themselves if left untreated, and if people rely on pharmaceuticals too much in day-to-day life. Furthermore, are there potentially better responses to ill health that are overlooked in the midst of pharmaceutical use (Moynihan, 1998)? These are certainly important issues to consider. As highlighted in chapter one, however, the literature which asks such questions constructs lay persons as passive consumers of medications.

Despite the historical tendency to view patients as 'victims' of medicalised conditions and doctors' orders, this research emphasises that lay persons are active agents in medication use. While medications are sometimes used in automatic and trivial ways in the households studied, these participants are also very capable of being highly critical about medication use. In constructing their medication practices and making medical decisions, the participants drew upon many forms of knowledge. As they researched medications, both lay and expert knowledge were considered from medical professionals, family members, trusted friends and various media. As participants medicated their children, resisted medications, and sought health and wellbeing through lifestyle considerations, they considered expert opinion, shared and lived previous experiences, and emotion and intuition (see 'Intuition and medication practices'). Thus, their medication practices, beliefs and understandings reflect a complex interaction between medical discourses and personal health biographies.

An important part of being an adequate care giver entailed acting as consumers who assume responsibility for the payment of medications and other medical

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services required by their children. However, this does not imply that participants interact with medications as though they are mere 'consumable goods'. Nor are lay persons merely 'consumers' of medications (Doran et al., 2005). In the current research, participants described themselves as researchers, advocates, observers, gate keepers and dispensers of medications, as well as consumers. Participants' medication practices emerge from a complex interaction of these many roles (Doran et al., 2005). In their multi-faceted roles, participants demonstrated their ability to navigate complex fields of (sometimes conflicting) information, to challenge or query medical advice, to resist medication use, and to make judgements or amendments to medication use or other medical interventions based on their own knowledge or intuition.

Previous research has also pointed to the agency of lay persons utilising medications. Non-compliance studies, for example, have transformed notions of 'deviant' non-adherence to medication regimens. Non-adherence is now more likely to be perceived as an expression of individual agency and autonomy (Adams et al., 1997; Conrad, 1985; Pound et al., 2005). In chapter one, the examination of parental experiences of caring for ill children revealed that parents exert substantial efforts before making the decision to refuse or accept medication use. In the present research, participants stressed their sense of agency in making such decisions. Maddison, for example, asserted that choosing to resist or engage in medication use is a "personal choice". In addition, the participants hold very strong beliefs about the impact of direct-to-consumer advertising, arguing that advertisements in no way compel them to head out and purchase publicised medications.

Nevertheless, 'choice' is an interesting concept when it comes to caring for their ill children. On one hand, participants assert their agency and demonstrate this in various household medication practices. On the other hand, participants also describe instances where they experience a diminished or limited sense of choice. The wider social trend to resort to pharmaceutical use (Busfield, 2006) is reflected in the beliefs and practices of participants in this research. For example, some participants feel obligated to resort to pharmaceutical use in dire health circumstances, despite concerns regarding medication dependency and side effects. In many instances, pharmaceutical use envelopes moral and ethical dimensions. Consider the plight of parents caring for children with ADHD. They may be chastised for refusing to medicate their children and experience significant pressure from other social actors to do so (Blum, 2007; Bussing & Gary, 2001; Hansen & Hansen, 2006). The need to find solutions to their children's health problems reflects notions of 'ideal' parenting to which these participants continually attempt to aspire.

Giddens (1984) argued that social systems may both constrain and enable human action. Lay persons may sense choice and freedom around medication use. Nonetheless, the easy accessibility of medication in the community, a general over-reliance on pharmaceuticals, or trends toward reducing suffering might also be constructed as reducing certain freedoms (Conrad, 1992). The ways in which wider social structures (such as the dominance of biomedical knowledge) impact private medication practices and individual agency are both significant. Based on this research and the literature presented in chapter one, it is important to recognise the power and limitations of individuals and institutions.

### Giving

Gift exchange theory offers a useful lens through which to appreciate the complexities of relationships with medications in everyday life. Previous research has recognised and documented the social lives of medications and the capacity of medications to imbue various emotional, moral or ethical dimensions entwined in caring (Cohen et al., 2001; Conrad, 1985; Hall, 1980; Helman, 1981; Hodgetts et al., 2011; Rogers et al., 1998; van der Geest et al., 1996; Viswanathan & Lambert, 2005; Vuckovic & Nichter, 1997). In addition, research has also explored how care connects people (Bondi, 2005, 2008), and how

relationships are central to many forms of caring (Bondi, 2008; Evans & Thomas, 2009). This thesis links these two research domains, exposing the intricate links between the meanings medications carry and the relationships in which they are immersed. This connection is a central theme of gift exchange theory, which recognises that objects are "linked to the giver, the recipient and the relationship that binds and defines them" (Carrier, 1995, p. 10).

The participants in this research identify many transactors of medications, including themselves and their children, other family members or close friends, medical professionals and retail staff (such as at the pharmacy). The meanings medications carry vary substantially across these relationships. For instance, the exchange of medications between parents and retail staff is perceived as largely commercial. In these transactions, participants consider themselves consumers responsible for the payment of medications or other services required by their children. Natalie suspects that many retail staff are likely to view medications merely as products to be sold (see 'Researcher')<sup>29</sup>. Staff in retail positions were more likely to be viewed as simply impersonal, interchangeable and inexpert purveyors of consumer goods. Consequently, medications or information transacted from retail staff may be viewed with scepticism or suspicion by participants. Similarly, actors or actresses who feature in television advertisements for medication were not considered credible or reliable sources of information, and participants perceived the medications they promote as potentially dangerous or illegitimate.

More enduring relationships were established and maintained between participants and their Family General Practitioners. Participants perceived them as trusted experts in the medical field and sought their advice on multiple occasions. For these participants, medications provided by the doctor bear a

<sup>&</sup>lt;sup>29</sup> The participants in this research can only offer insights into how medications may be viewed by other transactors. Accurate meanings or interpretations should be informed by these transactors themselves (for example, retail staff or doctors).

degree of legitimacy that is not necessarily apparent with medications accessed through other sources. Furthermore, doctor prescribed medications may be perceived as stronger and more potent, but also more effective than medications obtained elsewhere (for example, over-the-counter).

Between parents and their children, medications have personal significance that is bound within the close and unique relationship between a parent and their child. When the parents involved in this research administered medications to their children, these social objects came to symbolise their love, affection and need to reduce their child's suffering. Giving is central to parents caring practices and an integral part of their identity as responsible care givers. This is not relevant only in the context of providing medication, but also other practices. Some of these, such as dietary considerations, are explored in chapter five. Alongside the exchange of material items, in giving their time, effort and knowledge parents in fact give themselves to their children.

# **Emotion and intuition**

Many factors impact the medication practices parents enact in their household. Identity (Adams et al., 1997; Gervais & Jovchelovitch, 1998; Gunnarsson & Hydén, 2009; Milliken & Northcott, 2003), previous experience (Bajcar, 2006; Pound et al., 2005), medication understandings and beliefs (Hansen & Hansen, 2006; Jerrett, 1994; Shoemaker & de Oliveira, 2008; Viswanathan & Lambert, 2005), medical hegemony (Filc, 2004) and location of care (Dyck et al., 2005; Gesler, 1986; Gieryn, 2000; Mallett, 2004; Williams, 2002) are all central to medication practices. Emotion and intuitive knowledge also play an integral role in the care of ill children. As explored in chapters four and five, caring has many emotional dimensions. A focus on the 'care burden' has tended to emphasise negative emotional experiences such as stress, fear or worry. It is known, however, that many positive emotional experiences are derived from care giving tasks. Particularly in familial relationships, many find care giving a "deeply rewarding expression of love, pleasure and vocation" (Bondi, 2008, p. 250). There is substantial overlap between the emotional experiences documented in previous literature and those explored in this research.

'Feelings' are commonly (and falsely) perceived as irrational and "intrinsically unreasonable" (Bondi et al., 2009, p. 446). It is often thought that emotions have no role to play in the development of objective, value-free and reliable scientific knowledge (Bondi et al., 2009). This perhaps accounts for the difficulty these participants encountered when attempting to assert their own knowledge against that of medical professionals. Since the 1970's, feminist scholars have sought to remove the binary distinction between emotion and reason (Bondi et al., 2009). This thesis contributes to this endeavour, demonstrating that emotions have an important role to play in the generation of knowledge (Bondi et al., 2009), and further contesting the notion that knowledge is (or should be) 'value-free'. The emotional experiences of participants in this research are sensory in nature. Participants are 'felt' and 'touched' bodily by emotions (Bondi et al., 2009) such as 'gut feelings' concerning their children's wellbeing. Bondi and colleagues (2009) use the term 'emotional knowing' to describe such embodied experiences.

While parents may not be able to avoid or control the range of emotional impulses experienced while they care for their children (or are prevented from caring for them (Milliken & Northcott, 2003)), they respond to emotions in ways that have real and tangible impacts on daily household medication practices and social relationships. Emotional experiences may lead a parent to obtain medical attention for their child. Conversely, these experiences may also drive a parent to challenge medical knowledge, discontinue medication use or in others ways amend medication regimens without medical advice. Participants consider their intuited knowledge to be a valuable resource to draw upon when making medical decisions on behalf of their children. In doing so, they demonstrate how emotion and reason are "mutually interwoven with each other" (Bondi et al.,

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2009, p. 448). Even though experiences may be attributed to 'emotional' knowledge, this is in fact grounded in previous experience and comprehensive observational practices (see 'Observer').

The fact that mothers may 'know' as well as 'feel' or emotionally sense what is best for their children when they are ill should hardly be a criticism or marker of woman's irrationality. It may be better interpreted as a reflection of the close kin relationship between a mother and child, and as an example of the way in which emotions saturate environments existing external to a private sense of self (Bondi, 2009). Furthermore, these participants claim that if they felt out of their depths during the care of their child (such as when they lack sufficient knowledge or experience regarding an illness) they do not hesitate to seek professional medical advice. While these participants act as advocates asserting their own knowledge and perspectives, they hold no inflated illusions about their own medical expertise. They continue to trust and value the input of medical professionals, recognising their proficiency in the medical field. When it comes to their own children, however, mothers are experts of their health, wellbeing and subtle changes in their behavioural patterns (Callery, 1997; Spencer, 1984).

## Implications

Findings from this study have various implications for the way in which qualitative research regarding medications are conducted and interpreted. Firstly, it is apparent that medication understandings do not exist in a vacuum. Medication practices, and parents' responses to their children's ill health are enacted inside a medical discourse (Gunnarsson & Hydén, 2009). In chapters three and four, it is shown that participants' understandings of medications and their interpretation of what constitutes care often align with biomedical knowledge. In many instances in the households studied, accepting (rather than resisting) scientific medical knowledge reflected 'best' care. Automatic and mundane medication routines can result from over-familiarity with particular medications and practices, but also reflects the ongoing acceptance and legitimation of medical knowledge. Knowledge of prevailing medical discourses will provide researchers with a deeper understanding of medication beliefs held by lay persons and help to document substantial changes in medical discourse over time.

Secondly, a central point of this thesis has been to emphasise the agency of individuals as they use or resist medications in everyday life. Despite the persistent influence of biomedical knowledge, lay persons should not be viewed as victims or passive users of medications. Nonetheless, researchers "should not assume that lay knowledge will persist or triumph, exactly as [they] should avoid the view that expert knowledge is objective and all-powerful" (Dew & Lloyd, 1997, p. 400). This might seem like a rather paradoxical proposition; to recognise the power and agency of lay persons while simultaneously acknowledging the role of wider social structures on enabling or restraining social action. For this reason, Giddens' (1984) structuration theory has provided a valuable theoretical orientation. A fundamental component of this perspective is the duality of structure. That is, it emphasises power in human agents as well as social structures (Giddens, 1984). This perspective is useful in that it highlights there is a complex relationship between expert and lay knowledge (Dew & Lloyd, 1997). For health professionals, this presents somewhat of a dilemma. There is a need to understand that, whether permitted by medical professionals or not, lay persons actively engage in responses to ill health.

Thirdly, this thesis has embraced lay persons' emotional experiences as a legitimate and important source of knowledge. In doing so, this thesis reveals how emotional experiences are grounded in parents' tacit awareness of their children's health behaviours and how these experiences pervade medical decisions made by parents. Because the emotional experiences of parents have very real and direct implications for the care of children, researchers should be encouraged to pay attention to the emotional experiences of their participants.

Finally, it is imperative to draw meaning of contemporary medication use from the relationships in which medications are immersed. Gift exchange theory provides a theoretical foundation for the analysis of social and material objects. Rather than viewing objects as abstract and isolated collections of material utility and value (Carrier, 1995), it situates medications in interactions between individuals, acknowledging that they are bought, used, given and exchanged in social relationships (Carrier, 1995): "The significance of the object does not spring from its position in public structures of meaning and identity, but from its existence in a private relationship" (p.8).

# **Concluding comment**

Across many centuries of medicine use we can now, in hindsight, ascertain that many medications impact health in negative ways. The realisation that the pursuit of health through medicine use can in fact be very damaging to one's health continues to gain momentum (Moynihan, 1998; Moynihan et al., 2002). Consider the examples provided in chapter one. The Thalidomide tragedy and use of metals in the 15<sup>th</sup> century are particularly relevant. In the case of Thalidomide use, minimising women's morning sickness throughout pregnancy may have seemed a worthy medical endeavour, however, ten thousand children were born with birth defects (Duffin, 2010). Similarly, in the 15<sup>th</sup> century metals were often utilised until it was discovered that they are highly neurologically toxic (Duffin, 2010). The best of intentions with medical discovery has not always correlated with the best outcomes.

In light of these historical tragedies a healthy scepticism regarding medication use should be encouraged (Moynihan, 1998). For the participants in this research, scepticism about medications resulted in efforts to resist and reduce medication use. Given that medications routinely generate side effects that may outweigh the benefits (for example, see Rogers et al., 1998), and that medications may be used unnecessarily, or applied in unintentional ways (Spilker & Cuatrecasas, 1990), a sceptical perspective has the potential to help reduce superfluous medication use. It is also apparent that pharmaceutical use accounts for a large proportion of health costs (Doran et al., 2005). In many countries lowering health costs is an important policy direction (Braae et al., 1999). A healthy scepticism in lay persons and medical professionals may certainly help to reduce some of these costs.

It is paramount to avoid advocating for interventions that operate only at an individual level, especially since ignoring the social impacts on health and wellbeing is a major existing criticism of the biomedical model. The fluidity of medication beliefs and understandings has been a key finding of this thesis. Understandings of health and adequate responses to ill health continue to shift, as do patterns of health and illness and the needs of population members. These changes need to be continuously recognised at a policy level, so that social policy may address shifting health needs in present and future populations.

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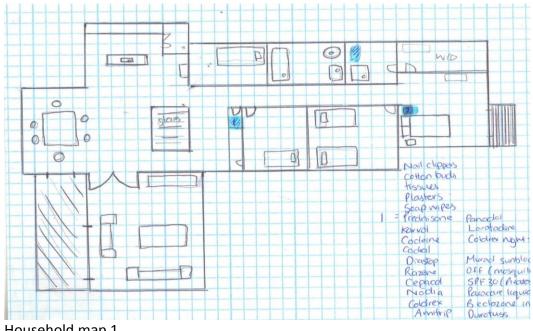
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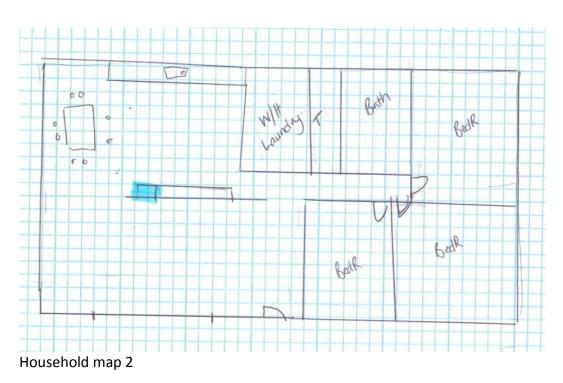
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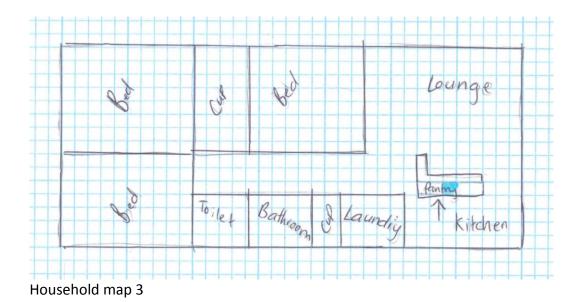
# **APPENDIX A**

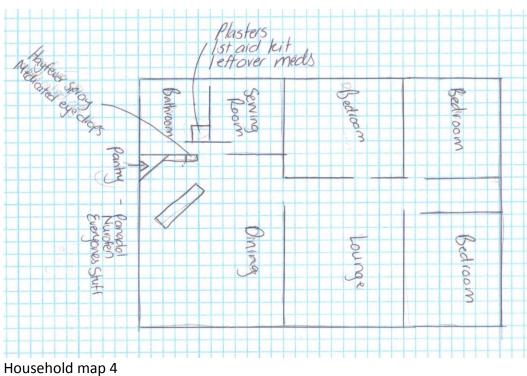
# Household maps











# **APPENDIX B**

# **Topics for household discussions**

The following list of topics to be covered by the researcher during the initial household discussion:

- The meanings of medications (our primary focus)
- Personal medication use, including the use of alternative medications and supplements, and storage (who in the household takes medications, what medications are taken, where and how are they taken, what are they used for, where are they stored in the home)
- The flow of medications through the household and beyond (how the medications arrived, if and how medications move beyond the house, how are medications disposed of)
- What material objects in the home are related to medication use (e.g., first aid kits, glucose meters, asthma inhalers, storage containers)
- Availability of medications in society today
- Uses beyond the prescribed
- Medications beyond prescription (supplements, pharmacy only, OTC, alternative include inhalers, topical creams)
- Issues of prevention/promotion/maintenance/cure (relation between)
- Morality good/bad Why? How?
- Risk safety, adherence, responsibility, trust
- Personal approach to medications (resisting/passive or active acceptance, etc)
- Relationships involving medications (sharing, caring, taking, nagging)
- Consumerism DTC marketing/pharma/regulation, etc

# **APPENDIX C**

# **Interview Protocols**

#### Phase one

#### Introduction: Medication practices, meanings, risks, and parenting

Talk with the participants and explain the aims of the initial interview and other activities (diary and photo production) involved in the interview.

- Discuss how media may impact medication practices/parental decisions
- Discuss how the parenting role influences medication use and understandings
- Explore the participants meaning of medication
- Get the participants to describe the process of how, when and why medications get from a provider to home.
- Describe the process of taking personal medications and administering them to others in the household
- Identify any risks involved in these processes

Why are medications used in your household? [Prevention of illness/maintenance of health]

Do you think medications affect your health? How? Do you use pharmaceutical/homeopathic medications? Why? How do you obtain medications? [Describe this process] How do you choose medications? Who would you talk to about it? What role do you play in children's medication use? What do you teach your children about medication? How do you teach them? What risks are associated with having medication in the house/taking medication? Do you adhere to medication instructions? (for you, your children?) What do you think about TV advertising? If you were to summarise what medications are, how would you do it?

### Mapping exercise, Medication storage

The participant is to draw a plan of the house and indicate where medications are kept. With their permission, they could also take photos of these sites and the medication stored there and reference them to the map. They will also be asked to gather medications and medication paraphernalia

- Discuss where medications are stored and why
- Any risks involved

- What the medications are, and what makes them medications
- Discuss medication paraphernalia
- Discuss photos taken

Is there a difference between medications at different locations in the house? What? Would medications still be stored where they are if there were no children? Why are these medications? What does the photo show? Who can access medications where they are? Why are they not stored in other places [provide example]? What other things are in these locations? [Are these things medications? Why/why not?]

Any experience's involving medications you would like to share?

#### **Closing the interview**

- Summarise the main points of the interview and encourage further input from participant.
- Assigned sub tasks to household members and given them relevant information sheets:
  - Medication use diary
  - Photo elicitation
  - General medications diary

#### Checklist

- Plan of house identifying medications location sought from household members
- Photos of medications locations taken and linked to the plan
- Participants asked to get out their medications and related paraphernalia
- Participants prompted to discuss all items listed on prompt sheet
- Assigned sub tasks to household members and given them relevant information sheets:
  - Medication use diary
  - Photo elicitation
  - General medications diary

## Phase Two Interview Protocol Photo Production and Diary Record

### Introduction

Talk with the participants and explain the aims of the second interview.

- Explore the photographs you have produced
- Provide you with an opportunity to reflect on photo production process
- Any changes in the way you think about medication in the last two weeks
- Any thoughts arising from the last interview about medications and your understanding of them?

### The experience of taking photographs

• Place all the photographs on the table so they may be viewed by participant and researcher

Can you think back to the beginning of the exercise and tell me a story about how you got started and what you photographed? How did you find taking the photographs? Were you able to take photographs of everything you wanted to take? What or who is missing? How did you find the exercise?

### **Exploration of Photographs**

- Description of photo [identifying features]
- Discussion of what the photo involves
- Discuss parenting roles that may have been captured in the photos
- Discuss media that may have been captured in the photos
- Which photo best captures the world of medications

Why did you choose this image?

What do they mean to you?

What does the image show?

What doesn't it show?

How are medications portrayed in the photo?

Did the photographs turn out like you expected?

If you were to do this again what other things would you photograph?

## The experience of keeping a diary

This part of the interview focuses on providing an opportunity to reflect on the diary writing process.

Can you think back to the beginning of the exercise and tell me how you got started?

How did you find writing diary entries? Were you able to write entries about everything you wanted to? What or who is missing?

### **Exploration of Diary**

Focus on media items, parenting role, medication understandings and practices, and risks involved in use

### • Media

Who do you trust/ not trust? Why? What/who are credible sources? What is advertised? Have you asked for advertised products?

### • Parenting

In what circumstances do you provide medication? Who administers medications to your children? Which medications do you use and why?

General

What makes a medication? When should they be used?

## **Closing the interview**

Summarise the main points from the discussion and encourage further input from the participant.

Would that be an accurate synopsis? Is there anything that you would like to bring up or thought should have been discussed? Do you have any questions concerning this study? What have we missed?

## **APPENDIX D**

# To Medicate or not to Medicate?

# **Information Sheet**

#### What is this research about?

Medications are widely available and commonly used by many people in New Zealand today. However, we know very little about how medications are understood by people, and how they are used in people's homes. This research aims to investigate popular understandings of medications and their uses. It is concerned with medications of all sorts – prescription medicines, over-the-counter medicines, alternative medicines and dietary supplements. It is important to note that we are not interested in any form of illegal drugs. The research is being undertaken by a team from Massey, Waikato, Otago and Victoria Universities and is currently funded by grants from the Health Research Council and the Royal Society of New Zealand. The master's thesis, Medications, Place and Parenting, being produced is partially funded by a University of Waikato Masters Scholarship.

#### What is involved?

We are seeking to work with households that contain one or more adults and at least one child under the age of 12 years with a chronic illness of any kind. We have a number of tasks, outlined below, that we would like to complete in each household, although it may not be possible to do every one of these in any particular household. Which of these we complete in each household can be decided by the household members involved.

#### The specific components of the research are:

#### Initial household discussion

First, we will hold a household discussion with all members of your household who are interested to participate. This will take place in your home, and involve a general discussion about medications, their meanings and what you do with them. We will also ask you about all the medications in your home, and to draw a rough plan of your house and locate on it the places where you keep medications. We would also like to photograph these settings and link them to the plan, but we will only do this with your permission. We would also like to see the range of medications, and related things like pill organisers and inhalers, that you have in the house, but only those things you are willing to show us. The discussion will be digitally recorded and transcribed so that the research team can complete their analyses. This meeting should last around two to two-and-a-half hours altogether.

Then we have two different projects that we would like any parent or guardian within the household to complete. It is not essential that we do all of them – it depends on how many people are present and who is interested to do each.

#### Carrying out a photo project

One person from the household will be asked to take photos of anything about medications – photos that show us "the world of medications". We will provide detailed

information on what is involved in this process. Photographs can be taken on your own digital camera or we can give you a disposable camera. These photographs will be printed and discussed in a recorded interview with the person who took them. The person will have two weeks to take the photographs, and the interview to discuss the photos will take about one hour.

#### Keeping a medication diary

One other person, a caregiver of the child or children in the household, will be asked to keep a medication diary. This involves keeping a daily record of any medications taken or administered to others each day for a week, and writing brief notes about that at the end of each day. This person should also note any time that medications of any sort come to attention in any way (while watching television, reading magazines, shopping, and so on- wherever medication come to attention). At the end of each day, this person will select one issue and write a little about it. We will provide detailed information on what is involved to this person. After the week is over, the person will then discuss the diary content with us in an interview. The entire task should take no more than 3 hours altogether, including the one hour interview which will be recorded for analysis.

Finally, after these tasks are completed, we will have a closing household discussion with everyone involved to review the project and to gather reactions and comments from household members. This discussion will take less than 2 hours, and will also be recorded for analysis. Your household will be given a \$100 voucher after the closing discussion as compensation for all the time this will involve.

#### How can you participate?

You are invited to take part in this study if your household includes at least one child who is younger than 12 years. If this is the case, please discuss the project with members of your household and then contact Brooke Hayward from the University of Waikato to discuss your participation. Her contact information is given below. She will answer any questions you have and make a time to come and meet with the members of your household who are interested to participate.

#### What are your rights if you decide to participate?

If your household is willing to take part in this research, you should know that all the information you provide during the study will be kept completely confidential. All the data will be stored in a secure place, and no one other than the researchers will have access to it without your consent. Your names will not be used to identify the materials, or used in any reports that come out of the research. Any personal or identifying features that are mentioned will be altered to make sure that everyone remains anonymous. The materials collected in the study will be used in the analysis for the research, and brief extracts from the interviews or diaries may be used in publications and presentations arising from the research. However, we will take care to ensure that these will not identify you in any way. We may also use the house plan and photographs in publications and presentations from the research, but these would have all identifying features masked.

You should also know that you have the following rights:

• Members of your household do not have to take part in this study at all, or in any specific component of it; anyone is free to decline.

- Members of your household can ask questions about the research before agreeing to take part, and anyone who agrees to take part can ask questions about the research in general, or any specific component of it, at any time during the study.
- Anyone taking part in the research can decline to talk about any issues, during any of our discussions.
- Anyone taking part in the research can ask for the recorder to be turned off at any time during discussions.
- Your household can withdraw completely from the study up to two weeks after our closing discussion. If you do, all recordings, transcripts, your house plan, and any photographs taken will be destroyed.
- You can request a summary of the findings to be sent to your household when the study is concluded.

#### How do you contact us?

[The contact details were provided for the masters student, the Principle Investigator, and the project administrator. They have been removed for privacy purposes]

This project has been reviewed and approved by the University of Waikato Human Ethics Committee. If you have any concerns about the conduct of this research, please contact the convenor of the Ethics Committee, [private details removed].

### **APPENDIX E**

Research reference:					

# Medications in everyday life

### **Consent Form**

We have read the Information Sheet and have had the details of the study explained to me. Our questions have been answered to our satisfaction, and we understand that we may ask further questions at any time.

We agree to participate in this study under the conditions set out in the Information Sheet.

We also consent for data from this project, with all identifying features removed, to be archived for further research projects and teaching purposes

Yes No	
Date:	
Signature:	Signature:
Full name (printed):	Full name (printed):
Signature:	Signature:
Full name (printed):	Full name (printed):
Signature:	Signature:
Full name (printed):	Full name (printed):

Which \$100 voucher would you like to be sent to you (please tick):
Pak 'n' Save Countdown Foodtown
Warehouse Petrol voucher
Would you like to receive a summary of the results? Yes No
Name:
Email address:
Or
Postal Address:

# **APPENDIX F**

### University of Waikato Psychology Department CONSENT FORM: PARTICIPANT'S COPY

Research Project:	To Medicate or not to Medicate
Name of Researcher:	Brooke Hayward
Name of Supervisor:	Darrin Hodgetts, Ottilie Stolte

I have received an information sheet about this research project or the researcher has explained the study to me. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw up until the completion of the research report. If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee, [private contact details removed]

Participant's		
Name:	_Signature:	_Date:

\_\_\_\_\_

#### University of Waikato Psychology Department CONSENT FORM: RESEARCHER'S COPY

Research Project:	To Medicate or not to medicate

Name of Researcher: Brooke Hayward

Name of Supervisor: Darrin Hodgetts, Ottilie Stolte

I have received an information sheet about this research project or the researcher has explained the study to me. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

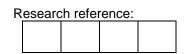
I agree to participate in this research project and I understand that I may withdraw up until the completion of the research report. If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee. Participant's Name: Signature: Date:

# APPENDIX G

# Demographic Information

Name	Age	Sex	Marital Status	Occupation	Age of children	Chronic illness

# APPENDIX H

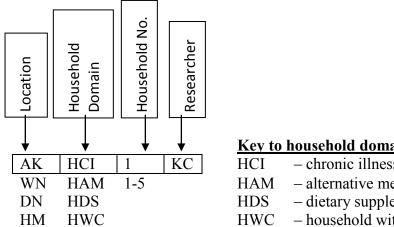


# Medications in everyday life Household researcher checklist

### To do prior to data collection

#### completed

Assigned research reference no. featuring location, household domain, no. of household and researcher (see below), and entered reference on this checklist and on consent forms



### Key to household domain

- chronic illness - alternative medications - dietary supplements - household with children

ALL name and contact details fields on information sheets replaced and printed on letterhead

## Materials to take

- multiple copies of information sheets -
- copy of household consent form (print double-sided)
- copy of household data sheet
- graph paper
- digital camera -
- digital recorder
- one copy of each task information sheet -
- one copy of each task consent form
- disposable camera (NB. Remind photographer to use flash when taking photos on disposable camera)
- diary x 2
- household checklist
- household reimbursement form (during exit interview)

### To do during data collection

- Copy of the information sheet given to each household member
- Details of information sheet explained to participants
- Participant questions sought and answered
- Discussed consent form contents with participants re using data beyond project
- Participants completed consent form and household data sheet

#### START DISCUSSION

(Digitally record household identifier, data domain and researcher name prior to discussion commencing)

- Plan of house identifying medications location sought from household members
- Photos of medications locations taken and linked to the plan
- Participants asked to get out their medications and related paraphernalia
- Participants prompted to discuss all items listed on prompt sheet
- Assigned sub tasks to household members and given them relevant information sheets:
  - Medication use diary
  - Photo elicitation
  - General medications diary
- Organised a future meeting with individuals carrying out sub-tasks and for household exit discussion:
   Medication use diary

- Medication use diary	Day	_ Date		
- Photo elicitation	Day:	Date:	Time:	
- General medications diary	Day:	Date:	Time:	
- Household Exit discussion	Day:	Date:	Time:	

### To do after data collection

• Household plan and consent forms forwarded to [Name removed]

1	a	2
1	9	2

•	All discussion and interview recordings and digital photos from household uploaded onto web OR downloaded to CD and sent to [Name removed]	
•	Photos and diaries uploaded onto web OR sent to [Name removed] (depending on format used)	
<u>To</u>	do during Exit Interview	
	<b>ART EXIT INTERVIEW</b> gitally record household identifier, data domain and researcher name prior to discussion commencing)	
•	Participants have been asked about key points that have emerged for them during the project	
•	Participants have been asked if taking part in the project has made them think differently about anything	
•	Participants have been given their gift voucher, thanked for their participation and signed the household reimbursement form	

# **APPENDIX I**

# **Post Interview Notes**

Interviewer:

Date:

Interview Type:

Duration of the interview:

Household Type:

Location of interview (brief description):

Summary of Main points of interview:

Interview Impressions:

Impression of the interviewee:

Initial themes to emerge in the interview:

Potential revisions for the interview guide:

Personal reflection on interview technique:

Points to follow up in next interview:

# **APPENDIX J**

# **Diary Entry example**

#### **Entry Number One**

Today I went to the Doctor at Hillcrest Medical Centre. I looked up on Google before at some of the symptoms like peeing too much. Seems I might have a urinary tract infection. Told doctor this and he asked about symptoms, and confirmed what I had thought. I said I wanted drugs as it is very painful. I wanted it gone! He wrote me a prescription. He said I had to take them all even when the pain has stopped to finish the whole prescription. I hadn't heard of the medication before. We didn't really discuss any alternatives to medication. I wanted help fast! I went to the chemist next door and waited for the script. Took the meds home in my hand bag and they've stayed there all day. I'll keep them there so that I have them on me for when I go to work etc. I was meant to take first one with dinner but I didn't want to wait that long as too painful so just had one after seeing doctor.

Media item- Saw an ad for Family Health Diary on TV today. Was channel one around news time. Presume they play it then because parents or guardians are more likely to be watching TV at that time. Sneaky sneaky! Was around something to help in winter time I can't remember the name of. Was in a purple box though? Seemed like an alright product. Noticed there are some side effects listed in small print at the bottom of screen. A bit hard to read and they don't make much of an effort to make it clear.

# **APPENDIX K**

# Analysis Table

Theme	Description	Transcript	Diary or photo	Any inconsistency
Medication beliefs/ conceptualisations				
Risks or benefits				
Practices				
Rationale				
Roles				