Chapter 1

Introduction

Background to the study

Vaccination has been described as one of the most effective health interventions (Poland and Jacobson, 2001; Isaacs, Kilham and Marshall, 2004; Cooper, Larson and Katz, 2008; Bedford, 2008; Anderberg, Chevalier and Wadsworth, 2011) for eliminating childhood contagious diseases globally. Parents are therefore strongly encouraged to present their children for routine childhood vaccinations. Although this may seem like a straightforward imperative, a number of parents struggle with the notion of mass childhood vaccination, and as a result have made the decision not to administer routine childhood vaccinations for their child or children. This study speaks to those children, who are now adults and can reflect on what it was like to have had this experience, what it has meant to them, and how it has shaped their own definitions of health and illness.

The high visibility of controversies regarding vaccination and vaccine choices makes it increasingly important to understand how individuals have coped with being raised in this way. It will also be interesting to note their personal views on the topic of vaccination and what interpersonal and/or social implications their unvaccinated status has had on them. There are many theories on what ‘best interest’ really means for the child at the time when this decision is made for them. Identifying their experience will help to inform health care practice and improve communication strategies as to the outcomes, consequences, and/or benefits of these vaccine decisions that are made by parents on behalf of their children.

The research problem

Little is known about adults that were raised without routine childhood vaccinations. This study aimed to provide insight into the phenomenon through a phenomenological lens in order that it may be more deeply understood. The study aimed to make a pertinent contribution to the literature by gathering data and experiences about adults that were raised without routine childhood vaccinations, including a range of personal characteristics, health symptoms, history, opinions and behaviours, and to learn general patterns about the group under study, for the purpose of developing knowledge and understanding.

Context of the study

This study was conducted in Australia, with a majority of participants located in New South Wales.

Research aims

The purpose of this study was to gain information about, and insight into the experiences of adults that were raised without routine childhood vaccinations. A review of the literature identified that firstly there was little research specifically on people that had been raised without routine childhood vaccinations, and secondly that there was a large amount of literature about the parental decision-making process and reasons for not vaccinating. The focus of this research was to find adults that had been raised without routine childhood vaccinations in order that they could reflect on their experience and inform others about this under-researched phenomenon. An exploration of this group of people is useful in revealing experiences that have followed the vaccine decisions that their parents made on behalf of their children and in accordance with what they believed to be in their best interests.

Research questions

The overarching questions, ‘What was your experience of being raised without routine childhood vaccines?’ and 'What is the meaning given to those experiences?' guided the research and was supplemented by subquestions:

- What is the past and present state of health of these adults that were raised without routine childhood vaccinations?
- What diseases, if any, have they experienced?
- Were antipyretics and antibiotics also avoided?
- What health or social issues have they experienced?
- What health ideologies do they have?
- What outcomes have occurred as a result of being raised without routine childhood vaccinations?
- How was illness managed?
- What vaccine choices were made regarding vaccinations and with the participant’s own child/children?

The researcher was interested in exploring what this experience has meant to these participants and in understanding more about the health care choices that participants now make as adults and ultimately what vaccine decisions they make as parents themselves. The research questions were designed with the intention of learning as much as possible about adults that had been raised without routine childhood vaccinations.

Significance of the study

Non-vaccination and in particular the refusal of routine childhood vaccination is an important, poorly understood public health issue. The findings and interpretations of this research show that factors affecting vaccine decision-making are both personal and complex, and relate to sociocultural and philosophical ideologies. Health social groups and in particular, unvaccinated groups are important influences in our health care system and also in larger society, challenging notions of science and medicine, and expanding the definition of health and illness.

Furthermore, this study broadens health professionals' awareness of alternative users utilisation of health care, and their capacity to navigate between heterodox and orthodox medicine, in order to deal with their health problems in a way that is congruent with their personal beliefs and values.

The conclusions of the study will be of significance to a wide variety of health care professionals: practitioners, health promotion and policy makers, health and social science researchers, and academics. Most significantly, it is imperative that research accounts for a wide range of health care consumers, in order to avoid against picking and choosing who is 'worthy' of research and who is not, and especially not based on the premise of who is amenable to dominant health care views. This phenomenon is relevant, and worthy of research because it exists. Consideration must be given to groups that fit outside of mainstream conventions.

Organisation of the thesis

This section provides an overview of the thesis structure:

- The objective of Chapter 1, Introduction, is to provide an overarching understanding of the research problem and an overview of why and how the the research was conducted. In addition, the study context, problem, purpose and significance are presented.

- The purpose of Chapter 2, Literature Review, is to critically review the academic foundations of the research in relation to the perspective presented in the thesis.

- Chapter 3, Methodology and Methods, details the research design and the specific procedures used to conduct the study. The methodological framework, phenomenology is explained, so too is the way in which each step was carried out. Associations between the research questions and the data collection process are put forth.

- Chapter 4, Survey Results and Discussion, presents the results of the survey questionnaire and discusses the findings in detail.

- Chapter 5, Interview Results and Discussion, presents and discusses the findings of the in-depth interviews. Chapter 4 and 5 are the culmination of the data gathering, analysis and interpretation of the findings, providing interpretive insights into the findings.

- Chapter 6, Summary, Conclusions and Recommendations presents the inquiry conclusions, highlights theoretical contributions of the thesis and identifies related areas with the potential for future research.

Summary

This chapter has introduced the research by providing the background setting for the exploration. The research problem was identified and the purpose of the research explained. This chapter has also described the rationale and significance of the research. The next chapter will present the academic literature review on vaccination issues related to non-vaccination.

Chapter 2

Literature Review

Introduction

This study aimed to explore the phenomenon of being raised without routine childhood vaccinations. It was anticipated that the knowledge generated from this inquiry would offer new insights, and inform health care practice regarding this under-researched group. The literature concerning non-vaccination is largely based on parental reasoning about childhood vaccination and decision-making, however, there appears to be a lack of empirical research in the field of exploring adults that were raised without routine childhood vaccinations, demonstrating a need for exploration in this area.

An exploration of adults' retrospective reflection on their unique status will be useful in constructing meaning and understanding of their experience, both in terms of how they have coped with the decision that their parents made for them, and in developing insight into their health, their health care experience, and their own personal views on vaccination. It will also be useful to know what outcomes have resulted from the vaccine decisions that were made on their behalf, as there is currently no literature that follows the end results of these decisions.

The central focus of this chapter is an argument for the importance of studying adults that were raised without routine childhood vaccinations, employing a phenomenological design. It was anticipated that the information generated from this inquiry would offer a current awareness of this phenomenon, and inform and improve communication strategies in health care practice regarding this under-researched group. Moreover, intergenerational vaccine decisions are illuminated in this thesis as a new contribution to the literature, so too, is the depiction of the manner in which participants navigated between orthodox and heterodox medicine.

The literature review is arranged according to themes that were drawn from the literature; several main bodies of literature are examined thematically listed below.

Carrying out the literature review

To conduct this selected literature review, the researcher used multiple information sources, including keyword searches carried out with online databases, dissertations, Internet resources, professional journals, and periodicals. Online databases such as ERIC, PRoQuest, CINAHL, and Digital Dissertations were searched. Leading experts in the field were detected and their bibliographies were examined for relevant literature. Due to the paucity of material on adults that were raised without routine childhood vaccines, no specific delimiting time frame was used around which to conduct this search.

Organisation of literature review

The literature review is arranged according to thematic elements drawn from the literature. The dominant themes in the literature inspired the research questions, and some of the themes that started to emerge during the research warranted discussion of the literature related to these themes. These themes were confirmed in the survey and interviews. The themes in chapter 4 and 5 are similar to the themes in the literature review. This was intentional to cover all possible literature published to date. The overarching themes (beliefs and values, personal responsibility and choices) that emerged from the research were reviewed in the literature review chapter.

The chapter commences with an exploration of what is understood about issues surrounding non-vaccination: conscientious objection, non-compliance and reasons for declining childhood vaccines. The relevance of risk is then examined, so too is the relationship of risk and trust, as well as parental concerns in vaccine decision-making.

Further to this, the relevant theories of herd immunity are discussed, along with personal responsibility, and patient empowerment, including the notion of the expert patient. Medicalisation is explored, in addition to the impact of governmentality, addressing the conflict between public health and individual interests.

Consideration is given to the role of agency and structure on health care consumers, as well as the coercive nature of mass childhood vaccination. Several studies will be used to support the author's claim that some people experience mass childhood vaccination as coercive and, replete with risk. As the study considers the experiences of adults that are raised without vaccines, some attention is given to the stigmatisation and marginalisation of unvaccinated people, which has not yet been explored in the literature.

Background

Vaccine decisions are both personal and complex. Children who have received no vaccinations or few vaccinations have not been well researched (Smith, Chu and Barker, 2004). They are said to come from families that intentionally refuse vaccines (Omer, Salmon, Orenstein, deHart and Halsey, 2009). White and Thomson (1995) noted that some mothers had difficulty coming to terms with ‘artificial immunization’. Their philosophy of life is one where personal attention is paid to nutrition, childcare, child development, environmental issues, home nursing and research. Hamilton, Corwin, Gower and Rogers (2004) concluded that parents were aware that vaccines did not provide lifelong immunity, with natural immunity considered preferable to vaccine-induced immunity (Kennedy, Brown and Gust, 2005). Non-vaccinators were also found to be more concerned about long-term side effects of vaccines, rather than about the diseases themselves (Bennett and Smith, 1992).

Conscientious objection

In 1898, after forty-five years of mandatory small pox vaccination, conscientious objection was brought into being (Durbach, 2002), following progressive compliance decline (Bellaby, 2003). Conscientious objection exempted people ‘who were ‘honestly opposed’ to vaccination, and distinguished them from those who were too lazy or indifferent to having their children vaccinated’ (Salmon, Teret, MacIntyre, Salisbury, Burgess and Halsy, 2006, p. 437). In contrast to previously held views that conscientious objectors were apathetic and did not care, mothers were found to go through intense anxiety over subjecting their babies to vaccination, but also felt pressure from relatives and a sense of having to do the ‘right thing’ (White and Thomson, 1995).

The term conscientious objector is explained as an individual who has personal, philosophical, religious or medical beliefs or reason to not vaccinate their child (Durbach, 2002). Conscientious objectors to vaccination are often depicted as irresponsible, irrational, lazy, misinformed and/or in need of being educated (Poltorak, Leach, Fairhead, and Cassell, 2005; Elliman and Bedford, 2001; Dew, 1999), labelled as ‘free-riders’ and morally condemned for their non-vaccination decision (Ashton, 2004; Hodge and Gostin, 2003; Dew, 1999). Their children – the unvaccinated or partially unvaccinated – are often depicted as carriers of contagious diseases responsible for outbreaks of infectious disease that occur in the community (Hanna, Symons and Lyon, 2002), despite no research demonstrating that outbreaks only occur among, or are only transmitted by, unvaccinated people (Forsyth, Campins-Marti, Caro, Cherry, Greenberg, Guiso, Heninger, Schellekens, Tan, von Konig and Plotkins, 2004; Galil, Lee, Strine, Carraher, Baughman, Eaton, Montero and Seward, 2002; Yaari, Yafe-Zimmerman, Schwartz, Slater, Shvartzman, Andoren, Branski and Kerem, 1999).

Hamilton et al's. (2004) study conducted in New Zealand found that the parents in their sample were highly educated conscientious objectors, dispelling the myth of the ignorant, uneducated objector. Feiler-Mircus (2012) found that parents with higher education and income used heterodox medicine more than less educated parents with lower income; in addition the higher educated parents had not given their children the routine childhood vaccinations. New and Senior’s (1991, p. 517) qualitative study conducted in North West of England challenged the notion that dissenting parents were ‘irrational’, finding that although the decision of parents may sometimes differ to that of the health professional, the overwhelming majority of parents were only seeking to do what they believed to be in the best interest of their child. The assumption that parents base their non-vaccination decisions on ignorance and a lack of knowledge that simply needs to be filled was proven incorrect by New and Senior in their 1991 study. These authors noted that parents in their study had strong views about vaccination and had received a plethora of advice from professionals and family members. In addition, the parents had experienced difficulty in making the vaccine decision, describing it as ‘agonising’, and revealing very real concerns over possible side effects from vaccines. Moreover, the findings of this thesis have some similarities with New and Senior’s and Hamilton et al's findings, that clearly demarcated the strong views of participants, the difficulty in making the decision, the concern over possible adverse side effects, and the fact that they had also received advice from various sources, and finally that participants were not ignorant or uneducated.

Non-vaccinators have been identified as believing in safe alternatives and perceiving vaccines to be ineffective in preventing disease, and actively harmful in association with their personal health model (Bond, Nolan, Pattison, and Carlin, 1998). Bond et al. (1998) found that the non-vaccinating mothers in their study promoted physical and psychological wellbeing, rather than vaccines as a means of obtaining good health. Kennedy et al. (2005) also noted this key perception; the belief that the body could protect itself without vaccines, finding that some parents preferred natural immunity or disease-induced immunity as opposed to vaccine-induced immunity for a variety of reasons. These reasons included doubts about efficacy and/or safety of vaccines, concerns about overloading the immune system, worries surrounding chronic illness, having known a child that has suffered from an adverse effect of vaccination (Hamilton et al., 2004).

Children with an anthroposophical background, and also those that have been homeschooled have been associated with non-vaccination (Choi and Manning, 2010; Khalili and Caplan, 2007; Duffell, 2001; Hanratty, Holt, Duffell, Patterson, Ramsay, White, Jin and Litton, 2000). Other factors include previous experience, as well as beliefs about health, risk perception, influence of the media and advice from other professionals (Gust, Brown, Sheedy, Hibbs, Weaver and Nowak, 2005). Previous qualitative research has acknowledged the existence of other views about keeping the body healthy (Rogers and Pilgrim, 1995; Hamilton et al. 2004; Bond et al., 1998). This thesis concurs with the notion that the holistic ethos provides a rationale behind the non-vaccination decision. These holistic theories are discussed further into the chapter.

The holistic health care consumer

The decision not to vaccinate is poorly understood and generally not considered to be an acceptable option by orthodox professionals or by society. Power is embedded in particular roles within Western culture and within health care, with an obvious discordance between orthodoxy and heterodoxy, and decisions regarding children's vaccination schedules. These differences can be put down to varying paradigms and discourses on health and illness. To place the significance of ontological beliefs in context, it is salient to note that belief systems rather than access to vaccines have been nominated as the primary reason for vaccine exemption in the Western world (Richard, Masserey-Spicher, Santibanez and Mankertz, 2008; Parker et al. 2006; May and Silverman, 2003).

A deeper analysis of the holistic ethos is required for medical pluralism to exist, where an understanding and tolerance of other viewpoints prevails. Kelner and Wellman (1997) and Frank (2002) argue that people who use heterodox health care services subscribe to a different ideology, where deep regard is given to holistic principles and serviced by their own ability and preparedness to pay independently for these services. Kelner and Wellman (1997, p. 204) go further to illustrate the priorities that this particular health care consumer may have: 'a holistic understanding of health as physical, mental, spiritual and emotional wellbeing, a commitment to a proactive and preventative role in their own healthcare, an emphasis on individual and personal responsibility for all health care decisions'. Their decisions are made proactively. This type of health care consumer behaviour has been referred to as ‘smart consumerism’, where the consumer of health care picks and chooses services that they believe will be of benefit to them as individuals (Kelner and Wellman, 1997).

There is a desire for some patients to claim back more control over their own health and have a greater influence on getting well and keeping well. When researchers compared the attitudes of patients of general practitioners with patients of heterodox practitioners (Cartwright, 2007; Jørgensen and Launsø, 2005; Blais, Maiga and Aboubacar, 1997; Kelner and Wellman, 1997; McGregor and Peay, 1996) they confirmed that the latter group tended to take a much more proactive role and show greater self-responsibility for their health (Clark-Grill, 2010). Further to this, patients have been found to resent their own expertise being discounted against that of hegemonic orthodox medicine (Hobson-West, 2005). This finding concurs with Leask’s (2009) conclusion mentioned earlier, where discounting mothers views was proven to be unproductive. Patients have been found to be seeking an autonomous experience (Hobson-West, 2005), but most significantly, self-care activists have broadened the idea of laypeople having the capacity to deal with their own health problems (Brown, Zavestoski, McCormick, Mayer, Morello-Frosch and Altman, 2004; Goldstein, 1999). This point is relevant to this current thesis, where participants were identified as continually navigating between orthodox and heterodox medicine in an attempt to autonomously make health care choices.

Non-compliance

Non-compliance, or asking too many questions about vaccinations, or accepted vaccine standards, may prompt unwarranted responses from orthodox health care professionals (Laine and Davidoff, 1996). Certain mothers who held alternative views were said to have experienced ‘heavy handed or patronising’ treatment from their orthodox practitioner (Poltorak et al., 2005, p. 713). Other authors have raised the issues of unwanted pressure that parents have experienced from health professionals (Evans et al., 2001) to comply with routine childhood vaccinations.

The widespread nature of patient non-compliance in all fields of health care (Russell, Daly, Hughes and Hoog, 2003) has been a concern since the 1970s (Jin, Sklar, Oh and Li, 2008). A large proportion of patients have not viewed all of the treatments advised by their orthodox practitioners as necessarily good or in their best interest (Zola, 1981; Russell et al., 2003). Non-compliance has substantial consequences for society (Marston 1970; Lund and Frank, 1991). 'Compliance is not only assumed to be in patients' best interests, but is also equated with a 'social good' (Russell et a.,l 2003, p. 282), as a result the non-compliant patient can be viewed in a negative light (Ingram, 2009), with failure to comply with a prescribed treatment often viewed as the patient's 'disobedience' (Vermeire, Hearnshaw, Royen, and Denekens, 2001. p. 332). Patient compliance is an expected behaviour in orthodox medicine, with non-compliant patients sometimes considered 'deviant, unreliable, irrational, and/or uncooperative' (Stimson, 1974, p. 99).

Compliance is defined as 'a form of yielding to a group' (Statt, 1998, p. 28). In health care, the most commonly used definition of compliance is that 'patient's behaviours (in terms of taking medication, following diets, or executing lifestyle changes) coincide with healthcare providers' recommendations for health and medical advice' (Sackett, 1976). Adherence and concordance are other terms suggested in place of compliance (Jin et al., 2008). The term concordance advocated by Vermeire et al. (2001) was thought to encourage the patient's role in decision-making, as the failure to consider individual patients' viewpoints was noted as an important aspect of patient compliance (Roberson, 1992). This thesis concurs with Russell et al's. (2003, p. 281) work, that acknowledged the significance of the social context of patients' lives, arguing that non-compliance is not just a matter of patients choosing not to follow recommended treatment regimes, but that accepting health care advice and subsequent behaviour is associated with, and adapted 'to fit with their beliefs, life situations and circumstances'. This line of thinking also concurs with Hayes-Bautista (1976) who asserted that non-compliance in the form of modification of treatment plans was a way that patients exerted control, when the patient was dissatisfied with some aspect of the plan. This theory can be likened to the manner in which some people avoid all vaccines, or employ certain vaccines. The use of separate vaccines will be discussed further into the chapter.

Non-compliance and coercion

Compliance appears to be concerned with improving health care, but may also have motive of control and power over patients (Russell et al., 2003; Playle and Keeley, 1998). The literature has made explicit and implicit assumptions regarding the 'obvious' benefits of compliance (Marston, 1970, Mulaik, 1992; Russell et al. 2003), in justifying the authoritative way that it has been employed in all fields of health care, including mass childhood vaccination.

Non-compliance in routine childhood vaccinations is thought to have broad health implications, both for the individual child who is raised without vaccines, and also for the wider community. Non-compliance in health care, and the power dynamics between patient and professional has been analysed by many commentators who have illuminated the challenges that non-compliance raises, both to professional knowledge, and to the role of patient and professional (Playle and Keeley, 1998). 'The institution of public health has served as a network of expert advice, embodied in professionals such as doctors and health promoters, who have dispensed wisdom directed at improving individuals' health through self regulation' (Lupton, 1995, p. 10). Although Hobson-West (2005, p. 13) argued that expert advice was 'unlikely to be seen as coercive because it appeals to the shared value of health', this thesis argues that expert advice can and indeed has been seen and experienced as coercive to some consumers of health care. Opposition and various forms of coercion have occurred by many actors from the inception of vaccination in the 1850s.

Rogers and Pilgrim (1995) found coercion to be a means of governmental control, whereby mass childhood vaccination had been linked to school entry, and child benefit payments in certain countries. In addition, and as an extreme example, coercion was demonstrated during the WHO (World Health Authority) attempt to eradicate smallpox from Asia (Streefland, 2001; Greenough, 1995). At this time the military style operation was justified for the purpose of containing serious outbreaks that were occurring. Greenough (1995) drew some important findings from the analysis of this example, concluding that vaccination should be built around trust and social demand. Greenough argued that the long-term effects of this operation might have been negative for other health campaigns that required official, professional and popular cooperation for success. The long-term effects of the coercive measures used in this operation have been argued to have contributed to trust issues associated with health care workers (Casiday, 2005). Although this particular coercive behaviour occurred in Asia and India during 1973-1975, this thesis demonstrates that coercion, on a less extreme level, exists and has been experienced by some people that have failed to comply with official and professional recommendations for routine childhood vaccinations.

Reasons for declining childhood vaccines

There is a strong body of literature describing the broad reasons why parents do not vaccinate their children. The wide range of reasons may include beliefs and values: parental attitudes, preferring other models of treatment, subscribing to alternative worldviews or particular religious views, and or certain views about the immune system. Concerns over vaccine safety also play a substantial role, so too, trust and confidence in the advice of orthodox practitioners. In addition, some people also may feel that a medicalisation of health has occurred.

Individual worldviews may be complex, and may not be consistent with the views of the dominant orthodox medical profession (Flynn and Ogden, 2004). Opposing views exist within the literature as to who is usually an objector to vaccination. Some commentators have illustrated that many parents have similar concerns in regard to vaccinating their children, regardless of whether they did or did not vaccinate them (Gust et al., 2005). These authors suggest that assuming that conscientious objectors are either for or against vaccination may be an inaccurate, broad generalisation. There is however a strong body of literature that describes a majority of non-vaccinators as having a preference for heterodox medicine (Downs, de Bruin and Fischhoff, 2008; Hamilton et al., 2004; Hobson-West, 2003; Pilgrim and Rogers, 1995; Zuzak, Zuzak- Siegrist, Rist, Staubli and Simoes-Wüst, 2008; Vernon, 2003; Simpson, Lenton and Randall, 1995).

Feiler-Mircus (2012) study conducted with a self-reporting anonymous questionnaire found that parents who did not vaccinate, or partially vaccinated their children, used heterodox medicine more than parents who gave their children all of the recommended vaccines. This study was particularly interesting as it was conducted in Israel, and examined the relationship between parents education and socio-economic levels, in relation to the use of heterodox medicine and the avoidance of vaccination. The study found that the use of heterodox medicine was more common in families within a higher socio-economic bracket, and also, that these parents tended not to vaccinate as they had preferences for a more natural approach.

This thesis concurs with Feiler-Mircus (2012) findings revealing concerns that were linked with vaccination and disturbances in the immune defense mechanism. Most significantly, this group had a different outlook on childhood diseases and classified some diseases as being beneficial to the development of the child’s immune system. This is a fascinating finding considering that some parents actively demand vaccines to protect their children from childhood contagious diseases. The ideology can be traced back to a heterodox philosophy where notions of health, illness and diseases may be viewed in a different light.

The philosophies of heterodox medicine are based on varying paradigms of health and disease, which are often opposed to the orthodox paradigm (Berman, Swyers, Hartnoll, Singh and Bausell, 2000). Heterodox medicine is an important consideration, as heterodox users have shown a preference for using these therapies in place of orthodox medicine, in order to support immune function through illness. Heterodox approaches appreciate that health depends considerably on immune competence, and therefore the immune system is given a predominant focus. Many heterodox approaches purport to sustain, restore or boost immunity. There are numerous publications describing the therapeutic efficacy of heterodox modalities that are thought to mediate their effects through the immune system (Azike, Charpentier, Hou, Pei and Lui, 2011; Rich, 2010; Santich and Bone, 2008; Mansberg, 2007; Daley, 2007; Kendon, 2006; Stevenson, Matthias, Banbury, Penman, Bone, Leach and Lehman, 2005; Goldrosen and Straus, 2004; Drew, 2000; Oates, 2010). Heterodox medicine views health as something holistic that can be strengthened by working with the ‘vital force’. The holistic health ethos accepts that the human body has a vital force. The vital force is an important factor for heterodox practitioners working with an individual’s health and healing. The vital force of an individual relates to the energy of a person, to their immune system and to the disease resistance of an individual.

The literature has found that the so-called ‘lay’ theories of risk, such as theories on immunity, to be important aspects for consideration (Cassell, Leach, Poltorak, Mercer, Iversen and Fairhead, 2006; Casiday, 2007). Lay and expert perceptions vary considerably; lay perceptions tend to focus more on the lived experience, about harm and uncertainty, and expert assumptions have focused on the quantifiable (Casiday, 2007). Green et al., (1999, p. 52) succinctly wrote: ‘it is less a case of understanding and reacting to information in a different, but no less valid way’. Immunity is a major argument put forward as the reason that some people are against mass childhood vaccination: ‘unlike the state definition of immunity which is based on educating the immune system, some parents believed that their children would be better off if their immune systems were allowed to develop naturally’ (Brownlie and Leith, 2011, p. 205). Alfredsson, Svensson, Trollfors and Borres (2004) also found that the major reason given by the parents in their study for declining vaccines for their children was the idea of strengthening the child’s immune system. Antibiotics, antipyretics and pharmaceuticals were avoided wherever possible, while the disease process and symptoms of disease were treated with natural remedies, whenever possible. Pharmaceuticals would only be called upon as a secondary option, after the body had the opportunity to use its own defences, with the belief that in doing so the immune system matures and develops (Glöckler and Goebel, 2007). This thesis supports the hypothesis that non-vaccinating participants were more likely to have preferences for heterodox medicine.

Risk

As mentioned earlier, vaccine refusal is not only based on philosophical foundations, or a varying model of health and disease. Many commentators have found risk to be a predominant concept around vaccine refusal (Bond and Nolan, 2011; Alaszewski and Horlick-Jones, 2003). Risk is a personal matter, with complex factors effecting risk perception amongst individuals (Hobson-West, 2005) and determined by understandings, cultural predisposition and social networks (Petts and Neimeyer, 2004; Casiday, 2007).

Risk disputes arise from different worldviews of what constitutes risk, and what threats society and or individuals are willing to accept as real, or relevant. Risk disputes may account for the judgments made on dissenters and their children: 'Risk disputes express points of tension and value conflicts within society' (Casiday 2007, p. 1061), where 'narratives of risk are pervaded by concepts of accountability, responsibility, liability and blame' (Nelkin, 2003, p. viii). The role of risk has been related to the erosion of trust in government and science (Casiday, 2007, p. 1062). Routine childhood vaccination is not a one-off decision, but part of a process whereby individuals make decisions about vaccination many times, over the course of the recommended vaccination schedule, through a comparison of risks (Hobson-West, 2003) therefore, risk and trust are inextricably associated in considering childhood vaccination.

Several authors and risk managers (general practitioners and government bodies), have attempted to place childhood vaccination into the category of 'acceptable' or 'rational' risk, which may not be consistent with the personal nature of risk perception. Risk disputes can evoke tension within communities where variant opinions on risk exist; including risks other than those associated with vaccines, such as genetically modified foods, exposure to certain chemicals, and the fluoridation of city tap water. Other risks identified by Cassell et al., (2006) were the risks associated with certain foods, for example a large number of the participants in their study were vegetarian and had concerns about genetically modified foods and BSE (bovine spongiform encephalopathy), otherwise known as mad cow disease. These authors identified that certain health behaviours had some association with food choices. In contrast to Cassell et al's study exploring the prevalence of health beliefs associated with non-compliance of MMR, this study had only a few vegetarians but most significantly, a high number of participants were concerned with food additives, genetically modified ingredients and processed foods. There was a clear reverence for healthy lifestyle and an awareness of eating more natural foods. This line of argument concurs with Martin (2000, p. 135) who hypothesised that resistance to vaccination was more about choosing ‘positive health’, rather than simply about vaccine refusal. There appears to be a connection associated with declining vaccines and certain health behaviours, as was indicated previously in other bodies of work (Cassell et al., 2006). The survey section of this thesis explored health behaviours and lifestyle choices in order to account for any correlation with other health related determinants, examining the frequency of exercise, as well as diet, drinking and smoking habits.

Mass childhood vaccination is said to be in the best interest of the child; yet no studies have asked unvaccinated people how they have experienced being raised in this way. Studies to date have focused on the decision-making of parents and how they can be influenced to change, rather than what can be learned from them and from their experience. One of the major disappointments of the literature was highlighted by Hobson-West (2005, p. 16) who described health promotion, and its literature as focused on correcting ‘misperception’, and most importantly, as only seeking to ‘understand sources of opposition in order to counter them’. Despite this accurate depiction being advocated to further understand risk, there is, and continues to be a lack of understanding for others that do not measure risk in the same manner. This approach may have contributed to the erosion of public trust and has done little to enhance progressive change or to alter the ‘misperceptions’ of non-vaccinators.

Risk and trust

Alongside risk, trust has been established as a fundamental concern in vaccine decision-making (Calnan and Sanford, 2004; Petts and Neimeyer, 2004; Benin et al., 2006; Casiday, Cresswell, Wilson and Panter-Brick, 2006; Bedford, 2008). The literature has identified how trust in orthodox practitioners has been compromised, and how trust is salient to an individual's sense of certainty in who they feel that they can trust.

The definition of trust and the expectation that the general practitioner will act as a fiduciary agent for the patient is clarified by Calnan and Sanford (2004), however other issues like target setting may complicate this expectation, where general practitioners may face certain pressures to reach policy objectives. Brownlie and Howson (2006) also identified target setting as a tool of governmentality, where ‘good citizens’ (parents) go along with the advice of ‘experts’ (orthodox practitioner), regardless of their own personal beliefs on the matter.

Hobson-West (2005, p. 141) noted that the vaccine critical groups in her study were aware of how the ‘conflicts of interests’ compromise the independence of individuals’, influencing the level of trust that parents place in orthodox practitioners. Vaccine critical groups are described as indicative of those that oppose the ‘imperative of vaccination’. Although vaccination is not compulsory, Hobson-West (2005) indicates that there is a vaccination imperative whereby individuals are subject to the tools of governmentality that portray vaccination as the ‘right’ thing to do. The vaccine critical groups are said to have resisted this imperative; by reframing risk, and by challenging professional expertise and by constructing the parent as the vaccine expert (Hobson-West, 2007, abstract).

Parental scepticism may be further exacerbated by the knowledge that general practitioners may have been offered incentives and target payments to reach policy objectives (Jewell, 2001). Raithatha et al. (2003) and Petts and Neimeyer (2004) found that financial incentives offered to orthodox practitioners to promote vaccinations concerned some parents, as it represented a conflict of interest, compromising the ability to provide impartial information and most importantly compromising parental trust. Hobson-West (2004, p. 91) described ‘vaccine-sceptical parents being struck off GPs lists in order to maintain a surgery’s uptake figures and associated financial benefits’. Scanlon (2002), a public health consultant, reported that there has been a manipulation of vaccine coverage in order to meet targets:

> Falling rates of vaccine uptake and the subsequent loss of income experienced by several general practices failing to reach payment targets have prompted some general practitioners to take unusual measures. They have temporarily removed children whose parents object to vaccination with MMR vaccine from their lists immediately before they would have been included in the target group for vaccination. These children are therefore excluded from the denominator for calculating vaccine uptake. The general practitioners concerned write to parents informing them of the ‘temporary measure’ and undertake to provide all usual services to these children at no cost. The immediate result is that vaccine uptake appears artificially high and general

> practitioners receive payment for reaching vaccine targets. After the payment deadline is passed the patients are accepted back on the list (Scanlon 2002, p. 733).

Target setting and its surveillance, has been identified as a tool of governmentality which is discussed further into the review. Even though some orthodox practitioners experience target setting as coercive, and were found to be critical of it, target setting is accepted because it is consistent with the orthodox medical rationale (Brownlie and Howson, 2006). A general practitioner from Brownlie and Howson's (2006) study commented that it was wrong to receive enticements and that some orthodox practitioners felt that their expertise had been undermined by target setting. As a related consequence of financial incentives offered to orthodox practitioners, Raithatha et al. (2003) found that parents felt pressured by medical professionals to vaccinate their children, with little regard for the needs or wishes of them as individuals. Furthermore, Leask (2009) found that orthodox practitioners had to balance their obligation to help parents make an informed choice, whilst receiving financial incentives to maintain high vaccination rates.

Several scholars have determined themes of risk and trust as significant concepts in health care systems, and more specifically in health interventions such as routine childhood vaccination (Brownlie and Howson, 2006; Gilson, 2003; Hobson-West, 2003; Taylor-Gooby, 2002). A lack of trust is argued to increase public responses to risk messages and lead to questioning decisions of authority, or anyone not perceived to be independent (Petts and Niemeyer, 2004). A growing number of people are said to mistrust the preventative strategies put forward by government agencies. Raithatha, Holland, Gerrard and Harvet (2003) found that some parents lack trust in government agencies and may also have doubts in the medical profession as the ‘managers’ of vaccine risk. This study concurs with the authors above where participants expressed doubts regarding the knowledge base and accuracy of doctors.

Previous studies have identified the pivotal role of trust that mothers have in their risk managers (government and health professionals) in regards to mothers making vaccine decisions about their babies (Benin, Wisler-Scher, Colson, Shapiro and Holmboe, 2006; Raithatha et al., 2003; Casiday, 2007) and highlighted the importance of the source of information that is considered trustworthy, with low confidence and trust in vaccine information sources linked with vaccination refusal (Meszaros, Asch, Baron, Hershey, Kunreuther and Schwartz-Buzaglo, 1996; Poltorak et al., 2005).

This thesis concurs with other commentators (Krantz, Sachs and Nilstun, 2004) that identified some parents mistrust of advice obtained by orthodox practitioners and perceived the information they received as imbalanced. In addition, this thesis found that people making vaccine decisions were calling on more balanced vaccine information, as was the case in other studies (Gust, Kennedy, Wolfe, Sheedy, Nguyen and Campbell, 2008b; Raithatha et al., 2003). Although information is a key factor in informed choice, and noted by Brownlie and Howson (2005), it cannot be assumed that the information is automatically trusted, or that different types of information may be sought after and accepted by different individuals.

When risk issues arise, trust is said to play a key role in decision-making (Brownlie and Howson, 2005). 'To trust is to believe despite uncertainty' (Misztal. 1996, p. 18) where parents are asked to trust in 'particular strangers' (Gilson, 2003 p. 11). It is clear that parents are acting in the face of many uncertainties when they make vaccine decisions, with Brownlie and Howson (2005, p. 227) finding that parents discuss these uncertainties as 'knowledge' gaps and express shame about not 'being informed'. The notion of becoming informed has placed pressure on certain individuals to know and to seek information. 'Patients therefore, tend to become experts on their own health and decide about their treatment on the basis of active trust' (Giddens, 1994, p. 132). The theme of patient becoming expert will be discussed later in the chapter.

Risk related to parental concerns

Risk is strongly associated with parental concerns. Raithatha et al. (2003) carried out a qualitative study to assess the vaccine risk perceptions of parents who vaccinated their children in order to understand more about vaccine risk acceptability. Vaccine risk acceptability was found to be influenced by several factors: a balance of risk versus the risk of infection and the trust that is held in risk managers. In this context, risk managers within our Western culture are considered to be general practitioners and government bodies (Raithatha et al., 2003).

Some parents' concepts of risk has regarded childhood contagious diseases as a fearful entity to avoid at all costs. In contrast, other parents, were found to have grave fears regarding the safety of vaccines: 'responses to vaccination campaigns range from active resistance, through passive acceptance, to active demand...' (Casiday, 2007, p. 1059). Raithatha and colleagues (2003) conducted an in-depth, qualitative study, which found that if parents' risk acceptability levels move past a certain level, they would then no longer vaccinate their children. Topics related to parents' vaccine risk perceptions were examined, and their findings were described as fitting in to the psychometric paradigm, with increased risk perception appearing to be related to a fear of adverse reactions, doubt in scientific knowledge, and a lack of control over the situation.

A notable shift is evident in parental concern, from that of preventing childhood contagious diseases, to that of vaccine safety (Glanz, McClure, Magdid, Daley, France, and Hambidge, 2009; Gust et al., 2008b; Poland and Jacobson, 2001; Chen, 1999), with some parents reported to be questioning mass childhood vaccination and some believing that vaccines overload the system and contribute to the causation of chronic disease (Glanz et al., 2009). This rationale represents those individuals that follow the holistic ethos of healing, aiming to avoid any possible long-term side effects that may be associated with orthodox medical interference, and specifically vaccination. Parents have also been reported to be cautious about long-term side effects, with one reason associated with having known somebody that experienced an adverse effect (Evans et al., 2001). The literature suggests that risk information needs to consider long-term effects for parents to be satisfied with reassurances from government bodies and biomedical health professionals. Evidence-based research regarding long-term effects of mass vaccination is needed, with Dew (1999) positing that long-term reactions can go unrecognised. Further to this, Casiday's (2007) study in the United Kingdom used focus groups and individual interviews to elicit information from parents on MMR vaccine decision-making, and found that parents' reports of children's adverse effects from vaccination had at times been disregarded.

Parents were found to be more worried about the adverse reactions to the vaccine rather than about the risk that the disease posed (Downs et al., 2008). Vaccine and safety concerns are a recurring theme in the literature (Gust, Darling, Kennedy and Schwartz, 2008a and Gust, et al., 2008b; Freed, Clark, Butchart, Singer and Davis, 2010; Ragan and Duffy, 2012). Evans et al. (2001) found that all groups participating in their study were concerned about the duration of protection and the need for booster shots, which raised doubts about the efficacy of vaccines. Further, there are unknown risks, as Hobson-West (2003) described, and some groups opposed to mass childhood vaccination have concerns regarding the ingredients of vaccines and the possible unknown long-term effects on human health, from an evolutionary perspective.

Concern over the side effects of vaccines has been marginalised due to difficulty in ascertaining cause. Adverse reactions to vaccines are thought to be difficult to prove, with adverse events said to be only recognised within a certain period. The possibility of long-term vaccine damage has been inadequately acknowledged by orthodox medicine. Adverse effects from vaccines have been linked with a wide variety of different conditions, for example Andrew Wakefield's (1999) research linking autism and bowel issues with the measles, mumps and rubella (MMR) vaccination. Despite this research being discredited (Elliman and Bedford, 2002) many parents believe that the issue has not been resolved or explored thoroughly enough, and are sceptical of government's reassurances of vaccine safety perceiving widespread bias in official statements of vaccine safety (Evans et al., 2001; Cassell et al., 2006).

Parental concerns regarding childhood vaccinations abound, despite subsequent studies demonstrating no link between vaccines, autism or inflammatory bowel disease (Serpell and Green , 2006). Dew (1999, p. 380) identified that: 'representations of disease and vaccination vary according to different groups, with orthodox medical health promotion groups and dissenting parents taking diametrically opposed views, and incommensurable positions on the assessment of risk from disease and risk from vaccines'. The combining of heterodox medicine with orthodox medicine, commonly known as integrative medicine, has brought with it some contradictory and competing discourse (Miskelly, 2006). Miskelly (2006, p. 244) explained that the models vary in the way that they view illness, the orthodox model aiming to make a diagnosis, as opposed to the heterodox model that 'focuses more on constructing a meaning for symptoms than defining or labelling an actual illness or condition'. This competing discourse is particularly apparent in childhood routine vaccination, where an obvious dichotomy exists.

Risk and misconceptions

The literature revealed that parental misconceptions were problematic in the uptake of childhood vaccines. New and Senior (1991), found that there was a general assumption that parents were ignorant about vaccination and would comply with vaccination once they were 'properly educated'. White and Thomson (1995) argued that it was narrow minded to assume that parents were in need of being educated with regards to mass childhood vaccination, with Dew (1999) observing that the focus has always been on improving vaccine delivery information, for the purpose of improving vaccine uptake, rather than to understand a different ideology. Similarly, Hobson-West (2004) noted that government material was targeted at correcting parents' 'miscalculations' of risk associated with the MMR vaccination.

Hobson-West (2004, p. 96) asserted that 'Risk, devoid from its social and cultural context, loses most of its meaning' . Therefore, strategies, such as showing risk statistics and providing information to parents on the dangers of childhood diseases, in the name of 'educating' them, will do little to convince those that have a different worldview of health and illness. These attempts to 'educate' have a major flaw, in that they fail to understand the importance of the social and psychological factors that influence vaccine decision-making (Hobson-West, 2004). Developing insight, understanding and tolerance for other disparate views may be a more constructive means of dealing with non-vaccination and risk discourse.

The World Wide Web has been implicated in the 'wrong' type of vaccine information being accessible, and related to misconceptions regarding mass childhood vaccination, predominantly from anti-vaccination groups. Serpell and Green (2006) noted that parents use websites to seek out information, and Ziebland (2004) nominated health sites and discussion sites as the most popular websites on the Internet, impacting many aspects of health communications. As described by Ziebland (2004), this free access to information results in both a positive and negative effect. The patient interested in self-care, referred to as the 'expert patient', may not have the same reliance on doctors and their time, as medical information is readily available online. However, individuals that rely on the Internet for health care information must be wary of misinformation. High levels of discernment skills are required in knowing what health information to consider and what to ignore. The ability to discuss health care options with a qualified health care practitioner is invaluable.

Ziebland's study (2004) specifically looked at cancer patients, and the benefits that arise from utilising technology, like online support groups, and access to information available on the Internet that may be difficult to discuss. One of Ziebland's interviewees was in a situation where neither his general practitioner, nor his medical specialist were willing to provide information about different treatment choices, he therefore consulted the Internet for details of other available treatments. Vaccine communications may bear some similarities, where individuals are seeking more detailed information that they are not receiving from their health care practitioners. Several studies have found that many parents are not satisfied with the vaccine information that they receive (Wallace, Leask and

Trevena, 2005) and had accessed the Internet as result of this dissatisfaction (Smaibegovic, Laing and Bedford, 2003; Harrington, Woodman, and Shannon, 2000). In the Hamilton et al. (2004) study, adequate information was defined as impartial and accurate, in relation to the risks and benefits of vaccination.

Vaccine decision-making

Since the 1950s the vaccination schedule has become increasingly complex with much controversy and concern stemming from divergent views in weighing up risk of diseases compared with the side effects of vaccines (Petts and Neimeyer, 2004).

> The encounter between individuals and society raised by public health interventions is also morally complex and contains an implicit challenge to autonomy, since for every measure to improve the health of a group there will inevitably be a price to pay by the individual. A preventative measure, which brings much benefit to society, may also offer little to each participating individual and even contain the risk of unwanted side-effects (Krantz et al., 2004, p. 172).

In keeping with the literature, this study also found that mothers were the main decision-makers in regard to whether or not a child would be vaccinated, and ensuring that they either receive or avoid their vaccinations (Kriwy, 2012; Gust et al., 2008b; Brownlie and Howson, 2005; Petts and Neimeyer, 2004; Luman, McCauley, Shefer and Chu, 2003; White and Thomas, 1995). Mothers have been found to be primarily responsible for the health care of their children and this study reflects that sentiment.

Women are exhorted to take precautions before, during and after pregnancy to enhance the optimum health and development of their children. As a result, health conditions or problems or developmental delays in children are often attributed to their mothers failing to respond appropriately to expert advice concerning appropriate health promoting behaviours (Lupton, 2011, p. 638). Brownlie and Leith (2011) asserted that it is the mother who is judged on the infant’s wellbeing and to be seen as acting in the child’s best interest. ‘The pervasiveness and strength of this norm means that decisions made about babies have the potential to impact on the moral identity of the parent, particularly the mother’ (Brownlie and Leith, 2011, p. 199). Moral responsibility for Krantz et al. (2004) signified allowing individuals to freely decide what they believed to be right. Social responsibility was more narrowly defined as doing what was best for society. Vaccination can be interpreted as a social good, depending on acts of parental citizenship, whereby social programs such as vaccination call for every citizen to participate (Brownlie and Leith, 2011).

Omission bias was also found to be an important factor in decision-making, whereby parents were found to feel more responsible if the child died from a vaccine-adverse reaction, than by a decision to withhold vaccination from the disease itself (Brownlie and Leith, 2011; Asch, Baron, Hershey, Kunreuther, Meszaros, Ritov and Spranca, 1994). The anxiety over making ‘the right decision’ is also noted by Hobson-West (2007) and Sporton and Francis (2001), who found that parents that were actively involved in the decision-making felt a far greater sense of responsibility for any adverse effects related to their decision. When raising concerns with their orthodox practitioners, Casiday (2007, p. 1065) reported that parents experienced negativity when they attempted to question vaccines. Further to this, orthodox practitioners were not seen as providers of balanced information (Sporton and Francis, 2001), with Rogers and Pilgrim (1995) finding that health practitioners were perceived as an obstacle to making an informed choice.

Other authors had similar findings, with parents feeling pressured to vaccinate and practitioners not too concerned with individual needs (Raithatha et al. 2003). Jackson, Cheater, Peacock, Leask and Trevena (2010) noted that a large proportion of parents were unconvinced that the MMR vaccine was safe and (62% of 69 interviewed) concluded that their vaccine decision was not informed, despite having had their children vaccinated. Important themes have developed from a number of studies that relate to barriers to decision-making, including a ‘lack’ of balanced information and a lack of sharing information (Petts and Neimeyer, 2004). Health practitioners at the forefront of providing information to parents were found to be providing unbalanced information, with several studies revealing that it is essential for parents to be given accurate information concerning the pros and cons of vaccination (Gust et al. 2008b; Senier, 2008; Sporton and Francis, 2001).

Although it is acknowledged that there is strong imperative to obtain knowledge regarding vaccination (Hobson-West, 2005), Petts and Neimeyer (2004) found that parents felt a lack of control in accessing information, with a frustration that health professionals in the health service had little time to relay information. Low exposure to official or ‘real’ information was noted, with vaccination leaflets perceived as aimed at persuasion rather than information (Raithatha et al., 2003). Informed choice in terms of vaccine decision-making requires an availability of balanced information from a variety of sources, including both the advantages and the disadvantages, where the decision-maker can truly weigh up the benefits of either decision.

A lack of information is associated with complications in the decision-making process (Alaszewski and Horlick-Jones, 2003). Negative attitudes towards vaccination were found to be compounded by a lack of accessible information as well as by conflicting advice (Raithatha et al. 2003; Bond and Nolan, 2011). As Lewendon and Maconachie (2002) described, too little information is given about risk, making it difficult to make an informed decision. Further to this, Bond and Nolan's (2011) qualitative study conducted in Australia found that a lack of trust and poor communication between providers and parents exacerbated the belief that information was being kept from them, which resulted in frustration and anger for the parents involved. Informed choice on the other hand, denotes that an egalitarian relationship exists between orthodox practitioner and health care consumer, whereby the practitioner passes on the pros and cons of the various choices. In this ideal situation, the consumer then makes decisions autonomously from an empowered position (Frank and Stollberg, 2002, p. 226). Communication of risk is a crucial and sensitive step that may contribute to trust issues which then in turn may affect the consumer's health care decisions.

Decision aids have recently been implemented to aid parents in vaccine decision-making. Decision aids help to prepare people to participate in decisions that involve weighing advantages, disadvantages, and scientific uncertainty (Stacey, Bennett, Barry, Holmes-Rovner, Llewellyn-Thomas, Lyddiatt, Légaré and Thomson, 2011). The decision aid was implemented following a decrease in vaccine uptake, for the purpose of providing written and graphical information to assist with decision-making, helping individuals to understand relevant information and clarifying their values about the benefits and risks, to feel supported and to actively participate in decisions about their health (Jackson et al., 2010; O'Connor, Stacey, Entwistle, Llewellyn-Thomas, Rovner, Holmes-Rovner, Tait, Tetroe, Fiset, Barry and Jones, 2003).

Jackson et al. (2010) evaluated a web-based MMR decision aid in the North of England using a questionnaire and telephone interviews. Their findings revealed that over half of the parents in their study felt that the decision aid was slanted towards MMR. Delivering balanced information has been established in the literature as salient (Senier, 2008), although balance may be difficult to achieve because individuals have different views of balance depending on their own experiences, values and opinions. Jackson et al's. study is particularly interesting and relevant to this thesis as its findings show that promoting informed choice is the most effective strategy for vaccine uptake. Persuasion and/or coercion has been found to be counterproductive to vaccine uptake. One could conclude that providing more balanced information may be a means of embracing a diverse range of health care consumers and providing them with the information that enables them to make an informed decision.

Raithatha et al. (2003) concluded that pressuring parents to vaccinate was a negative outcome, which increased their feeling of lack of control. Leask (2009) concurred with this finding and advised a framework of communication and shared decision-making between general practitioners and mothers, to inform rather than persuade mothers about vaccinating their children. Previous studies have been focused on persuading conscientious objectors to comply with the orthodox model, rather than on creating insight, understanding (Hobson-West, 2003; Raithatha et al., 2003) and acceptance of other worldviews. Persuasion and coercive tactics were found to be counter-productive, leading to a decrease in trust of general practitioners (McMurray, Cheater, Weighall, Nelson, Schweiger and Mukherjee, 2004). Most importantly, Leask (2009) observed that it was detrimental to discredit a mother's source of information. Leask's Australian study and its findings were particularly relevant to this thesis, where similar associations were found and where the philosophy of an individual had been instrumental in their decision-making. Likewise, discrediting their views was found to be unproductive, and did not alter participants vaccine decision-making.

Patient-centered medicine

The erosion of public trust in health care, social and cultural changes, a decline in deference to authority and also a reliance on personal judgements of risk, are all said to be factors associated with a changing panorama, evident in health care choices (Calnan and Sanford, 2004). Western countries have seen immense change in health care. This shift has been termed patient-centered care. The term was first coined by Balint (1969, p. 269) who wrote that each patient 'has to be understood as a unique human-being'. From this definition Duggan, Gellar, Cooper, and Beach (2006, p. 274) argued that '[o]ne cannot be truly patient-centered if one lacks the attitudes and beliefs that underlie patient-centeredness, namely that all patients are unique individuals (as emphasized by Balint)'. Here lies a dichotomy in itself: the individual is emphasised as unique, yet modern health promotion has focused on not being individualistic with the herd immunity concept held as the ultimate sacrifice to self. ‘Self-determination means an individual cannot be coerced into accepting particular roles or responsibilities, however beneficial this might appear to others’ (Elliot and Turrell, 1996, p. 45).

Patient-centered care was an important part of the patients rights movement defined by Laine and Davidoff (1996, p. 152) as ‘closely congruent with and responsive to patients’ wants, needs, and preferences’. Patient-centered care involves sharing power and responsibility between the doctor and the patient and giving information to patients so that they can actively participate in decision-making (Lipkin, Quill and Napodano, 1984; Grol, de Maeseneer, Whitfield and Mokkink, 1990; Winefield, Murrell, Clifford and Farmer, 1996). Patient-centered medicine arose out of concern for the ‘over authority’ of orthodox medical practitioners on the individual and their autonomy (Parker, 2001). Duggan et al. (2006, p. 273) concluded that patients-centeredness ‘occurs when a physician encourages the patient to become an active participant in his or her own care. Rather than envisioning the patient as a passive ‘recipient’ of care, a physician should empower patients to ask questions, receive and understand information, and participate in his or her own health care decisions’. This thesis concurs with Caspi, Sechrest, Pitluk, Marshall, Bell and Nichter (2003, p. 61) who identified the contradiction in the patient-centeredness approach, noting that only a minority of heterodox users had open communications with their orthodox practitioners, due to a fear of being marginalised and intimidated by the medical establishment that is said to have ‘limited tolerance for alternatives outside of mainstream practices’.

The changing panorama in health care has brought about a changing culture of provider/patient interaction where health care consumers have increasingly sought information about illnesses and active participation in health care decisions (Woolf, Chan, Harris and Tunis, 2005; Benbasset, Pilpel, and Tidhar, 1998). Previously, health interventions were an issue for medical professionals only; more recently the general public have pursued opportunities to voice their needs and wants (Krantz et al., 2004, p. 172). Individuals will frequently take a stand on issues they consider important (Connelly, Keele, Kleinbeck, Schneider, and Cobb, 1993). Changing demands from health care consumers has shifted boundaries of what is considered a reasonable price for remaining healthy, creating the need for a new ethical model (Krantz et al., 2004). Parker, Staggs, Dayan and LeBaron (2006) acknowledged that different approaches were necessary for populations that held different belief systems. The majority of research has focused on finding out about parents’ decision-making processes, with the intention of improving uptake and understanding how the vaccination message can best be disseminated to the population that choose not to vaccinate, rather than accepting another worldview and implementing health care services that would better support their needs. The changing culture of physician-patient relationship was noted by Gust et al. (2005) who observed that patients wanted to be involved and informed in their own health care and in making health care decisions.

This changing panorama has brought with it patients and parents wanting and demanding information that they can use in order to make an ‘informed choice’. This is said to be the art of patient-centered care, and for some patients the ‘right to know’ is a salient issue. However, determining the appropriate amount of information and participation may also be an important aspect. For example, McMurray et al. (2004, p. 524) study revealed that information needed to be contextualised for the individual rather than just mass produced in promotional material. Most importantly, McMurray and colleagues (2004, p. 524) revealed that ‘parents need to be seen as partners in a learning enterprise, rather than passive receptors or empty cognitive vessels waiting to be filled’. McMurray et al’s findings were particularly relevant to this thesis that saw participants seeking a contextualised representation of their health care choices.

Negotiation has been nominated as a key strategy for resolving differences between patient and practitioner. Quill (1983, p. 229) defined the negotiation process whereby the process is undertaken by two people ‘with relatively equal power willing to be influenced by one another’. The process is said to require that each person identify their position and then attempt through compromise to achieve a common understanding. This recommendation may be a way forward, however some major hurdles exist in shared decision-making due to variant views and opinions. For example in Leask's (2009) study that questioned Australian orthodox practitioners about dealing with vaccine non-compliance, one compromise was considered offering a non-consenting mother ‘immunoglobulin and penicillin’ instead of a tetanus vaccine for her child. This compromise may have been acceptable to the orthodox practitioner, with orthodox views, however for the mother with variant views, it may not have been acceptable. Therefore resolving differences between patient and practitioner may be more about understanding that diametrically opposed views about health and disease prevention cannot always reach compromise, but require an acceptance of different views. As one orthodox practitioner described, it was most important to convey the message that it was the mother's own choice, acknowledging vaccine risks but operating from a more value neutral position. This finding concurs with

McMurray et al. (2004, p. 525) who emphasised the importance of practitioners presenting themselves as neutral professionals. This is particularly important considering that practitioners are no longer their patients' only source of information, with patients actively seeking out a variety of knowledge sources (Alaszewkski and Horlick-Jones, 2003). Leask (2009, p. 119) concluded in her study, where orthodox practitioners have tended to adopt the role of 'persuader rather than informer', recommending a communication framework of shared decision-making as a means of overcoming such challenges. In theory, shared decision-making appears to be an excellent way to attend to both patient and practitioner principles, however it could be argued that the dominant orthodox medical model leaves minimal capacity for such negotiation.

Power and control are described by Mead and Bower (2000, p. 1089) as having a history in the doctor–patient relationship, particularly socio-political critiques of medical patriarchy that called for change and 'greater recognition of the legitimacy of lay knowledge and experience, and greater respect for patient autonomy'. Further to this, as some participants that were raised without routine childhood vaccinations have described, they felt silenced by orthodox practitioners on vaccination issues. For these participants their lifeworld differs from the voice of medicine. As Mishler (1984, p. 63) elucidated, the 'voice of medicine' may interrupt the 'voice of the lifeworld' stripping away the personal meaning of illness. As observed by Dew (1999, p. 380), dissonance may exist between health promotion vaccine campaigns and the 'lived experience of the populace'. Patient-centeredness is a 'morally desirable feature of physician–patient interaction' (Duggan et al., 2006, p. 275) but clearly has its own challenges.

The shared decision-making model has issues with balancing power although positive health outcomes have been reported from incorporating this model (Mead and Bower, 2000). Duggan, et al. (2006, p. 273) argued that the '[g]enuine sharing of power, and genuine respect for autonomy, encourages patients to deliberate and form preferences'. Thus, shared decision-making as part of the patient-centeredness model clearly has inherently valuable features, however further dimensions on patient-centeredness for the heterodox user need to be explored.

Patient empowerment

The concept of patient empowerment was introduced by Rappaport (1987) and defined as a process by which people could gain mastery over their own lives. Patient empowerment has become an important principle for health care theory and practice (Rappaport, 1987). Patient empowerment was born out of the new public health ideals that attempted to involve citizens in their own health and community practices. It was devised as an integrative approach for the purpose of promoting the discourse of empowerment and participatory methodologies to promote health citizenship (de Souza, 2011). Ultimately, the goal of the new public health introduced in the late 1970s was to promote and protect the health status of both the individual and society (Tulchinsky and Varavikova, 2010).

Patient empowerment has played a crucial role in patient compliance with medical procedures, as well as preventative health care behaviour (Roth, 1994) and according to Roter, Hall and Katz (1988) has been particularly salient due to the emphasis placed on preventive health care and self-care. ‘Empowered patients attempt to take charge of their own health and their interactions with health care professionals’ (Roberts, 1999, p. 82). In this way, patient empowerment was seen to be beneficial to public health.

Definitions vary considerably in their emphasis on individual or collective responsibility for health, and on empowerment as either a process or an outcome (Tones, 2001; Israel, Checkoway, Schultz and Zimmerman, 1994; Rissel, 1994; Gibson, 1991). Funnell, Anderson, Arnold, Barr, Donnelly, Johnson, Taylor- Moon and White (1991, p. 38) initially defined the empowerment process as ‘the discovery and development of one’s inherent capacity to be responsible for one’s own life’. These authors added to the definition: ‘Fundamentally, patient empowerment is an outcome. Patients are empowered when they have the knowledge, skills, attitudes, and self-awareness necessary to improve the quality of their lives’ (p. 103).

Empowerment in health promotion means ‘a process through which people gain greater control over decisions and actions affecting their health’ (Nutbeam, 1998, p. 354). Health promotion may be considered empowering in the sense that something can be done about one’s own health with the personal choices that are made. However, critics have argued that the new public health puts pressure on individual citizens to be responsible for their own health and health care, while the role of the state in the provision of health care services and healthy environments is diminished (Zoller, 2005; Laverack, 2004; Petersen and Lupton, 1996). This theme can be likened to the ‘informed body’ whereby education and information about ‘healthy’ lifestyles is intended to change and to encourage certain health behaviours (Lupton, 1995). Other commentators (Henwood, Wyatt, Hart, and Smith, 2003) have suggested that the growth in health information availability has transformed the patient into a reflective consumer, making active decisions concerning treatment procedures.

The highest level of empowerment is said to occur when patients exert control (Connelly, et al., 1993). Education has been described as an important part of developing empowerment and a sense of control, becoming an active participant. Patients feel more in control and responsible for their health, which in turn encourages patients to ask more questions and to be more active. Patient consumerism arises when patients acquire various sources of information apart from that of their orthodox practitioner (Fang, Miller, Rizzo and Zeckhauser, 2011). Patient consumerism has meant that some patients are no longer willing to accept whatever their orthodox practitioner recommends, but require adequate information to process, so that they agree to and trust the course of treatment recommended (Haug and Lavin, 1981).

Reflection is said to be key in this process and tends to involve people who question taken-for-granted beliefs and practices (Jacobs, 2008; Mezirow, 1991; Freire, 1970). The patient empowerment dimensions indicate the need for health care providers to communicate with patients in an ‘open’ manner. An empowerment approach encourages a shift from a paternalistic model to a shared model of decision-making (Jackson et al., 2010) with a corresponding emphasis on promoting informed choice. This model of empowerment is complicated in that education may be perceived in various ways, and may become problematic when disagreement occurs about what constitutes knowledge, and education about behaviours that experts identify as conductive to health. This disagreement may be evident in beliefs about vaccination and the immune system. Routine childhood vaccinations have traditionally been justified, both for the best interests of the child, and for public health benefits (Krantz et al., 2004). However, there are variant perspectives on these claims and people search for the right to self-determination, which ultimately, may not conform with dominant ideas about health and health maintenance. Concurring with Isaac, Kilham and Marshall (2004), this thesis argues that best interest considerations in vaccination should acknowledge the fact that children grow up as part of a family and are also likely to oppose vaccination as adults.

Critics of patient empowerment have argued that the notion is problematic (Fox, Ward and O'Rourke, 2005), suggesting that doctors are strongly resistant to the notion of expert patients. Further to this, consumerist patients are said to place time demands on physicians (Fang et al., 2011) and as a consequence may be viewed with disfavour. Empowerment of patients is portrayed as an unproblematic solution for positive health outcomes 'without critical attention to the theoretical underpinnings of the concept (Spencer, 2012, p. 116). Comparably, Labonte (1994) asserted that health promotion has naively proclaimed that the community is the solution to all sociopolitical and economic health problems; affirming that health promotion is both empowering and disempowering.

Health promotion has purported to 'acknowledge diversity' and claims to recognise 'multiple discourses on health' allowing for 'those whose voices are often ignored or left out' (Robertson, 1998, p. 159). Disempowerment may occur with social labelling which may devalue patients' feelings, ideas, values and beliefs, as described by Hasenfeld and Chesler (1989), who examined empowerment in human services such as self-help groups and organised support systems, and found that social labelling was considered a barrier to empowerment. Moxley and Freddolino's (1990) model of advocacy was thought to be similar to empowerment (Connelly et al., 1993) where patients were encouraged to make and be responsible for their own decisions. The main flaw of empowerment, especially in the realm of health promotion, was identified by Rissel (1994), who noted Rappaport's (1987) lack of clear distinction between people as individuals, as opposed to collective groups.

In line with the literature, this thesis concurs with these commentators findings that knowledge was actively sort by participants in an attempt to make informed decisions about health care. However, the suggestion that providing more medical information would in itself, increase parent understanding, is not supported. Most importantly, the information would need to be balanced and need to address lay knowledge. Concurring with Cassell et al. (2006, p. 793) findings describing that 'there is a need to engage with, and share the discourse of, concepts of immunity which western science and medicine explicitly reject'. Further to this and going beyond Cassell et al's recommendation, simply engaging with and sharing the discourse of lay knowledge would be insufficient. The lay knowledge would have to be thoroughly explored and disproven in a credible manner for this approach to be effective.

Expert patient

The notion of the ‘expert patient’ has emerged out of health care policy that planned to ‘modernise’ the health services (Wilson, 2001, p. 134). Patient expertise has been associated with empowerment and a user-friendly health care experience (Fox et al., 2005). Expert patients, according to this view, are those who can manage their own illnesses and conditions by developing knowledge relevant to maintaining health and countering illness (Shaw and Baker, 2004). Ziebland (2004) offered insight into the compelling need to become an ‘expert’ patient, noting that ‘[t]he ability to access health information on the Internet may provide patients with an opportunity to display a particular modern marker of competence and social fitness’ (Ziebland, 2004, p. 1792).

The concept of the ‘expert patient’ was initially developed to focus upon individuals with chronic illness (Wilson, 2001). The titles ‘expert’ and ‘patient, evolved from the concept of the active patient (Neuberger, 1999; Roberts, 1999), although Neuberger (1999) argued that ‘active’ and ‘patient’ are a contradiction of terms, considering the Latin meaning of patient was to suffer or to bear, with an implicit assumption of passivity. Hobson-West (2005; 2007) described the concept of the ‘expert patient’ as advocated by the Department of Health, explaining that the vaccination imperative was an important aspect of the resistance model, where parents have become self-educated, which equates to personal responsibility. Brownlie and Howson (2005) also noted this imperative of parents to become knowledgeable for the sake of protecting their children, as a result of increased availability of knowledge, personal research is encouraged by other parents, as well as by health professionals. Leask’s (2009, p. 122) qualitative study, revealed that orthodox practitioners had recommended women to ‘more reliable’ websites to select the sources of information that were preferential to orthodox professionals. This tactic failed to consider that information appeals differently to individuals, and the selection of ‘certain’ sources of information may reflect bias to the health care consumer. This may lead to distrust of the physician and as a result, the patient may search for other sources of information.

Health communications in general has assumed an ignorant and passive audience (Tulloch and Lupton, 1997, p. 32). However, the review of the literature found that many non-vaccinators tended to be educated, and did not passively receive the messages of health campaigns and health professionals, but rather assimilated information from a variety of sources (Dew, 1999). The literature found that personal research for vaccine related information often included searching for recommended books, contacting parents’ groups for advice, searching the Internet, balancing the claims of individual mothers and the perspectives of anti-vaccination campaigners, and investigation on the history of science, public health and immunology. According to Alfredsson et al. (2004) however, few parents, whether vaccinators and non-vaccinators, had acquired information from the Internet.

Hamilton et al. (2004) nominated the orthodox practitioner as the parents' most important source of information in New Zealand. Hamilton et al. (2004) found that many parents believed information provided by their orthodox practitioner to be biased in favour of vaccination, and added that the side effects of vaccines had been minimised. Similar to this current study, Hamilton et al. (2004) revealed that pamphlets and booklets provided by the Ministry of Health and Immunisation Advisory Centre were funded by the Ministry of Health in New Zealand and clearly promoted vaccination. These sources were viewed as biased 'propaganda' by their participants, as was the case in this thesis, where government sources of vaccine information were dismissed as inadequate. These parents were seeking out balanced information about advantages and disadvantages. Because of this gap in information, parents may seek out their own sources of information, which may not be evidence-based. Bond et al. (1998) found that the information passed on to parents 'who require this depth of information' should acknowledge that some of these diseases are relatively mild but unpleasant, and that there can be serious complications from certain diseases. Other authors have also acknowledged that vaccines can cause harm (Poland and Jacobson, 2001).

The research process was purported by Poltorak., et al. (2005) as rarely satisfactorily concluded by any vaccination choice, but rather as accentuating a sense of doubt; only those mothers who researched to support a previously felt position, resolved upon a final decision that they felt clear about. The path to becoming an expert patient can be a complicated process, with pressure, difficulty and anxiety reported as part of the process (Casiday, 2006).

Information exchange was nominated by Fox et al. (2005) as the first step in becoming an 'expert patient'. Similarly, Petts and Niemeyer (2004) also found that parents had actively sought out information from health professionals and interpreted this information with the influence of their own beliefs, and the influence of their social networks. Through critically analysing the significance of the expert patient, and its contextual relationship to holistic ontological beliefs, it becomes possible to move beyond the simplistic biomedical account of health and illness, and recognise a discourse of wellbeing, involving individuals' own experiences, perceptions and conceptualisations of the body, health and illness as integral components of health care choices.

Single vaccines versus multiple vaccines

Vaccinations are often administered as multiple vaccines for obvious economic reasons and convenience. This had led to safety concerns associated with the administration of multiple vaccines, which were thought to have become an issue following Wakefield’s (1999) research that advocated single vaccines as a possible safer option. Thus, single vaccine options have joined the debate regarding safety concerns of overburdening the system. Some parents were found to believe that vaccines overload the system and cause chronic disease (Glanz et al., 2009; Hilton, Petticrew and Hunt, 2006; Offit, Quarles, Gerber, Hackett, Marcuse, Kollman, Gellin and Landry, 2002) although there is no evidence base to suggest that this is a factual hypothesis.

The use of single vaccines has emerged from the parents’ perspective as a possible safer way of giving vaccines to children, despite professional bodies reassurances that the measure is unwarranted. This development coincides with the erosion of trust where parents have expressed doubts about vaccines, despite assurances from risk managers (government bodies and health practitioners). Dempsey, Schaffer, Singer, Butchart, Davis, and Freed (2011) estimated that one in ten parents of young children were using an alternative vaccine schedule. An alternative schedule was considered to be a schedule other than what was recommended by the health authorities. This was further defined as either declining certain vaccines, or delaying vaccines until the child was older. In addition, the Dempsey et al. (2011) study found that there was a great potential for many more parents to change from their current practice of complying with the recommended vaccine schedule, to implementing an alternative schedule. Parents were found to request separate vaccines with the rationale that, given separately, they are less likely to cause an adverse reaction.

The use of single vaccines and or delayed vaccination was also noted by Casiday (2006) as a strategy that some parents employed when faced with uncertainty and contradictory information. Other parents noted that they felt pressured to consent to multiple vaccines rather than pursue the use of single vaccines (Brownlie and Leith, 2011). A strict vaccine schedule and combination vaccines may be a hindrance to the flexibility favoured by certain health care consumers. Mollema, Staal, Van Steenbergen, Paulussen and Malker's (2012) noted that a large percentage of anthroposophical patients in the Netherlands wanted more flexibility to pick and choose which vaccines were administered. Mollema et al's study including an anthroposophical perspective was of particular interest to this thesis, as there were a portion of participants with an anthroposophical background that represented a similar perspective.

Herd immunity

The concept of herd immunity was first coined a century ago (Topley and Wilson, 1923) and has re-emerged in contemporary debates regarding vaccination. Mass childhood vaccination relies on herd immunity (Hobson-West, 2003) for the rationale of 'reducing the circulation of pathogenic micro-organisms within a population' (Rogers and Pilgrim, 1995, p. 73) and is therefore an important consideration for discussion.

Herd immunity is described by Doroshenko and Halperin (2007) as preventing infection in vaccinated individuals and preventing the spread of infection in vaccinated communities. This effect is explained as occurring when the majority of the population is vaccinated; it lowers the probability of the transmission of the disease from an infected person to other individuals (Doroshenko and Halperin, 2007). The effects of herd immunity depend on several factors, but most importantly the greater the number of immune individuals in a community, the less likely it is for the exposure and spread of infection to occur in a community (Doroshenko and Halperin, 2007).

It is important to outline the perceived advantages and disadvantages of herd immunity in order to gain a more thorough understanding of the concept and the way that different individuals may interpret the phenomenon. The advantages of herd immunity are demonstrated historically with the eradication of smallpox (Bond and Nolan, 2011) following a global vaccination effort. Herd immunity is said to be responsible, as eradication of the disease occurred despite the presence of unvaccinated people. Polio and Meningococcal serogroup C disease are also reported to have fallen rapidly after vaccination campaigns. The benefits of herd immunity are of particular importance for people who are immunocompromised and cannot receive vaccines (Doroshenko and Halperin, 2007; Fine, Eames and Heymann, 2011; Luyten, Vandevelde, Van Damme and Beutels, 2011). Newborns are a particularly vulnerable group relying on herd immunity. In the first instance, three doses of the vaccine are required to provide adequate protection to pertussis, which often does not occur until six months of age. In the second instance, newborns have a high rate of exposure to older family members and health care workers who may be a source of disease transmission (Forsythe, 2007).

The disadvantages of herd immunity are outlined by Doroshenko and Halperin (2007, p. 38), who suggested that there may be long-term effects of herd immunity due to the disruption of the 'natural balance of infections in a population, resulting in a shift in the age of susceptible individuals'. Widespread vaccination programs amongst children may reduce the incidence of infection that may lead to future changes in the age distribution of cases. These authors provided an example of when this is thought to have occurred in the United Kingdom, during 2005, where an outbreak of mumps affected 40,000 young adults, as opposed to children. Several participants in the present study were especially concerned about the impact of vaccinations interfering with the natural cycle of health and disease. Further to this argument, Doroshenko and Halperin (2007) nominated various diseases caused by serotypes; a pathogenic strain, not included in the vaccine and causing significant infections. These authors provided an example of the PCV-7 (pneumococcal conjugate) vaccine that was introduced into the routine vaccination schedule, which brought about associated risk of other diseases, such as otitis media (Doroshenko and Halperin, 2007).

Fine, Eames and Heymann (2011, p. 915) illustrated that consequences that have arisen from herd immunity, stating that 'herd immunity is not the same as biologic (immunologic) immunity, individuals protected only by indirect herd effects remain fully susceptible to infection, should they ever be exposed'. They asserted that this problem manifested with measles, mumps and pertussis outbreaks in adulthood. These adults were protected by herd immunity as children and therefore did not experience the childhood diseases, creating an accumulation effect. Other possible negative effects of herd immunity have also been associated with varicella vaccination programs, which have reduced the incidence of chicken pox and reduced adults exposure to the virus. 'Varicella infection can present as an acute condition, chickenpox, mostly affecting children and as a reactivation of dormant infection leading to presentation of zoster in later life' (Doroshenko and Halperin, 2007, p. 39). This lack of exposure is argued to have impeded adults from gaining a natural immune boost, which has resulted in an increase in the incidence of the more serious form of shingles in adulthood and counterbalanced the benefit in children (Brisson, Edmunds and Gay, 2003; Goldman, 2005; Goldman and King, 2013).

This point is significant, in that those who may potentially become infected are likely be older and far more susceptible to experience the condition with more severe morbidity and mortality than having the disease as a child (Luyten et al., 2011; Goldman, 2005). Brisson, Edmunds and Gay (2003) hypothesised that the burden of varicella would be significantly reduced following mass infant vaccination, mass varicella vaccination is expected to result in long-term implications; namely a major increase in herpes zoster amongst those whose childhood vaccination has lapsed. Brisson, Edmunds and Gay (2003) and others (Schuette and Hethcote, 1999; Brisson, Gay, Edmunds and Andrews, 2002; Brisson and Edmunds, 2002; Brisson, Edmunds, Gay, Law and De Serres, 2000) predicted that there would be consequential effects caused by a pronounced rise in zoster morbidity as a direct result of the lack of adult exposure to herpes zoster, where a vital mechanism is thought to play a crucial role in zoster protection by boosting specific immunity reducing the risk of reactivation. Brisson and Edmunds (2003) suggested that the best way around this effect was to administer varicella vaccination to adolescents, rather than to infants.

The concept of 'herd immunity' is a scientific concept as Hobson-West (2003) described, and linked to the notion of community good. The literature considers altruism in terms of why a parent should vaccinate, not because the parent believes vaccination to be in the best interest of the child, but because mass childhood vaccination is viewed as being evidence that the parent is a responsible member of society. The priority in the herd immunity debate is on community benefits over individual costs, raising ethical arguments about individual liberty. The orthodox medical paradigm has hovered around 'herd immunity' as the main reason that everyone must be vaccinated. According to the WHO, 95% of children need to be vaccinated to ensure protection by herd immunity or there will be a resurgence of measles as an endemic disease (Wood-Harper, 2005). The notion of herd immunity is an established theory within orthodox medicine, but from an heterodox perspective this theory is not straightforward, and other ontological and epistemological perspectives may be worthy of consideration. As Brownlie and Leith (2011) described, parents' understandings and beliefs about their children 'are not ones that parents can simply be re-educated out of ... they speak to ontological beliefs about what it is to be a parent and an infant' (Brownlie and Leith, 2011, p. 207).

The notion of herd immunity was not found to be a universally accepted concept (Rogers and Pilgrim, 1995; Skea, Entwistle, Watt and Russell, 2008). Although herd immunity has been promulgated as an accepted concept, some participants in these studies did not believe in the theory of herd immunity. Herd immunity was found to be unimportant to

40% of both compliant and non-compliant mothers in Cassell et al’s. (2006) study that examined mothers’ experiences of, and attitude to the MMR using a survey. Interestingly, when discussing the implications for others and their decision not to vaccinate their own children these parents dismissed arguments about vaccinating to promote herd immunity as irrelevant because they viewed catching diseases in childhood as a means of ensuring natural, life-long immunity.

This thesis concurred with the findings of Skea et al’s. (2008) analysis of an MMR Internet discussion thread which revealed that some parents questioned the notion of herd immunity because they were unconvinced about the effectiveness of vaccines. Further to this, the Skea et al's. (2008) study discussed the implications of herd immunity at length, confronting the issue of vaccinating children in order to be socially responsible, and protecting those children that are too young to be vaccinated, or those that are immunocompromised. Although many vaccinating parents in their study believed that non-vaccinators should participate in mass childhood vaccination for the sake of the community, non-vaccinators held different views about being ‘socially responsible’. Some non-vaccinators were recorded to be concerned for the sake of others, and considerate of the possible risk to others, but questioned the risk of vaccination for their own child. Some parents were not convinced about the efficacy of vaccines. Other non-vaccinating parents felt strongly that it was unfair that their children should have to assume the risk of receiving vaccines, which was most true to the findings of this thesis.

Much of the biomedical academic literature has implicated free-riding as a general motivation for declining vaccination (Serpell and Green, 2006; Ibuka, Li, Vietri, Chapman, and Galvani, 2014; Fine, Eames and Heymann., 2011), this study challenges this assumption, concurring with Harmsen, Ruiter, Paulussen, Mollema, Kok, and de Melker's (2012) study, this thesis argues that herd immunity is inconsequential to a large number of people that choose not to vaccinate their children. This finding is in contrast to a large amount of literature which has portrayed non-vaccinators as taking advantage of herd immunity. It challenges the notion of the free-rider and puts forward a divergent perspective whereby herd immunity is described as unfavourable; obtrusive to the natural developmental stages of childhood, by parents who lamented that their children would not be exposed to certain diseases.

This thesis refutes Skea et al's. (2008) recommendation that vaccine promotional material targeted at parents should present distinctions between healthy and vulnerable children, for the purpose of improving vaccine uptake. This argument was not supported in this current study, as discussed in the findings, this thesis contends that people that hold holistic theories of the immune system may not consider vulnerability to be a relevant point for arguing that only certain children should be entitled to exemptions. Perception of vulnerability may be disputed, evidenced in participants discourse that conveyed all newborn babies and infants as vulnerable. This point is in line with Casiday's (2007, p. 1066) qualitative study in the UK where parents expressed concerns about MMR safety and ‘clearly resisted the notion that their children should assume this risk in order to help protect others from infection’. On the contrary, Skea et al’s. (2008) study portrayed how judgements towards non-vaccinators have been associated with expected social responsibilities, including the idea that 'healthy children' should carry the burden of vaccinating, as opposed to 'vulnerable children'. The study was useful in observing MMR dialogue and the issue of social responsibility, where some parents have attempted to influence others and explicitly judge non-vaccinating mothers. So too, Leach et al's. (2005) study nominated that the vulnerability of a child was based on a mothers personal assessment, portraying the delicate nature of classifying one child as more vulnerable than another.

This thesis adds to these studies supporting the hypothesis that vulnerability of children is weighed as a highly personalised matter. Further to this, mothers perceptions of vulnerability may have little to do with perceiving some children as healthy and some children as vulnerable, therefore this channel of promoting vaccines may be unproductive.

Personal responsibility

In the dichotomy that exists between orthodox medicine and heterodox medicine, vaccination remains an issue that divides the view of responsible health care choices. Orthodox medicine is very clear in depicting vaccination as the responsible pathway; however, heterodox medicine is more obscure, with much of the non-vaccination ideology associated with a heterodox background (Feiler-Mircus, 2012; Downs, de Bruin and Fischhoff, 2008; Hamilton et al., 2004; Hobson-West, 2003; Frank, 2002; Pilgrim and Rogers, 1995).

The medical establishment has sent out mixed messages to health care consumers, in that individual responsibility has been encouraged and emphasised as an essential aspect of a healthy lifestyle, where a central focus is placed upon conscious decisions about food and exercise and choosing healthy habits (Hobson-West, 2005) and avoiding chronic disease associated with modifiable risk factors. Yet, in contrast when it comes to vaccination decisions the individual health care consumer is expected to take a passive stance and vaccinate for the good of the community, according to the practices that the orthodox experts from the hierarchal system agree to be conductive to health. Elliman and Bedford's (2001) study found that parents' epistemological approach was fundamentally different to the epidemiological view with which health policy makers were concerned. This difference equates to a large divide in decision-making. Non-vaccinators were less fearful of diseases in general, perceiving that they were a normal part of the cycle of life (Evans et al., 2001). They expressed a preference for their children to contract the childhood diseases while they were young, in order to avoid a more serious case of the illness that has been associated with contracting the diseases as adults.

A strong theme that emerged from Raithatha et al's. (2003) study was a pronounced sense of personal responsibility, and blame assumed by parents for the possibility that harm might come to their child, either through disease or through vaccination adverse effects. Raithatha et al's findings were useful in that it established that parents reported a lack of accessible information and conflicting advice. And in line with this thesis, participants felt very responsible for the potential consequences of their decision, and also that parents felt unfairly pressured to vaccinate by the medical profession. One could conclude that responsibility in vaccine decision-making is personal and complex, and involves issues related to trust in risk managers, and the quality of vaccine information that is dispersed. Additionally, details and information that may be considered as overlooked, or disregarded, could also have great importance to credibility.

The public versus the individual

Heterodox medicine resonates strongly with the lived experience of health and illness which is inherently personal and complex. The discourse of wellbeing epitomised in the heterodox ethos 'places the unique self of the client at the centre and defines wellness through values such as individual fulfilment, freedom, agency and control' (Sointu, 2011, p. 357). This is not to say that collective values are not appreciated, but rather that health is viewed as a highly personalised matter. Hunter (2012) drew attention to anthropological and sociological critiques of holism, which illustrate concerns regarding the naturopathic concept of holism that has defined illness as individually based and ignorant of social and political aspects of ill health. Hunter argued that '[t]he focus on the participation of the individual in treatment does not detract from an understanding of how the individual is socially located' (p. 276). Hunter posited that these aspects of naturopathy have not been well articulated by scholars and described the social and human rights movements of the 1970s, including the women's health movement and the growth of self-help, as illustrating a clear and broad commitment to social and political views on health. 'The emphasis on prevention and lifestyle enhancement makes the practice of naturopathic medicine inherently social, requiring close consideration of the interactions among body, mind, and environment and an understanding of how health and social conditions are interrelated' (Tippens and Connelly, 2007, p. 783).

As such, it is important to note that although heterodox therapies are based on perceptions of the individual and their role in health and illness, the individual is also perceived as inextricably connected to their social environment explained by Hunter (2012, p. 276): 'the fundamental premise of naturopathy is that disease causation is not necessarily located in the individual, but may well be found in the social and political milieu. Illness is considered an imbalance between the individual and the world'. Tensions between individual control and state control have been regular themes in vaccination discourse. It is interesting to note the changing platform that government agencies have used in encouraging the uptake of childhood vaccines since the safety issues have become so prevalent. The argument has moved from protection from contagious diseases, to best interest theories, and to social responsibility, which Dew (1999) described as encompassing the notion that the mother has a moral obligation to the rest of society to vaccinate her child. The dominant orthodox model has high expectations of citizens, exhorting individuals to forgo their own beliefs for the sake of the hierarchical orthodox view that defines the standard of knowledge.

Casiday (2007) raised the point of contention between the public health mandate of protecting all children and the parental responsibility of protecting one's own children, where parents whose conviction was against vaccinating asked why their children should assume the risk in order to protect others: 'Parents, clinicians and epidemiologists speak different languages of risk' (Casiday 2007, p. 1067). Casiday (2007) identified that risk has strong ties to a particular kind of social outlook and thus is an important factor in looking at the non-vaccinators. Public perceptions of health risks are influenced by how individuals within their social context interpret health risks impacted by personal networks (Krantz et al., 2004, p. 173). Poltorak et al. (2005, p. 717) found that 'parental reflections and approaches to vaccinations were guided by highly personalised assessments of a particular child's vulnerabilities to disease and vaccination and public health framings of these have little resonance with them'.

Mass childhood vaccination is argued to be beneficial to individuals, but the benefit to the community is the main concern, and certainly explicitly implied as more important than any individual cost. In other Western countries, state sanctions have been enforced on dissenters, for instance, imprisonment and withholding of child benefit payments (Isaacs, Kilham, Leask and Tobin, 2009; Stafford, 2008; Hobson-West, 2003; Durbach, 2000). School entry and therefore education may also be withheld from children that are not vaccinated. In Australia, unvaccinated children can gain entry to school, but their parents must sign a legal document that states that in an outbreak they will be removed from school for long periods of time. Dew (1999) described this form of treatment as discriminatory, as the child is disadvantaged educationally by being away from school, and the parent/s are disadvantaged financially by having to take time off work to attend to the child.

Some of the parents interviewed in Skea et al's. (2008) study did not vaccinate and did not accept the idea of social responsibility to vaccinate, making assessments about the level of risk that they were being asked to take for the sake of herd immunity. So too, Casiday (2007) reported that some parents rejected the idea that their child should have to assume the so-called 'risk' for the sake of herd immunity. This was an interesting finding, as like the participants in this thesis, there was a rejection of the vaccine imperative of the public health messages that were framed towards them.

Conflict between public health and individual interests: Impact of governmentality

Government has erroneously assumed that members of the public will trust the risk sources of information that they are provided with. The literature has demonstrated that large amounts of people have been dissatisfied with the content of vaccine information that they have received (Gust, Kennedy, Wolfe, Sheedy, Nguyen and Campbell, 2008b; Raithatha et al., 2003) and as a result seek out their own sources.

Common interest between community health needs and individual health needs may vary, as public perceptions about risk are broadly determined (Krantz et al., 2004). Conflict between public health and individual interests may arise when individuals view the attributions of risk differently, and where there is discrepancy between the desire to experience health and illness in a certain manner, and where there is a demand to conform to expected social behaviour. Krantz et al. (2004, p. 173) predicted that a changing disease panorama would move the boundaries of what was considered to be a ‘reasonable price for remaining healthy’, with a shift in parental concern from preventing disease transmission to vaccine safety. This concept is evident in the growing number of parents that are declining vaccination with under-vaccination appearing to be an increasing trend. (Glanz, Newcomer, Narwaney, Hambidge, Daley, Wagner, McClure, Xu, Rowhani-Rahbar, Lee, Nelson, Donahue, Naleway, Nordin, Lugg and Weintraub, 2013).

Evans, Stoddart, Condon, Freeman, Grizzell and Mullen (2001) noted that parents received unwelcome pressure from health professionals to comply with mass childhood vaccination. When choosing not to vaccinate, difficulties may arise when that child requires medical diagnosis and assistance throughout their childhood. The hierarchy of orthodox medicine in health care equates to the fact that non-vaccinating mothers may at some point need to rely on orthodox practitioners in their institutionalised role as gatekeepers (Calnan and Sanford, 2004) to desired health care services, and treatment including referrals and diagnostic tests. Although some of these mothers would likely prefer to attend a hospital that uses heterodox services such as homeopathy and Ayurveda, these options are not available as part of the health care system in Australia.

Expert orthodox knowledge that aims to improve population health through behaviour modification is a form of governmentality (Foucault, 1979) and biopower (Foucault, 1990). In this way, populations are governed at a distance by relying on people to act on health promotion guidelines, whereby healthier lifestyle choices are made by the population, which ultimately reduces the costs to governments by improving individual and population health (Thompson, 2008). Governmentality, as explained by Thompson (2008, p. 77), is a balance between being ruled by force or by self-rule, but further to this dynamic is a strong message from governing bodies endorsing ‘particular forms of citizenship’. This directive is evident in the obligatory nature of mass childhood vaccination, which is put forth as a duty of citizenship. Opposition to vaccination equates to an opposition to medical science (Dew, 1999), which can raise conflicts for the individual opposing this directive or imperative. Vaccine decisions move beyond the health sector into the domain of education where, during an epidemic, government has the power to remove or exclude children that are not fully vaccinated from school. Dew (1999) posited that this discriminates against the child as well as the parent who is then forced to take time off work to care for the child. 'Accepting vaccination means accepting the state's power to impose a particular view about the body and the immune system – the vision developed by medical science' (Martin 1994, p. 194). The anatomo-politics of orthodox medicine is described by Turner (2006) as involving the discipline of individuals with the surveillance and regulation of populations. This so-called discipline is evident in the exclusion of unvaccinated children in certain settings and also in the penalties for non-compliance issued to non-vaccinating parents.

The dominant orthodox model is 'imbued with scientific, professional and institutional authorities. It is by no means the only model and does not describe how most persons experience their health' (Labonte, 1993, p. 4). Further, health promotion is questionable in its social marketing strategies to educate society to the terms of the state, where concepts of neoliberal economic ideology are influential (Labonte, 1993):

> Canadian health promotion literature on community mobilisation sometimes reads as a manual on how to get community groups to 'buy into' the government's agenda (e.g. Health and Welfare, 1992) which often means imposing the language, concepts and cultural norms of bureaucracies onto community groups (Labonte, 1993, p. 9).

Good citizenship is defined as complying with the practices and behaviours that experts agree are conductive to health (Brownlie and Howson, 2005). The notion of 'health citizenship' is closely associated with participatory methodologies. The concept of citizenship includes the double imperative of 'rights and responsibilities,' in that a good citizen is one who recognises and enacts both his/her rights and duties.

Citizenship, as represented in the new public health emphasised both the rights and the obligations of individuals to take up and conform to the imperatives of 'expert' public health knowledge. A useful citizen was construed from a duties discourse perspective. The 'duties discourse' emphasised responsibility of people to fulfill their personal, social, and civic obligations by being actively involved in participatory processes. According to Petersen and Lupton, 'ideal 'healthy' citizens have their children immunised according to state directives', as well as complying with other procedures such as cervical screening (Petersen and Lupton 1996, p. 69). Zoller (2005) distinguished health citizenship from 'health activism', arguing that unlike citizenship, activism affects power dynamics that impact health, including social norms, embedded practices, policies, and/or dominant groups. Parents of children that are raised without routine childhood vaccinations and the children themselves, are represented in particular ways to promote government strategies for compliance (Dew, 1999). The mass media is well-known for presenting material in a particular manner, and using ‘cultural resonance’ to influence ‘widely held cultural concepts’ (Hansen, 1991, p. 452). ‘Individuals who are confronted with the discrepancies between their lived experience and the images they receive may increasingly question these images’ (Dew, 1999, p. 393). Vaccination is portrayed as a social good, depending on acts of parental citizenship, as noted in Brownlie and Leith’s (2011) study that found parents well aware of this state imperative concluding that some parents framed their vaccine decisions on the expectation of being seen as a good citizen.

The social science ontological perspective is useful in explicitly acknowledging that agency, or the ability to act autonomously is impacted and limited by social structural influences, in regards to the choices and opportunities that are available within society. Social influences are known to effect human behaviour and take various forms including peer pressure, conformity, persuasion and marketing. Heterodox therapies pose a direct challenge to the authority of the orthodox medical profession, as well as raising important policy issues (Sharma, 1992), as is evident in routine childhood vaccination. Individuals that resist government imperatives may be reclaiming control and self-determination over the self, the body and the environment (Williams and Calnan, 1996). Ideas of risk are posited by Casiday (2007, p. 1061) as having a great deal to do with ‘cultural predisposition toward a particular kind of outlook’. Risk is complex, encompassing various influences such as beliefs, trust, communication and knowledge forms.

Medicalisation and hegemony

Historically, orthodox medicine represents the most successful model of health in the Western world (Robertson, 1988), with this model defining the limits of ‘normality’ and the proper functioning, deportment and control of the human body (Williams and Calnan, 1996). Orthodox medicine is often described as hegemonic, as is mass childhood vaccination (Rogers and Pilgrim, 1995). Hegemony was defined by Gramsci (1957) as the way in which life, and understanding, and thinking become dominant in a social formation.

Orthodox medical knowledge has been thought of as ‘true knowledge’ that is superior over other forms of knowledge, however an ‘increasing body of opinion rejects the notion of “objective” knowledge and sees medical knowledge and practice as “socially constructed”’ (D'Cruz and Jones, 2004, p. 703). Further to this, orthodox skills and knowledge have ‘created a dependence through the medicalization of life which has now undermined and taken away the public’s right to self determination’ (Williams and Calnan, 1996, p. 1610).

Medicalisation, as described by Poitras (2012, p. 51) is defined as:

> a societal process where more and more aspects of everyday life come under medical dominion, influence and supervision. The process of medicalization is part of a larger historical transition involving social values associated with traditional institutions, such as the church, the common law and the family, being replaced by the values of science and the scientific method. The practice of medicine has been an important player in this transition. The observation that medicine had ‘nudged aside’ or ‘replaced’ religion as the dominant moral force in the social control of modern societies is a central theme in medicalization.

This description reveals the immense impact that medicalisation can have on people's everyday lives and in particular on health considerations including childhood vaccination. The hegemonic nature of mass childhood vaccination and its consideration as an expert intervention has placed the rejection of vaccination as an unacceptable decision. Dissent, refusal and resistance to vaccination have been considered a threat to state power (Streefland, Chowdhury, and Ramos-Jimenez, 1999) and its 'ability to regulate populations (the social body) *and* to discipline individual bodies' (Scheper-Hughes and Lock, 1987, p. 8, italics in original text). Furthermore, vaccine refusal is said to have the capacity to negatively effect public good and therefore the state may see it as their responsibility to safeguard public health. This point is of particular relevance to this thesis in the analysis of why non-vaccination has not been accepted by society.

Stigmatisation of non-vaccinators and the unvaccinated

Unvaccinated and undervaccinated children have been stigmatised as carriers of contagious disease and their parents sometimes condemned as a direct result of their non-vaccination choice. Despite the marginalisation and stigmatisation of unvaccinated people, this phenomenon has not been studied or accounted for in the literature.

Stigmatised labelling may occur when there is a lack of understanding for other worldviews that go against a mainstream belief. Stigma refers to any attribute, trait or condition that distinguishes the person as unacceptably different from what time and place dictate to be ‘normal’ and that elicits community sanction (Scambler, 1998).

The pro-vaccination rhetoric sets a certain expectation or imperative (Hobson-West, 2005) to take part in mass childhood vaccination. Parents who decline vaccinations for their child may be labelled by the mainstream community and socially stigmatised. The unvaccinated child may also be labelled a carrier of contagious disease. Non-vaccinators that do comply with government recommendations risk being stigmatised and labelled for going against 'the herd'. Skea et al. (2008) found that some vaccinating parents were critical of non-vaccinating parents, urging them to comply for the sake of being socially responsible. Parents concerned about the side effects of vaccines on their child can be regarded as taking an individualistic stance (Hodge and Gostin, Ashton, 2004) and accused of having little regard for society or the rest of 'the herd'. If their refusal of vaccines is related to vaccine safety they can be made to feel as though they have no right to question the orthodox experts (Brownlie and Howson, 2005).

For Scambler (2009, p. 450), stigma represented an infringement against norms of shame, while deviance represents a breach of norms of blame. Stigma signalled an 'ontological deficit' (involving 'being' imperfect) and a failure therefore to conform; while deviance signalled a 'moral deficit' (involving 'acting' inappropriately) and a matter therefore of culpability. Certain behaviours and experiences are said to be defined as medical conditions, and those definitions can function as type of social control (Conrad and Barker, 2010; Zola, 1972). Conrad and Barker (2010) argued that it is not the condition that makes it stigmatising but the social response to it, and the type of individuals who suffer from it that make a stigmatised condition (Conrad, 1987). This is evident in the so-called vaccine-preventable illnesses that exhibit in unvaccinated children. If a vaccinated child contracts a vaccine- preventable disease, unvaccinated children are immediately blamed for transmitting it and causing suffering and/or death to those who contract it. Stigma as described by Burris (2008, p. 3) as a 'barbaric form of social control'. Stigma and social labelling may create marginalisation and social exclusion, which is evident in unvaccinated children being excluded from attending day care centres (Public Health Queensland, Exclusion of unvaccinated children from child care, Amendment Bill 2013).

Unvaccinated and undervaccinated children are often portrayed as carriers of contagious diseases and deemed responsible for outbreaks of disease that occur in the community (Kennedy et al., 2005; Hanna, Symons and Lyon, 2002), despite the literature demonstrating that outbreaks of diseases occur in highly vaccinated populations that have sustained high rates of vaccine coverage (Forsyth et al., 2004; Galil et al., 2002; Yaari et al., 1999). Dew's (1999) work on disease representations and the state, illuminated the discrimination of both the unvaccinated child in the education system and against the parents economically, where one parent will presumably have to stay away from paid employment in order to care of the child forced out of school.

Adults have been identified as a salient source of pertussis infection in the community and a major reservoir for the spread of infection to infants. Forsyth et al. (2004) and Yaari et al., (1999) regognised vaccinated adults as well as adolescents as a major source of pediatric infection of Bordetella pertussis. Forsyth et al. (2004) reported that the increase in pertussis disease in adults and adolescents as due to waning vaccine-induced immunity and increased recognition of pertussis disease. ‘No paper demonstrates that outbreaks of diseases occur only in the unvaccinated’ (English 1995, p. 159). Kennedy et al. (2005, p. 253) declared that these unvaccinated individuals may transmit disease to children and adults with valid medical contraindications to vaccination. Krantz and colleagues (2004) raised the issue of bias in the diagnosis of disease directly related to risk, where orthodox practitioners were three times as likely to obtain pertussis laboratory tests on unvaccinated children than on vaccinated children presenting with upper respiratory tract symptoms, but without classic pertussis symptoms. It may be simplistic to blame unvaccinated people for outbreaks when there may be an array of reasons why vaccines may not be effective in certain situations. Krantz et al. (2004, p. 173) argued that no vaccine is 100% effective, describing the measles vaccine as producing beneficial results under ‘ideal conditions’, suggesting that deployment of the vaccines can encounter problems, with transport, cold chain and other logistics often reducing the effectiveness of the vaccine. Seronegativity has been described as a real issue, where vaccinated individuals show negative results or a lack of antibodies on serological examination (*Dorland’s Medical Dictionary,* 1989).

Seronegativity was estimated in a 1991 study conducted in Australia to be between 5 and 25% (Barrand, Chapman, Jeffs, Jack, Wenzel, Bridges-Webb and Levy, 1991), meaning that a large cohort of vaccinated individuals believe that they are ‘protected’ and are contributing to herd immunity when they may not be. Jacobson and Poland (2004) suggested that in addition to these types of vaccine-related failures, there may also be a genetic basis to the ability of a vaccination to produce immunity against a certain disease. Cherry and Harriman (2012) added that in addition to unvaccinated children, vaccine failure and waning immunity were a large problem. Also, because pertussis circulates amongst adults, and is often not diagnosed, adults are considered the major cause of pertussis infection in infants (Cherry and Harriman, 2012; Cherry, 2010).

Respect for difference

There is a paucity of literature that accepts or embraces diversity in vaccine non-compliance. Mollema et al's. (2012) study using focus groups, and exploring GPs who were childhood vaccine providers' in the Netherlands concluded that parental choice should always be respected and empathised with, irrespective of whether they shared the same opinion as their GP or not. The findings of this study are inspiring in that the GPs who were the participants in the study had found a way to respect non-vaccinators and make them feel welcome regardless of their vaccine choices. Rejectors of vaccination were acknowledged as concerned about health. This study highlighted that more communication was required when parents exhibit skepticism towards vaccination. Concurring with Benin et al. (2006), who identified that the dissemination of vaccine material was an insufficient means of communicating about childhood vaccines. These commentators placed trust in physicians as the main promoter of vaccine acceptance. One could therefore conclude that the pivotal role of trust is essential in the communication process and vaccine hesitant parents have been reportedly alienated from the medical establishment (Benin et al. 2006) further exacerbating the sense of distrust.

Liamputtong (2010) called for developing understanding in health care decisions that exist outside of the mainstream view. Hobson-West (2003, p. 278) described the resistance to vaccination as signifying the ‘fundamental opposition to the dominant biomedical understanding of health and disease’, noting that understanding would not be revealed with the use of traditional language of risk and risk perception. This prediction is supported by Martin’s (2000, p. 135) observation that resistance to vaccination was about choosing a holistic way of life, rather than simply about the refusal to vaccinate. Previous studies have focused on persuading conscientious objectors to comply with the orthodox model, rather than on creating insight, understanding (Hobson-West, 2003; Raithatha et al., 2003) and acceptance of other world views.

Summary of Chapter 2

This section has examined the pertinent issues surrounding non-vaccination; reasons for declining childhood vaccinations, the impact of government and policy-making on vaccination, risk disputes and decision-making, immunity, the use of single vaccines as opposed to multiple vaccines, as well as orthodox and heterodox belief models. Patient empowerment, active decision-making, and the influence of belief systems were issues under consideration in this review, as were the marginalisation and stigmatisation of non-vaccinators and the unvaccinated. From the literature reviewed in this chapter, an argument was made that vaccine decisions are both personal and complex. Vaccine decisions are based on multifactorial influences, including beliefs and values pertaining to health and illness.

The most insightful literature to this thesis was the work of Rogers and Pilgrim (1995), who first determined that mass childhood vaccination was incompatible with the notion of the health promoting patient. Their work revealed the contradiction between British health promotion policy which advocated the self-reliant, health promoting, informed agent involved in taking responsibility for individual health as opposed to the 'doctor knows best' assumption (Rogers and Pilgrim, 1995, p. 87). Furthermore, these authors found that the notion of herd immunity fit poorly with human agency, as they explained 'one implies groups of animals to be manipulated by a higher authority, the other suggests that patienthood is about choice, responsibility and partnership'. This analysis can therefore be used to reveal the inherent tensions, contradictions and discrepancies in health promotion.

Developing Rogers and Pilgrim's theory further and advancing the research, health promotion campaigns have increasingly emphasised self-responsibility, proactive behaviour, and individual action in discourses of wellbeing, with the intention of improving health determinants and reducing health care costs. As such, patients have become more willing to question authority, deal with associated consequences of non-compliant behaviour, and ultimately, navigate and negotiate between heterodox and orthodox medicine, in order to make decisions encapsulating their personal values, priorities and expectations.

As mentioned earlier, this current study refutes much of the biomedical academic literature that has implicated free-riding as a general motivation for declining vaccination, alongside other commentators (Serpell and Green, 2006; Ibuka et al., 2014; Fine et al., 2011). In addition, this thesis challenges Skea et al's. (2008) recommendation that vaccine promotional material targeted at parents should present distinctions between healthy and vulnerable children for improving vaccine uptake. This approach was not supported in this study. As discussed in the survey findings chapter, this thesis contends that people subscribing to holistic theories of the immune system, may not consider vulnerability to be a relevant point for arguing that only certain children should be entitled to exemptions. The perception of vulnerability may be disputed, with participants discourse in this study depicting all newborn babies and infants as vulnerable.

This thesis attempts to gain insight into the personal experiences, behaviours, outcomes and implications for adults that were raised without routine childhood vaccination. This study adds to the current body of literature by establishing a connection between intergenerational vaccine decisions, and demonstrates the way in which unvaccinated participants navigate and negotiate between orthodox and heterodox medicine according to their own social context.

The next chapter, Chapter 3, presents the research methodology that guides the study.

Chapter 3

Methodology and Methods

Introduction

The aim of the study was to explore the experiences of adults that were raised without routine childhood vaccinations. This exploration was undertaken from within a phenomenological framework, employing a mixed methods design. The first phase of the study used a survey questionnaire in an interpretive way to extrapolate themes. These themes became useful for further exploration in the second phase of the research, which employed in-depth interviews.

This chapter begins with the research questions and their purpose, then proceeds to describe the phenomenological approach that uses a mixed methods design with both quantitative and qualitative strands to most accurately answer the research questions. The terms ‘quantitative research’ and ‘qualitative research’ are briefly outlined in this chapter, as well as the types of quantitative and qualitative research tools that are utilised for the study. The chapter then proceeds to discuss how phenomenological methodology is appropriate for this study.

This chapter also describes participant selection, the method of data collection, data analysis, validation and possible limitations of the current study.

Research aim and research questions

The purpose of this study was to gain insight into the experiences of adults that were raised without routine childhood vaccinations. A mixed methods study begins with a strong mixed methods research question or objective (Tashakkori and Creswell, 2007).

A review of the literature identified that firstly there was no research specifically on people that had been raised without routine childhood vaccinations, and secondly, that there was a large amount of literature about the parental decision-making process and reasons for not vaccinating. The focus of this research was to find adults that had been raised without routine childhood vaccinations in order that they could reflect on their experience and inform others about this under-researched phenomenon. These adults have lived with the vaccine decisions that their parents made on their behalf, according to what the parents believed was in their child's best interest. An exploration of this group of people is useful in revealing experiences that have followed this decision.

The overarching questions were 'what are the experiences of those who were raised without routine childhood vaccines?' and 'what are the meanings given to those experiences'?

The research subquestions were:

- What is the past and present state of health of these adults that were raised without routine childhood vaccinations?
- What diseases, if any, have they experienced?
- Were antipyretics and antibiotics also avoided?
- What health or social issues have they experienced?
- What health ideologies do they have?
- What outcomes have occurred as a result of being raised without routine childhood vaccinations?
- What vaccine choices were made regarding vaccinations and with the participant's own child/children?

The researcher was interested in exploring what this experience meant to these participants as well as understanding more about the health care choices that participants make as adults and as parents themselves. The research questions were designed with the intention of learning as much as possible about adults that had been raised without routine childhood vaccinations.

Methodological framework

Phenomenology is the interpretive study of human experience. According to von Eckartsberg (1998, p. 3), the aim of phenomenology is to examine and clarify human situations, events and experiences 'as they spontaneously occur in the course of daily life'. In phenomenology, one studies a phenomenon, the way it appears in experience or consciousness. Phenomenological methodology owes its roots to phenomenology, the philosophy that dates back to the work of Husserl (Wilson, 2002). Edmund Husserl and Martin Heidegger were students of the philosopher William Brentano who first wrote about the phenomenological method as an inquiry in the last part of the nineteenth century (Spiegelberg, 1976). Husserl and Heidegger further developed Brentano's early works. There are different types of philosophical phenomenology, which are implemented according to the type of phenomenon being studied, and the knowledge being sought. These include Transcendental Phenomenology (Husserl, 1971), Hermeneutic Phenomenology (Heidegger, 1962) and Existential Phenomenology (Merleau-Ponty, 1962).

Phenomenological possibilities are so vast that 'any object, event, situation or experience that a person can see, hear, touch, smell, taste, feel, intuit, know, understand, or live through is a legitimate topic for phenomenological investigation' (Seamon, 2000, p. 158-159). Thus, this study of exploring the experience of adults that were raised without routine childhood vaccinations is a legitimate topic for a phenomenological exploration. Phenomenological research seeks to uncover the meaning of humanly experienced phenomena through the analysis of subjects' descriptions (Parse, Coyne and Smith, 1985). The number of subjects for a phenomenological study varies considerably and depends on the nature of the phenomenon explored. Tesch (1984) argued that between ten and fifteen participants is usual for a phenomenological study. However, other researchers have used far fewer participants. In a phenomenological analysis the question, 'What is this kind of experience like?' is asked. Phenomenological research searches for a deeper understanding and insightful descriptions of lived experiences. Phenomenology was described by Carpenter (2010, p. 125) as 'a methodological approach with a strong and dynamic philosophical and epistemological foundation that seeks to understand, describe, and interpret human behaviour and the meaning individuals make of their experiences'.

Phenomenological reflection is retrospective (van Manen, 2006, p.10), in that one can look back and reflect on what it was to have lived through that experience. Moustakas (1994, p. 13) explained that '[t]he aim is to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it'. Through this reflection, we make meaning of our lives. Frankl (1988, p. 7) captured the idea of making meaning through phenomenology in the following quote: 'Phenomenology is an attempt to describe the way in which man understands himself, in which he interprets his own existence, far from preconceived patterns of interpretation and explanation such as are furnished by psychodynamic or socio-economic hypotheses'.

Phenomenology as a methodological design can best reveal the individual's lived meaning of the world and in doing so develop understanding, according to the participants' construction of reality (Carpenter and Suto, 2008). This can be a particularly important factor in the consideration of a topic where there is a lack of information available and which needs to be better understood. Van Manen (2006, p. 9) described phenomenology as asking 'what is this or that experience like?' Phenomenology investigates *what* something is and not *why.* According to van Manen (1997a), from a phenomenological point of view, to do research is always to question the way we experience the world.

In phenomenology, the researcher transcends or suspends past knowledge and experience to understand a phenomenon at a deeper level (Merleau-Ponty, 1962). It is an attempt to approach a lived experience with a sense of 'newness' to elicit rich and descriptive data. 'Bracketing' is a process of setting aside one's beliefs, feelings, and perceptions to be more open or faithful to the phenomenon (Colaizzi, 1978; Streubert and Carpenter, 1999). The process of bracketing was a component of this research and is discussed later in the chapter. Colaizzi (1978) held that the success of phenomenological research questions depends on the extent to which the questions touch lived experiences as distinct from theoretical explanations. Exploring a person's experience of being raised a certain way illuminates this phenomenon in a way not previously studied.

Phenomenology is said to be constantly developing as the field of qualitative research evolves. 'The flexibility of phenomenological research and the adaptability of its methods to ever widening arcs of inquiry is one of its greatest strengths' (Garza, 2007, p. 338). Although phenomenologists cannot be placed under one unified school of thought, due to the variations in approaches used, their approach to uncover the meanings of humanly experienced phenomena is united. The focus for phenomenologists is on the social construction of the life-world, emphasising that people's actions can only be understood when they are situated in their everyday world and that 'people's actions should be explained with reference to their conscious intention and with reference to the typifications or categories of understandings that people develop' (Liamputtong and Ezzy, 2005, p. 20).

The phenomenological tradition seemed to resonate with the adults in the study, who were raised in one way and knew no other way. The ideology associated with being raised without routine childhood vaccinations was part of their everyday world and they grew up making decisions based on these understandings. Van Manen (1990) indicated how phenomenology is a kind of questioning that permits a rigorous interrogation of the phenomenon and that there is a re-thinking of things that are not well understood. It was this aspect of van Manen's description that led to choosing phenomenology as a methodological framework for this study.

The phenomenological analysis was based on guidelines set forth by Colaizzi (1978) and Osborne (1990). A phenomenological inquiry involves a three-step process: (a) gathering descriptions of lived experience – description; (b) reviewing data in order to reveal essential themes – reduction; and (c) determining the interrelatedness of the themes and how they reflect the essence of the phenomena – interpretation (Lanigan, 1988). The process is helpful in initially setting aside preconceived ideas and focusing on describing the lived experiences of others. In this study, reflecting on the lived experience was analysed. The ultimate goal of a phenomenological reduction is to determine which parts of the descriptions are essential and which are not. The researcher must decipher the essential description of the contents and the particular underlying structure that relates the elements into a unified experiential whole. The end result of phenomenological research is to arrive at a non-reductive structure that unites the invariant elements of an experience into a description of the experience reflecting the core elements shared by the participants. These are the structural elements without which the experience would be named something wholly different. Van Kaam (1969) called this process 'explication'; through the process of explication, implicit awareness becomes explicit. In applying the phenomenological method, data may be analysed in various ways.

The next part of this chapter describes the application of a phenomenological approach to the current study, and discusses the method of selecting the participants and research sites, the method of collecting data and the method of analysing the data.

Methodology

Mixed methods

The phenomenological approach is an appropriate framework for incorporating both a quantitative and a qualitative design and has been successfully utilised in health research (Plano Clark, 2010). The mixed methods research approach including a quantitative and a qualitative component was chosen for the study to best answer the research questions and to comprehensively provide an exploration of the phenomenon.

Greene (2007, p. 20) posited that mixed methods is an orientation toward looking at the social world ‘that actively invites us to participate in dialogue about multiple ways of seeing and hearing, multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished’. Although qualitative inquiry is distinctly different from quantitative inquiry the two have been brought together in order to obtain a breadth and depth of information that is not always possible using just one methodology. ‘Both qualitative and quantitative approaches have their strengths and weaknesses, and advantages and disadvantages’ (Kumar, 2005, p.13). It is important to understand the conceptual differences between quantitative and qualitative approaches in order to see why the two have been brought together in this research in a mixed methods design. ‘Qualitative researchers seek to uncover thoughts, perceptions and feelings experienced by informants. They are most interested in studying how people attach meaning to and organise their lives, and how this in turn influences their actions’ (Minichiello, Aroni and Hays, 2008, p. 9). In contrast quantitative research aims to count and measure things (Berg, 1989).

Casebeer and Verhoef (1997, p. 132) argued that it is more useful to see qualitative and quantitative methods as part of a selection of research techniques, ‘all of which are appropriate depending on the research objective’ rather than as a philosophical debate. Greene, Caracelli, and Graham (1989) developed a conceptual framework for mixed methods inquiry. They maintained that a combination of methods is both appropriate and constructive when the two strategies ‘overlap in their intent, yet also capitalize on the strengths of one or both methods to secure additional information’ (Greene, Caracelli and Graham, 1989, p. 262). The mixed methods approach is said to be most appropriate ‘when the methods used are similar (such as a scaled quantitative questionnaire and a structured qualitative interview) and when the methods examine different facets of the same phenomenon’ (Clarke, 2009, p. 297).

The premise of implementing a mixed methods design is that the use of quantitative and qualitative approaches, in combination, will provide a better understanding of the research problem than either approach alone (Creswell and Plano Clark, 2007, p. 5). Further, its use involves the intentional collection of both quantitative and qualitative data and the combination of the strengths of each to answer research questions (Creswell, Klassen, Plano Clark and Smith, 2011, p. 5). A quantitative approach, using a survey, is an efficient way to gather a breadth of information about a particular topic of inquiry and most particularly is a useful way of collecting descriptive statistics about a range of personal characteristics, health symptoms, and history of behaviours' (Schofield and Knauss, 2010, p. 214). Moreover, surveys have been described as ideal for collecting information about beliefs, attitudes, expectations, knowledge and health care satisfaction (Schofield and Knauss, 2010).

Descriptive statistics include measures of central tendency and measures of dispersion (Pierson, 2010). Qualitative research was employed to gain the deep insight that was required in order to draw meaning out of the data derived from the in-depth interviews. A mixed methods approach, incorporating a quantitative strand and a qualitative strand enables the strengths of both methods to compensate for the limitations of other methods (Bryman, 2008, p. 603). A further reason for choosing a mixed methods approach was that participants could choose how much they wanted to take part in the study. The quantitative research strand used an online survey, which was seen as far less demanding than the in-depth interviews of the qualitative strand. Taket (2010, p. 334) contended that the mixed methods approach could be personally empowering for participants, reinforcing their sense of autonomy by allowing them to choose how data is provided.

Mixed methods research in the health sciences has become an important consideration. Creswell et al. (2011, p. 2) posited that methodological diversity was important in 'enhancing the quality and scientific power of data'. This diversity in multi-level approaches was argued by these authors to be essential in investigating 'complicated health problems, such as the patient's point of view and cultural and social models of illness and health'. Research problems most suitable for mixed methods are those in which the quantitative approach or the qualitative approach alone is inadequate to develop multiple perspectives and a complete understanding about a research problem or question (Creswell et al., 2011, p. 6). These authors postulated that mixed methods research in health science may broaden, enhance and enrich the meanings and provide multiple perspectives for researchers in order to gain a more complete understanding of a problem.

'Triangulation' is a process where the researcher uses multiple data sources, investigators, methodological perspectives and/or theories to provide corroborating evidence (Denzin, 1970; Kimchi, Polivka, and Stevenson, 1991). 'The intent of using triangulation is to decrease, negate, or counterbalance the deficiency of a single strategy, thereby increasing the ability to interpret the findings' (Thurmond, 2001, p. 253).

Triangulation is a method used by qualitative researchers to check and establish validity in their studies by analysing a research question from multiple perspectives. The key to knowing whether to use triangulation is explained by Streubert and Carpenter (1999, p. 307): '[i]f different philosophic and research traditions will help to answer a research question more completely, then researchers should use triangulation'. Triangulation is a method of cross-referencing data to help ensure trustworthiness of claims and allow diverse viewpoints or standpoints to cast light upon a topic (Bryman, 2003; Olsen, 2004). Data triangulation is one method that can reduce the likelihood of misinterpretation of the communication of the data; it also enhances in-depth understanding of the phenomenon under study (Bloomberg and Volpe, 2008). Finally, the benefits of triangulation include 'increasing confidence in research data, creating innovative ways of understanding a phenomenon, revealing unique findings, challenging or integrating theories, and providing a clearer understanding of the problem' (Thurmond, 2001, p. 254).

The mixed methods research design has been noted as controversial, but capable of bringing fresh perspectives through contradiction and discovery of paradox (Bazeley, 2006; Caracelli and Greene, 1993; Greene et al., 1989; Rossman and Wilson, 1985). The disadvantage of the mixed methods design is the extensive time required to carry out collection and analysis of multiple forms of data. Other potential methodological issues and challenges arise as a direct result of using two variant philosophical approaches. Bryman (2008, p. 23) posited that qualitative and quantitative approaches differ in their ontologies, epistemologies and research strategies. These philosophical differences were overcome by recognising and honouring the different perspective of each (Creswell et al., 2011), and adopting a philosophical position of pragmatism (Tashakkori and Teddlie, 2003; Johnson and Onwuegbuzie, 2006). 'Pragmatism', as articulated by Kidder and Fine (1987), argued that understanding of an inquiry can be enhanced by exploring convergences generated from alternate paradigms. Pragmatism, as explained by Grbich (2010), was seeking the middle ground in one's approach to research, whereby the focus is the research question, rather than the philosophical position. In this approach, the research question is answered by whatever mix of data collection is thought to most accurately answer it.

The following section will discuss quantitative research and then move on to qualitative research.

Quantitative research

Quantitative research uses numbers and statistical methods. It tends to be based on numerical measurements of specific aspects of phenomena; it abstracts from particular instances to seek general descriptions or to test causal hypotheses; it seeks measurements and analyses that are easily replicable by other researchers (King, Keohane and Verba, 1994, 3–4).

Quantitative health research involves the measurement of health phenomena, where the resulting data are often analysed using statistics (Pierson, 2010). Quantitative research is almost unlimited in the number of phenomena that can be studied (Muijs, 2011, p. 2) and is good at providing information in breadth from a large number of units; however it is limited in its ability to deeply explore a problem. The main concerns of the quantitative paradigm are that measurement is reliable, valid, and generalisable in its clear prediction of cause and effect (Cassell and Symon, 1994).

Quantitative researchers seek explanations and predictions that will generalise to other persons and places. Careful sampling strategies and experimental designs are aspects of quantitative methods aimed at producing generalisable results. In quantitative research, the researcher's role is to observe and measure, and care is taken to keep the researchers from 'contaminating' the data through personal involvement with research subjects. Research 'objectivity' is of utmost concern (Glesne and Peshkin, 1992, p. 6). Quantitative methods are useful if quantifying the variation of a phenomenon is important. Quantitative data has the advantage of making observations more explicit; making it easier to aggregate, compare and summarise data; allowing for the possibility of statistical analysis and other varieties of analysis (Babbie, 2007). Statistics may act to test, confirm or contradict the conclusions that have been drawn on the basis of understanding (Kumar, 2005). Statistics help researchers to 'quantify the magnitude of an association or relationship, provide an indication of the confidence you can place in your findings and help to isolate the effect of different variables' (Kumar, 2005, p. 12).

Online data collection has been found to be a convenient form of collecting data from participants (Evans and Mathur, 2005). The diversity of available questions can also be an advantage. An online survey allows for a wide range of question types to best suit the inquiry; these include dichotomous questions, multiple-choice questions, scales, questions in a multimedia format, both single-response and multiple-response questions, and even open-ended questions (Evans and Mathur, 2005). For this study, an email survey was thought to have several advantages. A web-based survey questionnaire is a simple and effective means of collecting data as it allows anyone, with Internet access and an email address to respond. Email surveys are said to be more cost-effective than postal surveys (Sheehan and Hoy, 1999). Email survey responses are postulated as having a higher and a faster response rate with Sheehan and McMillan (1999) indicating that the average postal survey took 11.8 days, whereas the average email took 7.6 days.

Another beneficial option with employing a web-based survey is that it allows for the precise tracking and recording of the survey distribution. This equates to the researcher having access to when the survey is sent, opened, deleted or when a reply is provided. The ease of data entry and analysis was an advantage (Evans and Mathur, 2005); the process of completing the survey was simple, as were the tabulation and analysis of the responses. Once the final questionnaire is submitted, the researcher instantaneously has all the data stored in a database (Wilson and Laskey, 2003). The data is already in electronic format resulting in significantly reducing the time required to generate information, compared to postal surveys (Cobanoglu, Warde, and Moreo, 2001). However, from Sheehan and McMillan (1999) perspective online surveys can make it difficult to achieve full anonymity for participants. These authors suggested that confidentiality might be considered a satisfactory alternative to anonymity. Internet security may also be an area of weakness in an email survey (Berry, 2004). Another factor that could be considered a disadvantage of the survey is the impersonal nature of online surveys (Evans and Mathur, 2005). This may limit the ability of the researcher to probe deeper into certain issues. Further to this disadvantage, quantitative research has the potential of losing the richness of meaning from the data (Babbie, 2007).

Reliability and validity of the survey

Many researchers recommend using a pilot study to ensure reliability and validity in a survey before the commencement of data collection (Imms and Greaves, 2010). Importance should be given to the participants understanding of each question (Lee, 2004). The pilot test is an important element in the research, assisting researchers with the refinement of research questions (Miles and Huberman, 1994), highlighting any flaws, limitations, or weaknesses within the design and allowing the researcher to make necessary revisions prior to the implementation of the study (Kvale, 2007).

Qualitative research

Qualitative inquiry covers a wide range of interpretive methods to describe, decode and translate a phenomenon (van Manen, 1990). Qualitative research essentially aims 'to capture lived experiences of the social world and the meanings people give to these experiences from their own perspectives' (Corti and Thompson, 2004, p. 326). Qualitative research uncovers the essential meaning of the experience being investigated (Burns, 2000). Qualitative methods are interpretive, portraying a world in which reality is socially constructed, complex and ever changing (Glesne, 1999). Qualitative paradigms offer the researcher the opportunity to develop an idiographic understanding of participants and what it means to them, within their social reality, to live with a particular condition or be in a particular situation (Bryman, 1988). It thus facilitates an understanding of the complexity of sociocultural phenomena and, as such, affords possibilities for informing practice (Boyle, Morse, May, and Hutchinson, 1991).

Qualitative research provides a holistic view of the phenomena under investigation (Bogdan and Taylor, 1975; Patton, 1980). Three major processes are involved in phenomenological analysis. They are intuiting, analysing and describing (Parse, 1989). These processes are consistent with the fundamental presuppositions of phenomenological research articulated by Giorgi (1970, 1975a, 1975b). Intuiting means that the researcher comes to know the phenomenon as the subject describes it. The idea of intuiting is to grasp the unique nature of the phenomenon by openly looking, listening and feeling (Spiegelberg, 1976). Therefore, the researcher is first required to remain faithful to the phenomenon as described by the subject in the context of the situation as it emerges in everyday life (Parse, 1989).

Analysing is the second measure in the process of investigating a phenomenon. The attempt is to uncover the constitutional elements of the phenomenon in order to know the whole of it, to shape its meaning as a lived experience (Parse et al., 1985). The researcher searches for the meaning through rigorous adherence to the rules of phenomenal analysis (Parse, 1989), which are discussed below.

Using the analytical method suggested by Wertz (1983) and Giorgi (1985), systematic readings of the transcript are undertaken by first dwelling on the phenomenon (through empathetic immersion and reflection), then describing emergent psychological structures (i.e., constituents and recurrent themes). In a phenomenological study the research questions posed are usually broad and open-ended. ‘The phenomenological interview involves an informal, interactive process and utilizes open-ended comments and questions’ (Moustakas, 1994, p. 114). According to McNamara (2009), the strength of the general interview guide is the ability of the researcher ‘to ensure that the same general areas of information are collected from each interviewee; this provides more focus than the conversational approach, but still allows a degree of freedom and adaptability in getting information from the interviewee’. This type of interview approach ensures a level of flexibility, based on perceived prompts from participants (Turner, 2010). Patton (2002, p. 350) suggested that asking opinion questions were useful in gaining an understanding of the cognitive and interpretive aspect of the individual’s thought processes.

Lived experiences revealed through phenomenology provide data that engenders meaning and insight into behaviours (Creswell, 2009; Moustakas, 1994). The use of phenomenological research presents a feasible and appropriate investigation of human experience in the realm of the human sciences (Nicholson, 2009; Seebohm, 2005; van Manen, 1990). In phenomenological studies, different types of data can be used. For example, van Manen (1997b) stated that there are different approaches to ‘collecting’ or ‘gathering’ lived experience material. Stone (1978) identified three main sources of data collection in a phenomenological study. They were in-depth interviews, documentary evidence and case study analysis with interviewing being used to a great extent in phenomenological studies.

In-depth interviews highlight subjective experience, enabling the researcher to interpret social reality through the meanings that the informants attach to their life experiences (Minichiello et al., 2008). There are several advantages in using in-depth interviews, as they allow participants to describe what is meaningful to them, which may result in participants feeling more relaxed and communicative, while at the same time the researcher can access the individual’s words, perceptions and interpretations (Minichiello et al., 2008). In addition, in-depth interviewing enables the researcher to use probing techniques in order to gain a deeper understanding of the meanings that participants attach to primary questions (Stewart and Cash, 2005). The disadvantages of in-depth interviews outlined by Minichiello et al. (2008) are that they are more intrusive than quantitative techniques. They can be time consuming and emotionally draining to researchers and also more expensive than other approaches, due to travelling costs and the production of transcripts. In addition, to obtain the best results, in-depth interviewing requires a high level of skill and experience (Minichiello et al., 2008).

Transcribing data

Patton (2002, p. 308) believed that ‘the creative and judicious use of technology [could] greatly increase the quality of field observations and the utility of the observational record to others’ without being obtrusive. This was considered a significant advancement for interpretive methods (Markle, West and Rich, 2011).

Guion, Diehl and McDonald (2001) explained that transcribing involves creating a verbatim text of each interview by writing out each question and response using the audio recording.

Rapley (2007, p. 50) provided a detailed description of the transcription process:

> The actual process of making detailed transcripts enables you to become familiar with what you are observing. You have to listen/watch the recording again and again. ... Through this process you begin to notice the interesting and often subtle ways that people interact. These are the taken-for-granted features of people's talk and interaction that without recordings you would routinely fail to notice, or fail to remember, or be unable to record in sufficient detail by taking hand-written notes as it happened.

The qualitative approach of analysis begins with the transcription process. Transcription, pointed out by Hycner (1985) is an important step in phenomenologically analysing interview data. This analysis includes the literal statements and as much as possible noting significant non-verbal and para-linguistic communications. Hycner recommended the use of a margin to the right of the transcription so that the researcher will later be able to make notes about the units of meaning. Bailey (2008) noted that transcription was the ‘close observation of data through repeated careful listening (and/or watching)’. Bryman (2004, p. 482), following Heritage (1984, p. 238), expressed the same ideas and provided six explanations as to ‘why you should record and transcribe interviews’:

a) It helps to correct the natural limitations of our memories and of the intuitive glosses that we might place on what people say in interviews;

b) It allows more thorough examination of what people say;

c) It permits repeated examination of the interviewees' answers;

d) It opens up the data to public scrutiny by other researchers, who can evaluate the analysis that is carried out by the original researchers of the data (that is, a secondary analysis);

e) It therefore helps to counter accusations that an analysis might have been influenced by a researcher's values or biases;

f) It allows the data to be reused in other ways from those intended by the original researcher – for example, in the light of new theoretical ideas or analytic strategies.

The process of data analysis

The analytical process was guided by Colaizzi's phenomenological framework in data analysis outlined by Carpenter (2010, p. 133-134) and adapted:

Stage 1. Acquiring a sense of each transcript. Transcripts are read several times to develop familiarity with the data.

Stage 2. Extracting significant statements. Data sections (units of meaning) are highlighted in the transcripts that inform an understanding of the experience to the researcher. Each statement is labelled with participants' pseudonym, page and line number, and then cut from the transcript copy and assigned to a work sheet.

Stage 3. Formulation of meanings. The researcher's interpretation of meaning is identified by significant statements from the transcripts. An analytical column included on the worksheet can be used to reflect on the researcher's assumptions and/or any related literature. Lapadat and Lindsay (1999) further described this phase as one where meanings are created in a way that further facilitates the interpretation and analysis of the data.

Stage 4. Organising formulated meanings into clusters of themes. Statements along with formulated meanings are grouped together to form a theme.

Stage 5. Exhaustively describing the phenomenon being explored. The main themes are described in detail along with verbatim quotes.

Stage 6. Describing the fundamental structure of the phenomenon. Theme descriptions are reduced to a statement of their fundamental structure. This stage involves reviewing, modifying and developing the preliminary themes.

Stage 7. Returning to the participants. Colaizzi suggests that the final validation involves returning to the participants for another interview to ensure that they can recognise the themes, according to their own experiences. However, Stage 7 is not always feasible.

Further to the point of returning to the participant for validation, Ashworth (1993, p. 15) provided a critical exploration of participant validation, supporting it on moral and political grounds but warning against taking participants' evaluations too seriously, stating that it may be in their interest to protect their 'socially presented selves'. Mays and Pope (2000, p. 51) argued that researchers seek to provide an overview whereas individual participants have individual concerns, which may result in discrepant accounts. Atkinson (1997) warned of the pitfalls of 'romanticising' respondents' accounts. Respondent validation exercises, such as reading of drafts, make considerable demands on participants' time and, depending on the research topic and content of transcripts, can even be exploitative or distressing (Barbour, 1998), although Barbour (2001) noted that participant validation can be valuable in action research projects, where researchers work with participants to facilitate change. Most health services research, however, involves a one-off data collection exercise, in which Barbour suggested that participant validation may not be necessary.

The next section focuses on the validation of data collection, analysis and the study by looking at trustworthiness, validity and reliability of the study as a whole.

Validation

Validation of the qualitative approach examines the trustworthiness of the research, including validity issues and reliability concerning various aspects of the current study using a phenomenological research methodology.

The concept of validity in research is the extent to which a method of data collection represents or measures the phenomenon which it purports to represent or measure (Minichiello, et al., 2008). It is 'concerned with the integrity of the conclusions that are generated from a piece of research' (Bryman, 2008, p. 32). According to Taylor and

Bogdan (1998), validity occurs when the researcher correctly names one’s understanding of the informants’ perceptions, views, attitudes and behaviours.

Carpenter and Suto (2008, p. 148) argued that the concepts of validity and reliability are seen as incompatible with the ontological and epistemological foundations of qualitative research. Qualitative research is descriptive and unique to a specific historical, social, and cultural context (Johnson and Waterfield, 2004). It therefore cannot be repeated in order to establish reliability (Liamputtong, 2010). As Liamputtong asserted, qualitative enquiry cannot be tested in the same manner as quantitative research, as an individual socially constructs reality and while it cannot be measured, it can be interpreted.

The term ‘validity’ has been contested in qualitative research (Liamputtong, 2010; Finlay, 2006) as it is based on the assumption that the phenomenon being investigated possesses ‘reality’ in an undisputed, objective sense. Finlay (2006) illustrated that qualitative researchers in general view this as inappropriate, explaining that because of the diverse nature of the social world, it might be erroneous to assume the existence of one unequivocal reality to which all findings must respond. Qualitative research involves subjective interpretations by both participants and/or researchers (Finlay, 2006). Therefore, interpretation cannot be excluded from the research process, with any one analysis presenting as a ‘tentative statement opening upon a limitless field of possible interpretations’ (Churchill, 2000, p. 164). Many qualitative researchers prefer alternative criteria to the three concepts of reliability, validity and generalisability, which provide the basic framework for conducting and evaluating traditional quantitative research.

Qualitative researchers contest and reject these positivist concepts (Finlay, 2006) and the onus of having to fit into the rules and standards of quantitative inquiry, preferring other terms to produce rigour and trustworthiness in a study. The use of explicit criteria offers a qualitative researcher a means to highlight the strengths or limitations of the research being discussed and to claim rigour or critical thoughtfulness in the research approach. To further this argument, philosophical beliefs are articulated through language (Tobin and Begley, 2004), with language varying within philosophical perspectives. The transference of terms across paradigms has been argued as inappropriate (Hamberg and Johansson, 1999). The mixed methods, including the analytical tools, used in this thesis were fundamentally important to the findings and discussion. The research findings highlighted the view that in a qualitative paradigm, reality is socially constructed and indeed there are multiple versions of realities.

Bracketing and reduction

Validity or credibility and transferability in phenomenology are an important issue that should be addressed at the outset of the study by means of bracketing or reduction. Bracketing reduces the need for empirical judges in a phenomenological study (Giorgi, 1989). Taken-for granted assumptions and presuppositions about the phenomenon must be temporarily suspended by the researcher (Ehrich, 1996) and one must attempt to suspend one's biases by using the process of bracketing in order to understand the phenomenon under study (Omery, 1983; Valle and Halling, 1989).

The aim of bracketing is to 'encourage researchers to set aside as much as possible their internal beliefs, experiences, understandings, biases, judgements and assumptions in order that they might authentically listen to the participants' perspectives and describe the essence of the phenomenon being studied' (Carpenter, 2010, p. 131). We bracket 'our judgements about the factual, about what is the case, in order to become open to our own experience and to the understandable meaning implicit in this experience' (Lindseth and Norberg, 2004, p. 148).

Bracketing helps the researcher remain vigilant throughout the research process, specifically 'to the ways in which their personal intellectual baggage might distort the description of the phenomenon' (Finlay, 2011, p. 45). Bracketing was first articulated by Husserl as a 'radical, self-meditative process where the philosopher puts aside the natural world and world of interpretation in order to see the phenomenon in its essence' (Finlay, 2011, p. 74)). Husserl explained the process as involving a personal transformation and 'reorientation of the natural mundane attitude' (Husserl, 1936/1970, p. 258). He described the reflective process of bracketing:

> We can do nothing but reflect, engross ourselves in the still not unfolded sense of our task, and thus secure, with the utmost care, freedom from prejudice, keeping our undertaking free of alien interferences . . . and this . . . must supply us with our method (Husserl, 1936/1970, p. 134).

Merleau-Ponty (1962) referred to method not as techniques but as an attitude. Finlay (2011) explained that the process of bracketing is a phenomenological attitude, not simply an exercise, suggesting that reduction is a continuous process of engagement whereby the intrusion of pre-understandings is managed throughout the study and not simply dealt with as one step in the research. Other authors support the significance of ensuring that the bracketing process occurs throughout the research (Wilson, 2002; Giorgi, 1994; Oiler, 1982).

Finlay (2008, p. 2) eloquently described the reduction process:

> Reductions can be intertwined with reflexivity and . . . in this process, some thing of a dance occurs – a tango in which the researcher twists and glides through a series of improvised steps. In a context of tension and contradictory motions, the researcher slides between striving for reductive focus and reflexive self-awareness; between bracketing pre-understandings and exploiting them as a source of insight.

Validity or credibility also depends on whether the researcher has influenced the contents of the participants' descriptions and whether the transcription is accurate. In the analysis the researcher has to consider whether there are conclusions other than those the researcher has deduced (Polkinghorne, 1989). In considering rigour in phenomenological research, as with any qualitative research, there is a need to determine whether the study is believable, accurate and right, and whether it is useful to people beyond those who have participated in the study (Sanders, 2003). Of great importance is the ability to describe and demonstrate a clear audit trail of decisions taken during the data collection and analysis process. The researcher's role, thoughts, feelings and reflections help to promote the credibility of a study. Koch (1994, p. 978) supported this by stating: 'A decision trail provides a means for the researcher to establish audit trail linkages. Leaving a decision trail entails discussing explicitly decisions taken about the theoretical, methodological and analytical choices throughout the study'.

The integrity and quality of the qualitative research process has been postulated to require different criteria of evaluation from those of the quantitative approach, reflected in a preference for applying different terminology in discussing validity and rigour (Lincoln and Guba, 1985). Kirk and Miller (1986) noted that the in-depth interviewer is constantly engaged in checking perception and understanding against possible sources of misinterpretation to derive tentative conclusions for the researcher's understanding of the situation.

Rigour criteria

As mentioned above, qualitative researchers may use variant terminology to quantitative researchers in order to produce rigour and trustworthiness in a study. This thesis has applied the qualitative terminology suggested to produce rigour and trustworthiness within the epistemology pertinent to the qualitative paradigm.

Table 3.1 Rigour criteria employed in qualitative and quantitative research

QUALITATIVE	QUANTITATIVE
Credibility	Internal Validity
Transferability	External Validity
Dependability	Reliability
Confirmability	Objectivity

Source: Carpenter and Suto 2008, p.149.

Credibility: Credibility asks if the findings can be regarded as truthful (Raines 2008, p. 455) and how believable they are (Bryman, 2008, 34). Credibility asks whether 'the explanation fits the description and whether the description is credible' (Tobin and Begley, 2004, p. 391).

Transferability: Transferability replaces external validity for qualitative researchers. Instead of aiming for random sampling and probabilistic reasoning, researchers provide a detailed account of the setting and allow the readers to judge the applicability (Finlay, 2006, p. 10), being explicit about the limitations of a study and the transferability of its findings (Barbour, 2000).

Bryman described transferability as whether the findings of the study can be applied to other groups or contexts (Bryman, 2008, p. 34). Carpenter and Suto (2008, 149-150) posited that transferability relates to 'the degree to which qualitative findings inform and facilitate insights within contexts other than in which the research was conducted'. Exploratory qualitative studies may be 'theoretically generalizable' and provide an understanding of apparently illogical health behaviour, as is seen in childhood vaccinations (Barbour, 2000).

Dependability: Dependability replaces the concept of reliability and asks whether the research findings 'fit' the data that have been collected (Carpenter and Suto, 2008). Raines (2008, p. 456) noted that dependability 'addresses the consistency or congruency of the results'. An audit trail is of great importance whereby 'the process of research is logical, traceable and clearly documented' (Tobin and Begley, 2004, p. 392).

Confirmability: Confirmability replaces the concept of objectivity as well as considering the audit trail to demonstrate quality and the importance of reflexivity from the researcher. For Finlay (2006, p. 10) reflexivity meant that the researcher had acknowledged and accounted for her/his role and documented it in the research. Shenton (2004, 63) argued that, to achieve confirmability, 'researchers must take steps to demonstrate that findings emerge from the data and not their own predispositions'. The findings must be clearly linked to the data (Tobin and Begley, 2004; Padgett, 2008).

Ethical considerations and research design

Glesne (1999, p. 113) stated that 'ethical considerations are inseparable from your everyday interactions with research participants and with your data'.

Privacy and confidentiality are important aspects of research. Confidentiality involves a clear understanding between researcher and subject concerning the use of the data provided (Burns, 2000). Participants were informed at the outset of this study that confidentiality would be maintained at all times and were informed of their right to withdraw at any time without penalty (Glesne, 1999). Informed consent was obtained in writing from participants prior to involvement in the study.

Ethical issues are a vital consideration in the protection of participants in qualitative studies. The researcher is responsible for advising participants of the risks involved and protecting them from harm. The basic premise of a research process involving voluntary participants is that they are informed about the study's purpose and the impact of the information on their lives (Bloomberg and Volpe, 2008; Marshall and Rossman, 2006; Merriam, 1998). Although it was determined that the research posed no adverse effects on the safety or wellbeing of the participants, all necessary protocols were followed to ensure the protection of their privacy, identity and rights.

All participants were advised of the purpose of this study and about the methods of data collection. All audio-recorded and transcribed interviews remain confidential and cautionary measures were taken to secure the storage of electronic and hard-copy record; only the researcher has access to this material.

Insider/Outsider controversy

The notion of insider/outsider status is described by Gair (2012, p. 137) as ‘the degree to which a researcher is located either within or outside a group being researched, because of her or his common lived experience or status as a member of that group’. There are advantages and disadvantages to being both an outsider and an insider. Insiders are argued to be ‘endowed with special insight into matters necessarily obscure to others, thus possessed of a penetrating discernment’ (Merton, 1972, p. 11). Insider status can have advantages in gaining access to the field but the status also has its limitations (Minichiello et al., 2008). Many researchers have noted that insider researchers may have a deeper insight into the topic, which an outsider may not interpret in the same manner (Zinn, 1979; Blauner and Wellman, 1973; Valentine and Valentine, 1970).

Breen (2007) took a broader view of the insider/outsider dichotomy, suggesting that all humans are insiders: humans studying humans. This perspective is supported by Minichiello et al. (2008) who argued that insider researchers are more likely to challenge theoretical frameworks due to their insider knowledge which may be more attuned to interpretation, whereby an insider and an outsider may interpret knowledge in different ways. From another perspective, Zinn (1979, p. 213) warned that the subjectivity of the insider researcher ‘will lead to bias in data gathering and interpretation’. Minichiello et al. (2008) disagreed, arguing that those who voice this objection assume that outsiders are ‘value-free’ or free of their own suppositions. The key point taken from Minichiello and colleagues, therefore, is that the insider must be critically aware of different interpretive schemes and ensure that all information is probed for details.

The insider/outsider positioning is a complicated argument. D’Cruz and Jones (2004) suggested that researchers can be insiders, outsiders, and sometimes both. They acknowledged that an outsider might not gain the same access to the field as an insider, but caution that, in the recent past, insider status might have been used to avoid negotiating access, this in turn entrenching rather than avoiding researchers’ power in relation to participants. Brayboy and Deyhle (2000) stated that an insider’s view can evolve over time, and will be enhanced through researchers’ actively aligning themselves with research participants. Mies (1983, p. 123) also promoted this sentiment, speaking of ‘conscious partiality’, an apparently one-sided view, looking through the eyes of participants. Although insider status is not necessary in conducting research it can help ‘to unravel the experience of the other’ (Daly, 1992, p. 110) but may also present challenges to the research. Most evident in the literature is the need to be aware of the inherent complexities in both insider and outsider concepts.

The involvement of what might be considered as an insider in this research allowed for an understanding of the context and increased trust, which is believed to have increased the numbers of participants who volunteered to provide data. Some of the individuals in the study described being marginalised by orthodoxy and were therefore initially cautious, wanting a confirmation of the researcher's background. For this sensitive research, some disclosure from the researcher was essential, as potential participants would initially not respond until some disclosure had occurred. The researcher identified herself as a naturopath researching adults that were raised without routine childhood vaccinations and the participants seemed content with that. Once the researcher had declared her background the issue was not discussed further. Reciprocity is explained as a fundamental part of phenomenological research which brings about a genuine rapport with participants (Carpenter 2010, p. 130). Reciprocity was established early on by the researcher's self-disclosure and perceptions of respect for the participants.

The editor of the Natural Health Society magazine had been raised without routine childhood vaccinations, and became a participant and an important gatekeeper, placing an advertisement alongside a note in the editorial column on behalf of the research project. From there, participants expressed an interest until there were almost seventy survey participants. Snowballing became the sampling procedure, as people who saw the advertisement told others about it and contacted the researcher. The gatekeeper was an important part of this study allowing access to adults that were raised without routine childhood vaccinations. 'Gatekeepers can allow or deny researchers' access to the setting or to participants ... Working with gatekeepers can assist in increasing the trust and rapport with participants' (Liamputtong, 2010, p. 99).

Research design

In the phenomenological framework, a mixed method approach was chosen as the most appropriate means of answering the research questions:

- What was your experience of being raised without routine childhood vaccinations?
- What is the past and present state of health of these adults that were raised without routine childhood vaccinations?

- What diseases, if any, have they experienced?
- Were antipyretics and antibiotics also avoided?
- What health or social issues have they experienced?
- What health ideologies do they have?
- What outcomes have occurred as a result of being raised without routine childhood vaccinations?
- What vaccine choices were made regarding vaccinations and with the participant's own child/children?

The study was exploratory and sought to gather a wide range of information about a group of adults that were raised without routine childhood vaccinations. The quantitative strand of the study was a survey questionnaire, chosen because it was thought to be an efficient method of gathering a broad range of information. The qualitative strand (in-depth interviews) was proposed to address the aspect of meaning, where the concept of meaning could be explored more deeply.

The mixed methods approach was a means of gaining a broad spectrum of information about the group under study – both the experience of participants and information-specific data, like descriptive statistics. A mixed methods approach was used to answer the research questions, incorporating a survey questionnaire for the quantitative strand, followed by in-depth interviews for the qualitative strand. The survey questionnaire was useful in the initial phase of the research, gathering data and informing the subsequent phase of the research, the in-depth interviews.

The survey incorporated the use of statistics to provide the study with essential background information regarding the participants under study and also raised points from the comments section in the survey that the researcher needed to address in further detail. The survey questionnaire would provide demographic, contextual and perceptual information, and also lead to finding willing participants to take part in the in-depth interviews.

Descriptive statistics were reported to the researcher and were thought to be a useful background to inform and enhance the study, with the gaining of some relevant information about the group under study. With this rationale, a survey questionnaire was designed and implemented. Creswell et al. (2011) noted that one of the challenges with a mixed methods approach is in the integration of the two forms of data. Several approaches may be used, merging data, connecting data, and embedding data (Creswell et al., 2011). In this study ‘connecting data’ was used in the integration of the two forms of data. Creswell et al. (2011, p. 5) provided a description of ‘connecting data’ as a means of integration.

> This integration involves analyzing one dataset (e.g., a quantitative survey), and then using the information to inform the subsequent data collection (e.g. interview questions, identification of participants to interview). In this way the integration occurs by connecting the analysis of results from the initial phase with the data collection from the second phase of research.

The following flow diagram (Figure 3.1) will outline the research design.

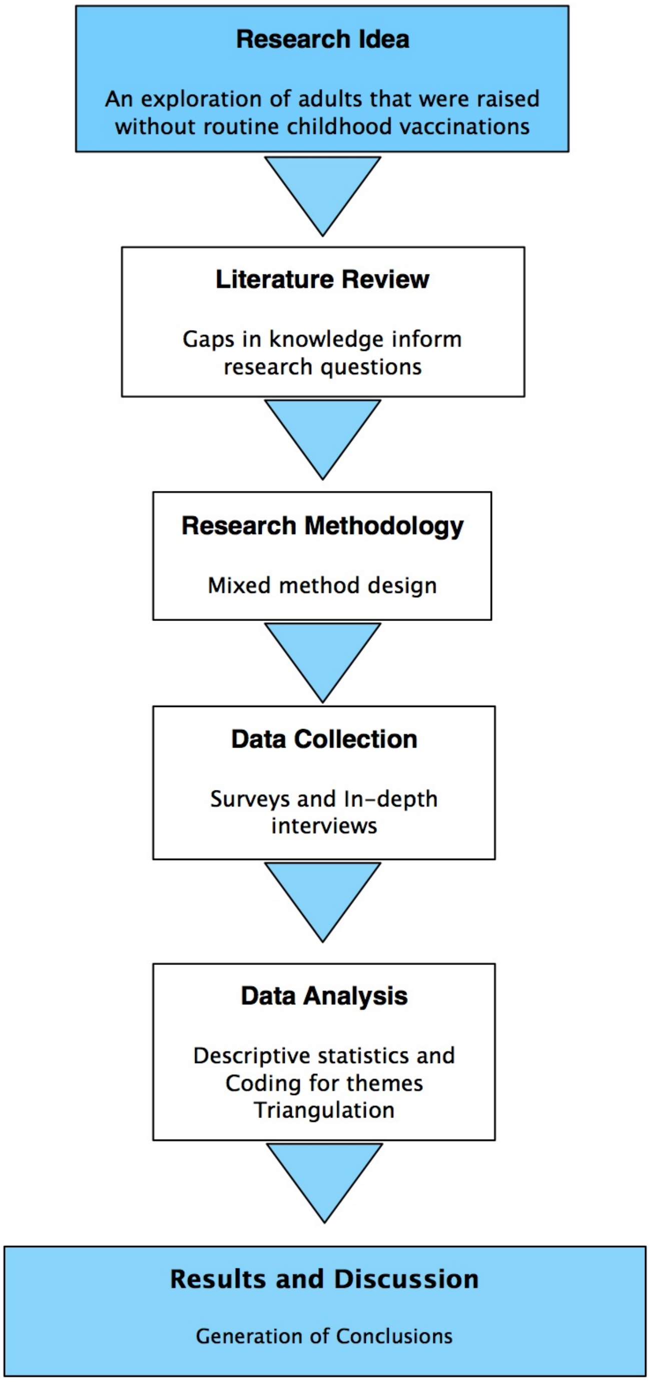

Figure 3.1 Research Design Flow Diagram

Methods

This section describes the methods used to conduct the research and gather, manage, analyse and report data obtained through the exploration. It demonstrates an understanding of the methodological implications of the links between the purpose of the study, the research questions and the research approach. It defines the research method and culminates in a brief summary.

The overarching question that guided the research was ‘What is the experience of being raised without routine childhood vaccinations?’ followed by sub-questions (see Research design in the previous section) which guided the process of data gathering and the methods chosen.

The mixed method approach to this research and the use of a phenomenological conceptual framework allows for, indeed accepts that reality is socially constructed and there are multiple versions of reality. The data collected and collated in this research records what participants reported to the researcher.

Survey questionnaire development

An online web-based program (‘Survey Monkey’) was chosen to carry out all of the functions that were required of the survey. The program assisted in the designing, sending, storing and returning of the survey, as well as a systematic plan for analysis of the survey findings.

The survey questions were developed by the researcher and were informed by the literature review. Large comment sections were incorporated into the survey, asking the participants to explain their answers in more depth. These large comment sections encouraged participants to ‘voice’ their views and lend themselves to the phenomenological approach adding valuable qualitative data.

The survey questionnaire consisted of 45 questions and explored a number of different areas. The first question of the survey determined the vaccine status of the potential participant, as it was hypothesised that some people may have had certain vaccines (e.g. tetanus and travel vaccines) outside of the recommended routine childhood vaccines.

The next group of questions (2–13) were based around demographics and the personal information of participants including gender, age range, where they grew up, and what type of schools they attended, as schooling has been nominated as a factor in a child's vaccine status (Kennedy and Gust, 2005). Of special interest was whether the participants had attended a Steiner school or been homeschooled, as these groups have been named in the literature as having a high number of unvaccinated individuals (Choi and Manning, 2010; Khalili and Caplan, 2007; Duffell, 2001; Hanratty et al., 2000). The level of education attained by both participants and their parents was also of interest, in addition to participants employment status and occupation.

The second major section of the survey (questions 14–17), asked questions concerning their personal history. The main reason that they were not vaccinated was explored, as well as who made the vaccine decision. Participants were also asked whether they had grown up with other unvaccinated people and whether they had felt stigmatised and/or unfairly treated because of their unvaccinated status.

The third major section of the survey (questions 18–32), looked at health-related behaviours: smoking, drinking, exercise and dietary habits. Information as to whether or not participants had experienced childhood contagious diseases was of particular interest, as well as any repercussions that they had experienced from having had a disease. Health-related behaviours were of interest in distinguishing a holistic picture of the individuals involved in the study. In addition, participants were asked about their level of contentment with their unvaccinated status, and were asked to reflect back on their unvaccinated experience and report anything of significance to the research aims, purpose and questions.

The fourth section (questions 33-45) examined participants' health care choices. Information was sought about where they had learnt their current health views and which type of health care practitioner they had used as a child and were using now as an adult. Participants' preferences for pharmaceuticals, natural remedies, or a combination of both were also explored. In addition, the survey investigated participants' level of satisfaction regarding their health and their preferences for travel vaccines. The question regarding their own preferences for vaccinating their children, current and future, was of particular relevance to observing generational behaviours and patterns. Participants were also asked about their interest in certain vaccines as there is substantial literature that has highlighted some parents' preferences for certain vaccines only. The final question of the survey questionnaire asked the participants if they would be willing to be contacted for a follow-up in-depth interview.

The survey then underwent a pilot phase in which seven people from the University of New England tested the survey and the questions, providing feedback as to how it could be improved. In total five academics and two PhD students read through the questions and attempted the survey to get a general feel for the process. As a result of the pilot study, adjustments and changes were made to the survey questions and also to the clarity of the survey process.

For a copy of the full survey questionnaire, please refer to Appendix 7.

In-depth interview guide development

The in-depth interview questions were initially developed from the literature and then refined from the survey questionnaire findings. Phenomenological research seeks to obtain descriptions of the experience under exploration, and therefore it was appropriate to use this research tradition for the qualitative strand of the research. Phenomenology was considered the best way to reflect upon the ‘essence’ of what it was like to be raised without routine childhood vaccinations, from the perspective of the individual who had had this experience.

General interview guide

A general interview guide was used in this study to provide the researcher with a focus for exploring the meaning of being raised without routine childhood vaccinations. The main research question in this study was: ‘Can you tell me about your experience of being raised without routine childhood vaccinations?’ Additional open-ended questions were employed to explore the participants’ health care choices, their experience with childhood illnesses and the health care they received. Participants were also asked about how they felt about being socially responsible and vaccinating their own children.

For the complete interview guide please refer to Appendix 3.

Ethics

Following completion of the research proposal, the survey questionnaire and in-depth interview questions, the researcher acquired approval from the University of New England

Human Research Ethics Committee to proceed with the research (HE10/217 valid from 01/02/11 to 31/12/2013). The approval process involved outlining all the procedures needed to ensure adherence to the standards put forth for studies involving human subjects, including participants' confidentiality and informed consent.

Ethical online behaviour was of great importance to the research; therefore nobody was sent an email or a survey without his or her consent. Consent was granted to the researcher from the potential participant by email or phone, informing the researcher of their interest in participating in the study and their contact details. The first step in their consenting to the survey was an email confirming that the researcher had permission to send it. Participants were informed of confidentiality at the outset, in the introduction section to the survey. At the end of the survey questionnaire, participants could indicate their willingness to be interviewed. One of the limitations of this process was that the survey questionnaire was linked to the in-depth interviews and because of this it was not possible to maintain the anonymity of those participants who agreed to be interviewed. The researcher needed to gather identification information and consent so that participants could be contacted for the qualitative phase of the research.

Recruitment into the study

The potential sample population was quite broad. It included any male or female 18 years and over. Originally the aim was to explore adults that were raised fully unvaccinated. The recruitment ended up extending to adults that were raised without routine childhood vaccinations because it was found that a substantial proportion had received a tetanus vaccine as a result of an injury, either as a child or as an adult. Travel vaccines were also accepted as they were not part of the routine schedule. The other group that presented were three adults that had been given their first vaccine as babies, had experienced an adverse reaction and never been given another. There were also three people from the older generation that claimed they had been given an injection at school without parental permission. Therefore the criteria restrictions for the study were that their parents had deliberately chosen not to give them routine childhood vaccinations. Vaccine choices are complex and wide-ranging and therefore it was considered important to understand more about why certain vaccines were chosen.

The researcher placed advertisements in a variety of different areas of New South Wales, including Nimbin, the Central Coast, Sydney's Eastern Suburbs and The Hills district, health care practitioners' waiting rooms, health food stores and community boards. Later, after much thought about where to find more participants, an advertisement was placed in the Natural Health Society magazine, which is distributed to members all over Australia. The advertisement had the researcher's telephone number and email address and the editor of the magazine included a brief editorial in support of the research.

Recruitment for survey questionnaire

Potential participants contacted the researcher by email or telephone to express an interest in participating in the survey after seeing an advertisement or being told about the survey by someone they knew. This worked well, as any queries could easily be answered and the link to the survey was promptly sent to them.

This method was particularly appropriate for the survey response as it was not invasive, or costly to the potential participants. The survey would be sent to them within the day of the request, as it was considered important to get it to the potential participants as soon as possible, while they were keen to participate and the advertisement was fresh in their mind. There was an excellent rate of response from the people that requested the survey. The survey questionnaire was sent with an email that had a hyperlink to the web-based survey using 'Survey Monkey'.

Recruitment for in-depth interviews

The survey questionnaire had a final section, where the participants could indicate their willingness to participate in the optional in-depth interview and leave their contact details. Participants were contacted via email or telephone and asked whether they were still willing to participate in the interviews and what time most suited them.

In phenomenology, researchers use participants to generate a fund of possible elements and relationships that can be used in determining the essential structure of the phenomenon (Valle and Halling, 1989). Therefore it was important to obtain rich descriptions from individuals who could provide insight into the experience being explored. In this study it was determined that participants would have not had any routine childhood vaccines to participate in the study.

The phenomenon being explored was of prime importance. There was an overwhelming response of adults willing to participate in the in-depth interviews. A large qualitative sample was not possible in relation to time, economy and available resources. Therefore a convenience sample was adopted, as travelling to interviews was a consideration for the in-depth interviews. The travel time allocated was a maximum of five hours' driving time by car, return. Although not ideal for in-depth interviews a telephone interview was attempted with one interstate participant in an effort to gain a broader aspect in the sample. A purposive sample was considered, however it was determined that the convenience sample may have been less prone to research bias and more convenient in terms of accessing participants face to face. The mixed methods process of incorporating both a survey and multiple interviews was time consuming, with the researcher simply running out of time to pursue more interviews.

Survey participants that were left out of the in-depth interviews were at a distance from the researcher. Therefore participants in New South Wales, from Sydney's Eastern Suburbs to the Blue Mountains, to the Central Coast were most represented. The researcher interviewed as many participants as possible and all were thanked for their willingness to participate in the study. An information sheet and consent form was sent to each of the participants who agreed to be interviewed and the completed consent form was returned at the time of the interview.

Survey questionnaire – data collection and analysis

The survey questionnaire was designed as part of the mixed methods approach, as a means to effectively gather data.

As noted earlier, the web-based online software program 'Survey Monkey' was employed to aid in facilitating the survey questionnaire. The program easily sent a link to the survey questionnaire, stored the completed surveys and aided in the analysis of the data. The benefits of the online survey were numerous. The capacity to send the survey after receiving an expression of interest by a potential participant meant that they would receive the survey within a few hours of displaying their interest. They could then easily complete the survey questionnaire online when they were ready and send it back with the ease of clicking the 'send' button.

The beginning of the survey explained the research process to participants so that they were aware of the two possible phases of the study. The survey questionnaire contained 45 questions with four main sections; all of these have been described in detail above. The first question asked participants to confirm their vaccine status of fully unvaccinated or partially vaccinated with a comment section to describe which vaccines they had received, if any. The next section was based around demographics and personal information. The second section covered issues pertaining to their history, such as reason that they were not vaccinated, who made the vaccination decision, and if they had grown up with other unvaccinated people. The third section considered health-related behaviours and what kind of diseases and ailments that they had experienced. The fourth section examined health care choices with questions regarding their current health beliefs and preferences for using various forms of medicine.

'Survey Monkey' enables users to create their own survey and produces its own statistical summary. It offers unlimited questions and unlimited surveys, custom themes, open-ended response categories and enhanced security. The survey data were automatically compiled into graphs, providing percentages and outcomes and stored in the 'Survey Monkey' database, which was password-protected. 'Survey Monkey' provided the results and descriptive statistics in PDF format at the completion of the survey.

Many survey questions had comment boxes to give participants an opportunity to explain and comment on their answers. Due to the qualitative nature of the responses, and through a process of identifying and examining text from these open-ended responses, the survey questionnaire generated many custom themes. The themes that emerged from this study were derived inductively from the data. The researcher was made aware of personal beliefs towards the phenomenon by bracketing presuppositions and personal beliefs regarding the phenomenon under investigation. Every effort was made to avoid imposing these views while analysing the data by scrutinising and questioning the researcher's own assumptions, biases, and perspectives. This involved continued critical discussion with the researcher's supervisors and personal reflection to help identify inherent assumptions and biases.

In order to categorise and code the data, statements, along with formulated meanings, were grouped together to form a theme. In some cases themes did not have enough data to support them and/or did not fit into any category; these were either removed or merged with other themes to become one theme, or generated a whole new theme. Other themes needed to be broken down to form separate themes. A template work sheet was designed with the identification details of the participant, their quote, the code or potential theme and the analytical memo where the researcher could add notes and key words (an example is provided in Appendix 4). Themes were further defined and refined, generating clear definitions and names for each of them. Simultaneously, large sheets of cardboard were attached to the wall and used as a working area for conceptualising and reviewing the emerging ideas (a basic version is in Appendix 6). This analysis resulted in several themes, which were consolidated to form main themes that were common to all of the participants' descriptions of being raised without routine childhood vaccinations. In addition to providing depth to the survey findings about the experiences of the participants, these emerging themes informed the in-depth interviews.

The survey questionnaire results, as well as the emerging themes, and related discussions are presented in Chapter 4 – Survey Results and Discussion.

In-depth interviews – data collection and analysis

Potential interview participants that were willing to take part in the in-depth interviews left their details at the end of the survey questionnaire. The researcher contacted them via email or telephone and organised a convenient date and time for the interview; then sent the 'Information Sheet for Participants' (Appendix 1) and 'Consent Form' (Appendix 2) to the confirmed participants. Before the start of the interview, participants' consent was finalised and participants were asked for permission to have the interview audio-recorded; all agreed. Broad open-ended questions were used to encourage participants to 'express their perceptions and understandings in their own words' (Carpenter, 2010, p. 128). Probing was used in particular instances when more information was required to gain a better understanding of what was being said. Minichiello et al. (2008) described the importance of probing to clarify and/or expand ideas.

The paramount intention was to learn from the participants, so the researcher began by asking each participant to speak about their experience of being raised without routine childhood vaccinations. The researcher allowed the participant to speak freely, with some probing questions to encourage more detail, and guided the conversation with a general question guide (described above). 'Funnelling', as described by Minichiello et al. (2008, p. 94), employed as a relaxed and non-threatening way of moving through the interview. Questions began in a broad sense which stimulated participants thinking about the issues generally, and then moved into a more specific style of questioning. An intentional non-threatening interview style worked well because many participants noted that they were used to having their views dismissed as nonsensical by mainstream professionals and the general public. Interview questions were developed and informed by the literature and the themes that emerged from the survey questionnaire. Field notes were taken after each interview in order for the researcher to reflect upon the interview and capture the context and meaning of what had been said and any insights that followed.

Transcribing

Following the interviews, the audiotapes were used to transcribe each of the interviews verbatim. The researcher transcribed each interview.

Data entry

The data was transferred to electronic spreadsheets; each response was manually copied and pasted into a separate cell of the spreadsheet. Simultaneously a unique participant identification code was attached to each entry where each response mostly occupied one cell, but if the response was multivalent it was split into separate cells along with the participant's identification number for each split response.

Coding and categorisation

'Numbers' which is the Macintosh equivalent of 'Excel' was employed for the process of creating a template style work sheet, using the 'cut and paste' function to create categories and organise the material. A single worksheet template was created, and duplicated for each person interviewed. Individual data and codes were entered for the thirteen participants, with their quotes placed in the appropriate category (an example is provided in Appendix 5). Colour coding was useful for the quick and easy identification of participants. The large sheets of cardboard attached to the wall were used as a working area for conceptualising and reviewing the emerging ideas. Each time the data was analysed categories became clearer and as a result a comprehensive list of exclusive categories was developed.

Basic word processing features were useful in aiding the analysis, and to detail and organise the themes. The text was examined and re-examined using a word processing feature: 'command f', was used to ensure relevant text had been identified to match themes. This process allowed the researcher to identify and locate a particular word in the template worksheets and where and when it occurred throughout the large volume of text. 'Wrap text' was used to keep long entries from running across the next several sheets of the spreadsheet. Computer-based worksheets to code the data were chosen as the most efficient and effective method of organising the data along with sheets of cardboard which were managed manually.

Analysis

In the process of analysis and synthesis of the in-depth interview data, a combination of techniques was employed. The preliminary interpretive phase and much of the analysis were carried out manually. Later a Macintosh computer was employed. Beginning manually allowed the researcher to become familiar with the analysis process and the main concepts that were raised. The use of a professional software program was considered, and even trialled; however, after spending much time and energy looking into the options, the researcher was far more confident with using the computer's inbuilt word processing software capabilities for assisting this phase of analysis. Serry and Liamputtong (2010, p. 396) and La Pelle (2004) contend that data analysis functions and even large complex research projects can be performed by powerful word processing software available on the computer.

Limitation and validity of in-depth interview results

The involvement of the researcher as an 'insider' in this research encouraged trust. As noted previously, some disclosure from the researcher was essential and once the researcher had declared her background it was not discussed further. Insider status gained the researcher an advantage of gaining access to the Natural Health Society magazine and also to the Steiner cohort (for participants).

Another potential limitation involved the researcher's heterodoxy background; every effort to distance the researcher from the researched was employed; regular reflective discussions with the research supervisors were important to ensure as much objectivity as possible. Ongoing vigilance was required in order to monitor personal beliefs and reactions to the research. A concerted effort was made to remain cognisant of personal biases, based on previous research experience, which could impact present descriptions. Presuppositions and biases toward the phenomenon were identified with the bracketing techniques described above. Although some authors suggest that the final validation of the data analysis should involve returning to the participants for another interview to ensure that the themes are recognised, this step was not feasible in this study due to financial and time constraints.

Triangulation of data

Methodological triangulation was used involving the use of quantitative and qualitative methods to explore the research question. Data was also collected from two different groups; people with anthroposophical backgrounds and subscribers to the Natural Health magazine. These two groups are considered different cohorts and allowed the researcher to gain insight into the experience of adults that were raised without routine childhood vaccines.

Different categories of data within these groups were cross-examined in the process of coding to determine points of similarity and difference. The combination and triangulation of the data sets provided the rich data that were coded, analysed and interpreted, and from which the findings emerged.

The in-depth interview results and related discussions are presented in Chapter 5 – Interview Results and Discussion.

Limitations of the study

The relatively small survey and interview participant numbers were a limitation of this research. Although a wide variety of unvaccinated people were sought to participate in this research, it was difficult to locate them. A larger study would be advantageous to further develop the research topic. This research project was limited by distance, time, and finances and was also limited to one country at one period of time. More participants might have been recruited if travel was more readily possible. A further limitation included the lack of prior research on the topic of unvaccinated people; it would have been useful to compare various studies. This research was part of a PhD research project and had institutionally instigated time requirements. Financial assistance was made available but was restricted to certain research activities.

Summary of Chapter 3

This chapter has discussed the methodological framework used and described the way in which this research has utilised a variety of research methods, both quantitative and qualitative, to gather a breadth and depth of information. The aim of the study was to develop insight into the experience of adults that were raised without routine childhood vaccinations. Every effort was made to ensure the exploration was conducted in a respectful research environment.

The next chapter will present the survey results, the emerging themes, and a discussion representing the main quantitative strand of the research.

Chapter 4

Survey Results and Discussion

Introduction

The survey was used to discover as much information as possible about adults that were raised without routine childhood vaccinations who participated in the study. Although multiple versions of reality exist in the qualitative paradigm, these questions were thought to be useful for collecting conceptual information about beliefs, attitudes, opinions, behaviours and experiences, as well as descriptive information. Descriptive information included, demographics and personal details such as where participants grew up, their gender, and age range, the type of school that they attended, their level of education, current occupations and employment status, and whether they were in contact with many other unvaccinated people. Comment boxes were included alongside many of the questions, as a means of eliciting some detail concerning participants' views and experiences, in relation to that particular question. This feature was utilised by many participants and enhanced the findings of the survey.

At the end of the survey participants were asked if they were interested in participating in an in-depth interview. Individuals that were willing to participate left their details and were contacted some time later. The process of selection is described and discussed in the methodology chapter. Results of the in-depth interviews are presented in the next chapter. Incidentally, Chapters 4 and 5 produced some unexpected, unanticipated findings, where the researcher found it necessary and logical to return to the literature. As a result there is some new literature presented and discussed in these chapters, alongside the developing themes.

Background to the survey

To participate in the study, potential participants contacted the researcher to request a survey be emailed to them. Participants without email were invited to make contact by telephone to receive a hard copy of the survey, with a return self-addressed envelope included, through Australia Post mail service. One person requested this strategy, and that participant's answers were entered manually into the survey by the researcher.

Survey Results

The online survey was sent via email to seventy-five persons who requested a survey in response to having seen the advertisement or from a snowball effect, and was completed by sixty-seven participants giving an 89.3% completion response rate. Forty-two women and twenty-five men took part in the survey, with participants ranging from age 18 to 93 years old.

The complete and detailed results of the survey are reported in Appendix 7.

The survey questionnaire began with an introduction page that thanked participants for their participation in the research and stated the aim of the project; to gather information about people who have not received routine childhood vaccinations.

The layout of the survey was explained and confidentiality was addressed (as discussed in the methodological framework, in Chapter 3 above).

Introduction to the Survey (question 1)

The first question of the survey aimed to confirm the vaccination status of each participant. Forty-two participants declared that they were fully unvaccinated. Of the twenty-five that noted that they were partially vaccinated, thirteen had received only a tetanus injection, as a direct result of an injury. Out of those thirteen, at least four had been adults at the time of their tetanus shot.

Five individuals declared that they had compulsory travel vaccines, with two of the five having been children at the time. Three individuals declared that they had received initial vaccinations as an infant, experienced adverse reactions to their first vaccinations as babies and never had any further vaccinations. Four of the older participants, had been given a vaccine (small pox and oral polio) while at school, without parental permission (1940s to 1960s).

Personal information and demographics (questions 2-13)

The majority of participants in this study were females (62.7%) and 37.3% of participants were males. The age of participants ranged from 18 to 93 years old; the mean age was 37 years old (Table 4.1). This diverse age range of survey participants was advantageous in gaining an insight into a wide range of experiences, affecting individuals at different periods of their lives. As a result, this study was able to develop insight about the vaccine decisions that unvaccinated adults are now making for their own children.

Table 4.1 – Survey participants, by age

age	percentage
18-19	12.0%
20-29	38.8%
30-39	13.4%
40-49	10.4%
50-59	9.0%
60-69	6.0%
70-79	7.5%
80-89	1.5%
90-99	1.5%

Regions in which participants grew up

The majority of participants (71.6%) grew up in New South Wales, from a diverse range of regions, Sydney suburbs (Annandale, Gordon, Lane Cove, Eastwood, Miranda, Bexley), Lithgow, Campbelltown, Wingham, Carlingford, the Hills district, the Blue Mountains, Bathurst, Nowra, Bellingen and Tamworth. The other places mentioned were Canberra (ACT), Adelaide (SA), Brisbane (QLD) and Darwin (NT).

Education of survey participants

Most study participants attended a state school (68.7%), followed by Steiner schools (26.9%) and private schools (22.4%); 13.4% were homeschooled. Some participants had attended more than one type of school (Table 4.2).

Table 4.2 – Participants' schooling history

State school	68.7%
Steiner school	26.9%
Private school	22.4%
Homeschooled	13.40%

The original consideration was that there would be many more participants that had attended a Rudolf Steiner School. Adherence to an alternative lifestyle (Rogers and Pilgrim, 1995) and/or the Steiner philosophy, have been associated with a holistic ethos, a preference for natural medicine and an avoidance of childhood vaccines (Rosenlund et al., 2009; Duffell, 2001). Considering that there were advertisements placed at several Steiner schools, there was a smaller than expected response from those locations. The majority of Steiner School participants that responded were familiar with the researcher through the school, or through others that knew the researcher. It is possible that concerns about confidentiality may have been a factor in this lower than expected response or simply that not many people from the school fit the criteria for participation.

Many of the survey participants went on to further study after high school: 25.8% completed a diploma or certificate, 15% completed an undergraduate degree and a further 15% have a post-graduate degree (Table 4.3). Their occupations varied broadly; health care workers, a radiographer, a registered nurse, a remedial massage therapist, teachers, a graphic designer, tradespeople and a cleaner. There were various types of engineers, a tree arborist, a finance/mortgage broker, a hospitality worker and a bank clerk. Also represented were a university tutor, a veterinarian, a car detailer and a trolley-collector. Most participants (36.9%) were in full-time employment, with a similar number of participants in part-time employment (33.8%). Some participants were students (16.9%) or stay-at-home parents (12.3%) and only 1.5% were unemployed.

Survey participants had a slightly higher level of educational attainment than the average Australian, as tabulated by the Australian Bureau of Statistics (Table 4.3).

Table 4.3 – Level of education compared with general population

Level of participants' education	Percent	Level of general population	Percent
Year 10	18.2%	Year 11 or below	29%
Year 12	21.2%	Year 12	21%
Certificate	25.8%	Certificate	17%
Degree or Postgraduate degree	30.4%	Bachelor degree or postgraduate degree	24.00%

According to the Australian Bureau of Statistics (2011, 6227.0) in 2011, 29% of people in Australia, aged 15-64 years of age, reported that their highest level of education was year 11 or below and 21% reported Year 12 as their highest level. Additionally, 17% had a certificate III or IV, and 24% had a Bachelor's degree or above. Compared with these statistics, survey participants had a higher rate of obtaining a diploma or certificate, 25.8% compared with 17% of the national average, and 30% had a Bachelor's degree or higher, with the national average being 24%.

Educational attainment of participants' parents

It is of interest to note the educational attainment of the participants' mothers, as the literature has made reference to the relatively higher educational status of mothers that choose not to vaccinate their children (Hamilton et al., 2004). There is a paucity of material written specifically about participants' fathers' educational status. Several authors have found that better educated parents have more concerns over contraindications than less educated parents (Ragan and Duffy, 2012; Hak, Schönbeck, De Melker, Nan Essen and Sanders, 2005; Gust et al., 2005; White and Thomson, 1995).

Of the participants' mothers, 35.8% held a degree and/or postgraduate degree. Similarly 31.4% of participants' fathers had degrees and/or postgraduate degrees. Mothers and fathers that had attained a Diploma or Certificate were similar: 17.9% for the mothers and 16.4% for the fathers of participants. The number that had completed Year 10 (17.9%) was the same. Year 12 was completed by 16.4% of mothers and 17.9% of fathers. ‘Other’ qualifications were identified from the answer selections: 11.9% for mothers and 13.4% for fathers (Table 4.4).

Table 4.4 – Comparison of participant’s mothers’ and fathers’ educational attainment

Level	Mother	Father
Year 10	17.9%	17.9%
Year 12	16.4%	17.9%
Certificate	17.9%	16.4%
Degree	31.3%	25.4%
Postgraduate degree	4.5%	6.0%
Other	11.9%	13.4%

Parents’ occupations ranged as broadly as that of their children, from allied health care workers, including fitness instructors, nurses, chiropractors, a pharmacist, an occupational therapist, a social worker, a herbalist and a naturopath. Also listed were a cleaner, a disability support worker, office workers, teachers, tradespeople, a property evaluator, station managers, an accountant, an information technology worker, a public servant, a flight attendant as well as a cabin supervisor, a bank teller, a technical writer, an antiquarian book dealer, a librarian, a stage manager, a shop assistant, a draughtsman, a factory worker, a chemist, a picture framer, a builder, a financial planner, a homemaker, a lecturer in philosophy, a musician, a chef, and a professor of accounting.

Anderberg et al. (2011) examined the correlation between education, income and the measles, mumps and rubella (MMR) controversy, reporting that education and income, directly influenced health outcomes. Their participant’s uptake of MMR was of particular interest. The more educated parents in their study were found to have responded more rapidly to the MMR controversy than the less educated parents. Furthermore, the educated parents also reduced their uptake of non-controversial childhood vaccines and explored the use of single vaccines available at private clinics. Educated individuals were thought to assimilate and apply new information in a manner, which enabled them to understand health information, weigh alternatives and make choices accordingly (Anderberg et al., 2011).

Unvaccinated history (question 14-17)

It was important to gain a general background history of participants to more fully understand their backgrounds and how their vaccination status has affected them personally.

The main reason that participants were not vaccinated

Participants were asked to clarify the ‘main reason’ why they were not vaccinated as children. Alternative health beliefs were identified by 75% of participants, followed by allergies; 9.6% of the survey participants declared that they had allergic reactions to a vaccine, or an older sibling had a reaction and subsequently they were not given further vaccines. Religious reasons accounted for 7.7% and 5.8% were ‘unsure’. Only 1.9% nominated socio-economic barriers and zero for ‘moving around frequently as a child’.

The findings from this online survey confirmed previous research in that the reason why many parents decline vaccination is due to alternative health views, at variance with the orthodox medical model of health and illness (Zuzak et al., 2008; Hamilton et al., 2004; Duffell, 2001; Rogers and Pilgrim, 1995).

Three participants disclosed, without being asked directly in the survey, that their parents had a mistrust of authority in regards to mass childhood vaccinations. Lack of trust in government was raised in the Raithatha et al. (2003) study, where people felt that vaccine leaflets were aimed at persuasion rather than information. The following excerpts from the survey participants illustrate some of the reasons that participants gave for not having been vaccinated:

> Scepticism of the value of vaccination was inherited from family values; however I have considered it since with no reason to change.♀
>
> My parents had no confidence in vaccination and I still don’t.♂
>
> (The decision was) influenced by an anthroposophic perspective of the human being and the ramifications of vaccination.♂

Most participants were well aware of why they had not been vaccinated but this one participant, who was ‘unsure’ of the reason, wrote:

> To the best of my knowledge it was just because mum didn't think a lot of them and some that were new, she didn't believe they had sufficient testing.♀

Parental trust and/or distrust in orthodox medical systems and in the government’s role in regulating risk are common themes in the literature. Hamilton et al. (2004) found that parents who do not vaccinate their children were distrustful of government health information provided to parents. Gust et al. (2008a) noted that parental perceptions of vaccine adverse reactions were responsible for instigating concern about vaccinating their children. In addition, many parents reportedly felt dissatisfied with the vaccine information that they had been given. Hobson-West (2004) argued that lower levels of uptake could be the responsibility of the information itself, rather than of the parents that make the decision. In terms of distrust, some parents have become increasingly uncomfortable with the risks that they are expected to take, with Bond et al. (1998) finding that non-vaccinators were concerned regarding long-term vaccine side effects and also the motives of medical advisors and the validity of the information.

The participants in this study, many of whom were parents themselves, raised the matter of vaccine side effects, and those that are harmed by vaccines. The issue of who is responsible for adverse outcomes from vaccines has been recognised as a point of concern for parents (Skea et al., 2008; Raithatha et al., 2003). Further to this, parents were also found to believe that adverse reactions were not accurately monitored and reported (Hamilton et al., 2004), partially due to the difficulty in ascertaining cause, where an adverse event does occur (Dew, 1999).

These studies on parents that declined vaccinations for their children bear some resemblance to some of the comments from unvaccinated participants in this survey regarding the topic of vaccine side effects:

> I still feel uneasy about the long-term effects of vaccination.♀
>
> I do see that some diseases appear to have been eradicated by vaccination but that suffering has been inflicted on some due to adverse reactions. ♀
>
> I don't have faith that these vaccinations are not doing more harm than is generally acknowledged.♀

> Every year a new flu vaccine is brought out; however we do not know the long-term effects of these vaccinations.♀

Some participants described an ethical opposition or a lack of faith in vaccination:

> I suppose my main concern is an ethical one. An adult makes a decision to impose a medical treatment on a child and that treatment does carry the risk of complications, even if it is only a small risk.♀
>
> I know that there are additives in vaccination such as formaldehyde and mercury, although if this were changed it wouldn't change my mind. I don't have a whole lot of faith in the mainstream medical industry.♀
>
> Healthy children do not need vaccines to keep them healthy and I believe that there is strong evidence of the inefficacy of many vaccines and damage done which is concealed at worst and not sufficiently researched at best.♀
>
> Just the other day I watched a program on ‘Gardasil’ being used in foreign clinical trials in India, and several of the girls actually died. Although the pharmaceutical companies denied all responsibilities, the families of those girls were sure it was the vaccination that had killed them. Part of my worries about vaccinations is that I don't know whether they have truly been tested. I always wonder if they are using the initial patients as test dummies without properly informing them.♀

This study found that personal experience and family history played a significant role in the reasons that these participants gave for not being vaccinated, with some people clarifying in the comments that either they or an older sibling or relative had experienced a reaction of some kind, which had turned the parent against vaccination.

Several participants noted that their parents had known of other children, or family members that had experienced adverse reactions to vaccinations:

> My sister had a reaction which caused her health to be compromised for over two years and it took a lot of alternative therapies to get her healthy again. Mum became very educated on this subject and found vaccines were dangerous and didn’t work.♂
>
> My grandmother had a child that died from vaccination so she vowed no child in her family would ever be vaccinated.♀
>
> I have personal knowledge of one young adult severely brain damaged as a child immediately after the triple antigen shot.♀

The financial gains of pharmaceutical companies have also been identified as having an influence on parental perceptions affecting vaccine decision-making (Casiday, 2007; Benin et al., 2006); this was also raised as a concern with many participants in this group of unvaccinated people. As health care consumers, survey participants described the tools of governmentality that were identified as coercive, with vaccine inducements to parents linked to family payments and maternity benefits incumbent on having their children vaccinated (Isaacs et al., 2004). This treatment can be likened to the original policy of the 1880s where opposers to the technology of vaccination were subject to the policy of 'Vaccination or Starvation', where refusal could mean a loss of livelihood (Durbach, 2000, p. 48). Most recently, in 2013, the threat for vaccine refusal has reached the education sphere, where policy makers are instigating that children without routine vaccinations cannot attend day care. Governmentality is defined as the way in which the state attempts to control individual citizens with powerful discourse, as discussed at length in the literature review in Chapter 2.

The following examples reveal a sentiment of distrust toward the government and associated bodies that represent, regulate and promote the administration of mass childhood vaccination:

> I don't want to support the corrupt and immoral workings of pharmaceutical companies. I don't agree with the fact that doctors are given financial incentives to administer vaccines, both by government and pharmaceutical companies.♀
>
> I do not like the drug company monopoly on doctors, hospitals and education systems.♂
>
> Facts such as GPs being given iPads for meeting their vaccination quota in the USA demonstrates that it is a profit making exercise by big pharma who have little interest or understanding in what it means to heal.♂
>
> When doctors get a certain majority of their patients vaccinated they get a 'bonus'. That raises a lot of questions.♀

Who made the vaccine decision

Participants were asked to indicate who had made the vaccine decision. This study revealed that 40.6% of participants' mothers were the vaccination decision makers, 1.6% of participants' fathers, 56.3 % both participants' mother and father and 1.6% of survey participants were unsure as to who made the decision. The findings of this study concluded that fathers were rarely the main vaccine decision-makers, but were frequently part of the decision-making process. Vaccine decision-making can be a point of contention within the marriage with some partners holding divergent views on the matter of vaccination for their child. In this study, it was noted that the parent exerting the strongest opinion about vaccination was more likely to influence the ultimate vaccine decision.

More women responded to the survey, possibly in keeping with the notion that mothers are usually the key decision-makers when considering vaccination for their children. The literature has found that mothers are the key vaccine decision-makers, often holding the position of being primarily responsible for the child's health care (Luman et al., 2003; Petts and Neimeyer, 2004; Poltorak et al., 2005; Gust et al., 2008a). White and Thomson (1995, p.74) conducted a study in New Zealand, finding that the mothers in their study felt the burden of being accountable for this decision, with strong sociocultural and philosophical indicators associated with vaccine decisions. Petts and Neimeyer (2004) and Poltorak et al. (2005) also identified this burden of responsibility in vaccine decision-making as having a female gender distinction. Fitzpatrick (2004) noted that vaccine decisions were more often maternal; however fathers are becoming more involved in vaccine decisions.

One of the survey participants felt strongly about the issue:

> I do not have any children yet but when I do I will fight to make sure that they are not vaccinated.♂
>
> Another participant agreed to comply with her husband's view on the issue:
>
> My husband was very much in favour of vaccination, I went along with him for peace and harmony in the marriage. Once they (the kids) were 15, I allowed them to make their own mind's up.♀

This participant describes who made the decision to decline vaccination:

> First mum, then she made dad read some things so he could make an educated decision.♂

Contentment with decision

Participants were asked whether they were content with the decision 'made on your behalf that you would not be vaccinated'.

In this study, it was found that 96.9% of participants were 'content' with the decision that was made on their behalf as children, 3.1% indicated that they were 'undecided'.

Goldwater, Braunack-Mayer, Power and Finlay (2003, p. 177), who examined the ethical position of best interest in vaccination of children, recognised that the family played a significant part in the child's development in terms of what views they would develop as adults. The parental contribution to the child's worldview is apparent in this study's findings, which gives credence to Goldwater et al's hypothesis.

> I held my parents' views highly, even though my friends found this eccentric.♂
>
> I have had reservations about the safety of vaccination throughout my life. I have read widely and am glad my parents made the decision they did.♀
>
> With what I know about vaccines now, I am extremely grateful to my late mother for her wisdom.♂
>
> Whilst I made fun of my parent's views as a child, I have come to understand how dangerous vaccination can be and that it causes many more issues than it claims to solve.♂

Including a question regarding whether participants were content with having been raised as unvaccinated was of particular importance, as the literature has hypothesised about the effects to the unvaccinated children, without having asked them. In this survey, the majority of participants had reflected that they were content with the decision, stating that it had been in their best interest. A substantial number of participants (20.5%) did however note that their preference was to give their children certain vaccines and no participants responded that they would give their children all of the recommended vaccines. This apparent inconsistency was found to be associated with other factors, like their perceptions of risk and responsibility and what they as individuals were prepared to take on themselves. One participant provided clarification in the comments section of the survey by describing herself as 'conservative and not willing to take risks', acknowledging that individuals are different and make choices accordingly.

Another survey participant wrote that she felt that she had no choice but to vaccinate her children:

> I believe my 'choice' does not exist and it was incredibly difficult to do it any other way, but the way prescribed by government, I don't feel I have any other option. It is so difficult to do things any other way that I have literally given up.♀
>
> I think the public are coerced e.g. recent government health check: if you don't they will cut family tax benefit. I believe vaccines lower our ability to fight diseases etc and all my children are adversely affected after a vaccine. I hate it.♀

Best interest discourse in the literature generally depicts vaccination as being in the best interest of the child, regardless of any personalised points of contention. Some literature however, does consider a broader representation when engaging in discussions on what is in the best interest of a child. Isaacs et al. (2004, p. 395) illustrated that the child is part of a family, whose worldview of health and illness does not include childhood vaccines. Furthermore, Isaacs et al. explained that to say that vaccination is in the best interest of the child is to ignore this important point. Moreover, compelling parents to unwillingly vaccinate their children could be considered a 'societal attack' on their child. These children were hypothesised by Isaacs et al. (2004) as likely to grow up disagreeing with vaccination.

There is a paucity of material that explores the retrospective reflections of people that were raised without routine childhood vaccinations. What may be in the best interest of an individual, from the perspective of the individual can be evaluated only upon their reflection of it; the retrospective view.

> I am extremely happy with the decision, I have had excellent health all my life and I attribute most of it to not being vaccinated.♀

> I have experienced very good health throughout my life in spite of me having several childhood diseases. I have a strong immune system and rarely catch whatever is going around.♂

> I am glad about my parent's decision, I don't feel that it has really affected my life in any drastic way.♀

Unvaccinated populations

Survey participants were asked if they were in contact with other unvaccinated people during their childhood. Twenty-two people (32.8%) answered that they were 'unsure', 25.4% answered 'some', 20.9% selected 'few', and 20.9% noted 'many'. In this particular study, these results may not be in line with the literature that suggests that unvaccinated groups are living in 'clusters' or near like-minded people. Salathé and Bonhoeffer (2008) hypothesised that individuals with a negative opinion about vaccination were more likely to be associated with like-minded individuals. This was not generally the case in this study, where a substantial number of participants were either not aware of others' vaccination status or said that they were in contact with 'few' unvaccinated people. Smith, Chu and Barker (2004, p.187) conducted a study in the United States, concluding that unvaccinated children were clustered geographically. The largest number of unvaccinated children were reported to be located in California, Illinois, New York, Washington, Pennsylvania, Texas, Oklahoma, Colorado, Utah and Michigan. These states were identified as permitting philosophical exemptions from the mandatory vaccination laws in America. There is anecdotal evidence, derived from the mass media, indicating that there are communities where unvaccinated populations are more prevalent. These clusters in Australia, for example are believed to exist in the Northern New South Wales regions, the Mid-North Coast and the Eastern Suburbs of Sydney, Sydney city and the North Shore of Sydney, although there are no available statistics or references to confirm this [[1]].

Treatment of children raised without routine childhood vaccinations

Survey participants were asked if they perceived that they were treated in a fair and unbiased way by the health/school system and the public generally. Sixty-five point two per cent (65.2%) said that they had been treated fairly; however many clarified this in the comments section of the survey, describing that they had not been in a position to know as the issue had not been raised. Twenty-one point two per cent (21.2%) said ‘no’ and 1.3% were ‘unsure’. Another survey question asked if survey participants had felt stigmatised as a result of their unvaccinated status. There were a number of instances where participants described being singled out as a result of not being vaccinated. Some survey participants wrote that it had not been an issue as they had not attended a mainstream school. Some participants wrote that it had caused problems later in life with employment issues, like one female respondent who had been working as a nanny and was asked to have a whooping cough vaccine. This request from her employer created tension in her working environment, compromising her employment. This participant did not get the pertussis vaccination that her employer desired and subsequently lost her job. For others, working in health care had created problems with the mandatory vaccination requirement.

A number of participants indicated that they had not encountered any notable implications as a result of their status, but that they believed their mothers had experienced judgemental actions or behaviour about not vaccinating them as children.

1Personal communication (2010) from an epidemiologist from the National Centre for Immunisation Research and Surveillance, Westmead Children’s Hospital. The greatest number of unvaccinated children were said to be from The Northern Rivers – Byron Bay, Lismore, Mullumbimby, Brunswick Heads and the Mid-North Coast – Bellingen and Dorrigo. In Sydney, the Eastern Suburbs – Woollahra, Waverley – Sydney city and the North Shore – Mosman and Manly.

One participant, now as a mother herself, has received similar judgement:

> As an adult in terms of my disagreement with having to vaccinate my own children, I am seen as unconcerned for the health of my children and ‘alternative’-ironic because the reason I don’t want to vaccinate is that I am deeply concerned about their health.♀

> I don't recall being treated any differently. Mum can recall receiving some criticism for her choice, but I did not 'wear' this.♀

The issue of negativity towards non-vaccinators was found to have social implications for parents and their children, with vaccinating parents sometimes reflecting harsh, critical and judgemental sentiments toward non-vaccinators (Skea et al., 2008)

Parents who decline vaccinations for their children are recognised within society as contributing to suboptimal vaccine uptake (Brown, Kroll, Hudson, Ramsay, Green, Vincent, Fraser, and Serdalis, 2010), which may be associated with the marginalisation of non-vaccinators. As Dew (1999) argued, parents may be seen as uncaring and judged harshly for resisting a procedure that is viewed by the majority of the population, as well as the health ‘experts’ as good for the general population. In this situation it seems that parents are expected to relinquish their own personal beliefs regarding the ideal way to raise their children, for the good of the community, despite their own objections to mass childhood vaccination. When asked if they had been treated differently, some participants noted that few people were ever aware of their status. The following quotes refer to the participants reflecting back on their childhood:

> Growing up in a Steiner school it wasn’t something that was looked down upon.♂

> I'm not sure that anyone knew that I was unvaccinated, so it never came up as an issue.♂

> I haven’t truly had to deal with them – health system. Never needed school, as we were homeschooled. Our ‘system’ – the homeschool network treated everyone fairly...as each family is effectively their own school with their own rules. The public – they have no idea if I’m vaccinated or not.♂

The survey benefited from the input of individuals that were homeschooled. Khalili and Caplan (2007) found that homeschooled children in America did not have the same state obligations to be vaccinated as children that attended state school. In Australia, homeschooled children may also avoid having to show proof of vaccination in order to enter state schools. The American laws were said to fail in protecting homeschooled children with vaccination requirements and health screenings. In addition, parents that homeschooled their children were found to be untrusting of government in general and also of the evidence given in support and encouragement of the dissemination of mass childhood vaccination (Khalili and Caplan, 2007). The nine homeschooled, unvaccinated participants in this survey appeared content with their upbringing. Similar to the Khalili and Caplan (2007) findings, the reasons that these participants cited for having not been vaccinated were health beliefs and religious beliefs. Like many of the other survey participants, the homeschooled, unvaccinated participants mentioned an avoidance of pharmaceuticals in particular, antibiotics, preferring natural remedies – this is explored in more detail later on. The issue of their parents being untrusting toward the government was not commented on and did not feature as a question in this survey.

The literature has identified governmentality and the powerful role that it plays in regulating the population and promulgating mass childhood vaccination with the potentiality of penalties for non-compliance (Casiday, 2007). Penalties may include missing out on family tax benefits or incentives and rhetoric concerned with failing in ‘duty of citizenship’ (Dew, 1999; Flynn, 2002). Furthermore, some paediatricians and general practitioners have refused to treat unvaccinated children (Casiday, 2007; Diekema, 2005), which is a strong message to parents to comply with the recommended vaccination schedule. Benin et al. (2006) found that most of the non-vaccinating parents in their study felt alienated by the medical establishment as a result of declining vaccinations, with Brown et al. (2010) recognising that some parents feared that their vaccine decision would impact negatively on their doctor-patient relationship. This study supports the finding that some participants felt that a non-vaccine decision affected the way that they were treated by health care workers and also had the potential to impact their schooling and education. This was evident in the accounts given by at least twelve individuals who declared that their status had affected the way that they were treated.

Some participants described being treated differently because of their unvaccinated status:

> I had one science teacher who said something rude about my mum not vaccinating me. She wrote him a detailed letter and he apologised.♀
>
> The teachers in Catholic school asked me strong questions about why I was not receiving the vaccination. I felt pressured and ridiculed.♀

> I don't usually mention to people generally that I'm unvaccinated. Only if I think they are likely to understand. I remember one teacher giving me a really hard time in high school when I told her I was not vaccinated against tetanus.♀

Other participants described that they had been labelled as ‘carriers’ and told that it was their fault that certain diseases were still around by other peers, parents, health workers and teachers.

> Within school I was often viewed as ‘contagious’ by teachers, as though I was a risk to other children and should be handled at arm’s length ... in more recent times I was required to work in a day care centre as part of my certificate and felt extremely ostracised by teachers at my TAFE. They treated me as if I was either ignorant, stubborn or completely stupid.♀

> I was an outcast at a holiday camp when the teacher found out that I was unvaccinated. She lectured me at age 12 about the dangers and gave me no attention during the camp. It was really awful.♀

> When I first started working in my late teens we were having a discussion one day and I mentioned that I was not vaccinated. My boss was horrified stating that I would be a carrier of all these diseases.♀

> We were labelled as carriers and told that it was our fault certain disease were still around. Especially by other peers’ parents.♀

Another participant stated that she was particularly concerned about how her unvaccinated status would affect completion of her university degree in Nutrition and Dietetics, because of the compulsory element that required her to work in a hospital and be vaccinated. This participant was unsure of the outcome and said that she was worried about not being able to complete her degree. Another participant studying a Psychology Honours degree, had reported that after speaking with the convenor at her university she would be placed in an out-of-hospital setting, either in private practice or in a research setting.

Work-related issues were a point of contention for some participants:

> I currently work in health. Immunisation is compulsory, but I managed to avoid filling out the form. My manager is aware that I would challenge the system if forced to.♀

The next excerpt reflects a participant's dreams of getting into the Air Force, which was restricted by the compulsory vaccination laws:

> I don't believe employers have the right to force you to vaccinate under the duty of care banner. I should be able to sign a waiver on this and take responsibility for myself. They are not going to help me if I get a reaction and my health is in danger. ♂

Several pertinent issues are raised in this comment. Themes of taking responsibility for oneself and the issue of who is responsible when adverse reactions do occur are relevant to the cogitation of risk and trust for some individuals in vaccine decision-making. Many studies have found that individuals are not content with the way in which adverse reactions are dealt with by professional bodies. Sporton and Francis (2001) found that the parents in their study perceived health professionals as reluctant to acknowledge the occurrence of side effects in children that had been vaccinated. Similarly, unvaccinated participants in this study also raised the issue of side effects.

Health history (question 18–32)

With the emergence of chronic diseases as the largest threat to health status and the largest cause of health expenditures and death in Australia (Australian Bureau of Statistics. *3303.0 Causes of death, Australia*, 2010), it was considered important to explore the modifiable risk factors that are known to exert a strong influence on health. Firstly to obtain a holistic picture, of whether vaccine status was separate to health status, or whether it was just one part of it, and secondly, to understand more about the impact of participants health behaviours on society, especially since they as a group had been judged for burdening society with free-riding. Participants were asked a wide variety of questions pertaining to their health; height and weight and their drinking and or smoking habits. Questions were included on exercise habits and their awareness of the influence of diet on health, also, the types of contagious diseases that they may have experienced as well as any long term implications of having had the disease.

In examining the health seeking behaviours in this group of unvaccinated people, 47.0% described their lifestyles as active, 47.0% as in between and only 6.1% as sedentary. Survey participants were asked about the regularity of exercise: 36.4% answered 3 to 5 times per week, 25.8% daily, 19.7% once or twice a week and 18.2% nothing specific. Ninety point nine per cent (90.9) of participants answered that they did not smoke and 9.1% said that they did. Seventy-two point seven per cent (72.7%) answered that they did drink alcohol and 27.3% noted that they did not. The Australian Bureau of Statistics (2012.a, 4835.0.55.001) has associated physical inactivity as responsible for approximately 7% of the total burden of disease in Australia. The National Health Survey found that the majority of adults (40%), were sedentary, followed by around 32% with low exercise levels, 22% reported moderate levels, and 6% high exercise levels (ABS 2007–08). In contrast, of the survey participants only 6.1% described their lifestyle as sedentary, 49.0% as moderate and 47.0% as active. These survey questionnaire participants appear to be more physically active than the average Australian.

In examining this group, and the information that was reported to the researcher, it is also interesting to make some kind of a comparison with other studies that have looked at alcohol consumption and regularity of exercise, found in other (vaccinated) groups. The Australian Bureau of Statistics (2012.b, 1301.0) display a study conducted by the WHO (2002) that found that being physically active was associated with positive health outcomes, such as reduced incidence of cardiovascular disease and a reduced risk of certain cancers and depression, with these factors ultimately lowering the total disease burden in Australia.

The National Health Medical Research Centre (NHMRC, 2009) found that a substantial proportion of people drink at levels that increase their risk of alcohol-related injuries, and their risk of developing health problems, and other social and developmental issues as well as absenteeism from work. The recommended guidelines state that healthy males should not consume more than four standard drinks and female’s two standard drinks on a single occasion. A single occasion is defined as where the blood alcohol level reaches zero. In 2004–05, based on the 2001 NHMRC short-term guidelines, 39.5% of all persons aged 18 years or over consumed alcohol at a risky or high-risk level (ABS, 2007-2008, 4832.0.55.001).

The majority of participants drank in moderation or on special occasions. Many participants clarified this in the comments section, indicating that they rarely drank. Others wrote that they would have a glass of wine on special occasions or some said one glass with dinner regularly, or three or four drinks a week, but few reported drinking large quantities or binge drinking:

> Three to four glasses of wine per week.♂
>
> Only on special occasions.♀

> Very rarely on a night out for a special dinner, not weekly.♀
>
> One to two drinks per week.♀

The few patients who said that they drank larger amounts of alcohol also acknowledged this behaviour as being destructive, which displays some level of knowledge, awareness, and responsibility for one’s own health.

> I have a healthy immune system when I’m not actively destroying it.♂

Health conditions experienced

Survey participants were asked if they had experienced certain childhood diseases and infections (Table 4.5). Chicken pox was the most common with 73% of participants reporting that they had experienced this disease, followed by measles at 48.4%. Mumps, whooping cough and rubella were also quite commonly experienced.

Table 4.5 – Participants’ typical childhood diseases and infections

	Yes	No	Unsure
Chicken pox	73.0%	19.0%	7.9%
Measles	48.4%	45.2%	6.5%
Mumps	27.9%	65.6%	6.6%
Whooping cough	23.7%	62.7%	13.6%
Rubella	21.4%	73.2%	5.4%
Meningitis	3.8%	96.2%	0.0%
Shingles	1.9%	96.3%	1.9%
Polio	0.0%	100.0%	0.0%
Diphtheria	0.0%	100.0%	0.0%
Hepatitis B	0.0%	100.0%	0.0%
Tetanus	0.0%	100.0%	0.00%

Participants were asked to indicate if they had suffered any long-term effects as a result of having a disease. A single person reported visual conditions but gave no explanation in the comment section.

The prevalence of certain conditions was of particular interest, as the literature does mention the hygiene hypothesis, whereby children that are exposed to certain allergens and childhood diseases may not be as inclined to suffer with atopic conditions (Risnes, Belanger, Murk and Bracken, 2010). This controversial concept has been associated with the Steiner philosophy (Anthroposophy) and natural medicine, where it is thought that the child that contracts measles may be less likely to develop allergies (Duffell, 2001; Schmid, Holzmann, Abele et al., 2008). Of the 67 survey participants, 65.6% 'never' suffered with allergies, 31.3% 'sometimes' and 3.1% 'always'. Ninety one point nine percent (91.9%) of participants 'never' had immune conditions, 4.8% 'sometimes' and 3.2% 'always'.

Table 4.6 – Participant's conditions experienced as well as the frequency of occurrence

	Always	**Sometimes**	**Never**
Allergies	3.1%	31.3%	65.6%
Skin ailments	3.2%	19.0%	77.8%
Immune conditions	3.2%	4.8%	91.9%
Asthma	1.6%	12.9%	85.5%
Behavioural disorders	1.6%	3.2%	95.2%
Irritable bowel syndrome	0.0%	8.1%	91.9%
Mental health conditions	0.0%	3.3%	96.7%

Asthma was 'never' experienced by 85.5% of participants and 12.9% had it 'sometimes'. Asthma was experienced 'always' by 1.6%. Immune conditions and irritable bowel syndrome were 'never' experienced by 91.9% of participants and 96.7% 'never' had mental health conditions. In addition 95.2% of participants had 'never' experienced behavioural disorders (Table 4.6). There seemed to be a low level of health conditions reported; however, this could also be due to the high level of healthy lifestyle choices that were found in this group of survey questionnaire participants. Unfortunately, there were no statistics available to compare with the general population.

Health care choices (questions 33–45)

This section is intended to provide insight into the health care choices of unvaccinated people.

Current health views of participants

Participants were asked where they had acquired their current health views. This study found that 74.6% of survey participants had learnt their current health views from ‘their parents’ and 69.8% from ‘self-learning’, followed by ‘health practitioners’ and a mixture of ‘other’ sources. The literature has confirmed that individuals assimilate vaccine information from a variety of sources (Casiday, 2007; Petts and Neimeyer, 2004; Hamilton et al., 2004; Dew, 1999). The finding of this study could be related to the fact that these adults were raised, by and large, by parents with natural health ideals. This would play a part in influencing their children’s ideologies, along with other types of similar ideals that they may have learned from their parents, such as the influence and benefits of diet and exercise. Participants in this study frequently referred to eating properly and getting adequate fresh air and exercise, as the key to good health, as well as avoiding processed foods. Similarly, in studies on mothers who do not vaccinate, identified participants’ tenets were a healthy diet, ‘good’ food, classified as fruit and vegetables and limiting or avoiding sugar and ‘junk’ food (Bond et al., 1998; Nolan, 1998, p. 443).

The survey participants exhibited high levels of awareness around the influence of a healthy diet, with 84.6% declaring that they were ‘very much’ conscious of the impact that diet has on health. This outcome is considered to be quite high. This percentage was followed by ‘somewhat’ (10.8%) and ‘not so much’ (4.6%). This is an interesting finding considering that the government has very much encouraged individuals to take on this type of self-responsibility in terms of health and wellness. However these two models of displaying a high level of responsibility and the passive acceptance of health information, may not sit well together. Rogers and Pilgrim (1995) described that the health care consumer who is actively involved in taking responsibility for their health and wellbeing, may not fit with the concept of mass childhood vaccinations. ‘CAM involves educating and training clients to listen to their bodies and take an active role in their own health’

(Kannan, Gaydos, Atherly and Druss., 2010, p. 731). On the contrary, in mass childhood vaccination, individuals are encouraged to passively accept information that they are given and to go along with the procedure of vaccination, whether they agree with it or not. Rothschild (1999) examined the societal issues in vaccination decisions, as opposed to what may be the conflicting rights of individuals, finding that cooperation required ‘an exchange in which each individual gives something of value and receives something of value ... in return’ (Rothschild, 1999, p. 24). ‘Active resisters’ to vaccination may not feel as though they are receiving this ‘something’ of value in exchange when they are being asked to go along with a medical procedure, with which they may not agree.

The following excerpts depict this view:

> I don't have a whole lot of faith in the mainstream medical industry. It is the whole attitude towards healing and the body. Controlling instead of supporting. I think that we need to see the benefit in illness.♀
>
> Maybe we would have been better off just focusing on strengthening our bodies against these things instead of fighting them and messing with them.♀
>
> Making a newborn baby (who's just entered this world) sick and weakening their still developing body and immune system is ridiculous to me. Humans should rely on their own natural goodness – good eating, good values, good exercise, good lifestyle not on drugs.♂

Type of health care practitioner most commonly visited

In Australia, an estimated equal number of visits are made to heterodox and orthodox practitioners and approximately A$1.86 billion are spent per year on heterodox health products, which equates to almost half of the total ‘out-of-pocket’ expenditure on non-subsidised health care products in Australia, at around A$4.05 billion dollars (Xue, Zhang, Lin, Da Costa and Story, 2007).

It is important to clarify that orthodox intervention was avoided whenever possible with the use of home care and often natural remedies for ailments. This finding gives credence to the study by Glanz et al. (2013) that found parents who choose not to have their children vaccinated are less likely to trust orthodox practitioners and more likely to use heterodox practitioners than parents who have their children fully vaccinated. However, if and when diagnosis or treatment was sought, orthodox practitioners were identified as the most common type of health care practitioner that these participants visited as children, followed by a naturopath and then a homeopath (Table 4.7). In some cases multiple practitioners were used. As adults, participants chose general practitioners most commonly, followed by naturopath and chiropractor/osteopath. There could be several reasons that general practitioners were indicated as the most common if and when a practitioner was sought.

Table 4.7 – Comparison of the type of health care practitioner that unvaccinated participants visited as children, and now, as adults

	as a child	as an adult
GP	48.3%	43.6%
Naturopath	34.5%	41.8%
Homeopath	22.4%	20.0%
Herbalist	8.6%	16.4%
Chiropractor/ Osteopath	8.6%	32.75%
Medical specialist	6.9%	7.3%
Unsure	5.2%	N/A

Of the sixty-seven participants as adults, 43.6% most commonly relied on the general practitioner compared to 41.8% relying on a naturopath and 20.0% on a homeopath (Table 4.7). A high number of participants used an orthodox practitioner despite holding alternative health beliefs, although the vast majority of participants that nominated a general practitioner added that they would rarely visit one. This was interesting considering that the literature has associated this group of parents as having views on health and illness that are not in alignment with the orthodox model. This outcome could be influenced by the fact that general practitioners are covered by Medicare, therefore the parent does not usually pay out-of-pocket. Another interpretation could be that parents do trust the diagnosis of a medical doctor in terms of pinpointing what is wrong, but will not necessarily take the prescribed course of treatment. Haug and Lavin (1981) and Calnan and Sanford (2004) described the general practitioner as an institutional 'gatekeeper' to health services and medication, who is therefore relied upon for their influential role in health care.

Additionally, some participants in this study noted that they relied on general practitioners' 'sick' certificates when they were sick and needed to justify time off to their employers. Some participants stated that they had an open-minded orthodox practitioner; others stated that they did not raise their own views with their general practitioner to avoid confrontation, but were dependent upon them when they needed a medical diagnosis, or a medical certificate. Furthermore, because of the hegemonic position of general practitioners, parents may be reliant on, and or morally obliged in their roles as 'good parents' to seek out the opinion of an expert, who, in the general population is considered to be the general practitioner.

Participants described what health care was employed during childhood:

> So rarely not worth mentioning, never been to hospital.♀
>
> Home care is all I ever recall. We would fast, sleep and detox naturally to help body heal itself.♀
>
> I have no recollection of attending a doctor in my childhood.♀

Interestingly, Crawford (1980, p. 366) argued that holistic health clients 'seek to reduce the reliance of individuals on medical practitioners and substitute individual and group activities aimed at improving health, coping with chronic disease, acquiring diagnostic and therapeutic skills and adopting disease prevention practices'.

Crawford's (1980) depiction of the holistic health client is evident in many of the participants in this study that received mostly home care for their ailments, or treatment from a heterodox health practitioner.

> I always considered going to the doctor and being vaccinated to be a less desirable state.♀
>
> I take a multi-vitamin when I am feeling run down or if I feel like a cold is coming on I take colloidal silver. I also try to attend the chiropractor once a month.♀
>
> Participants clarified that they rarely go to visit the doctor except for serious conditions that may be unmanageable with home care:
>
> I don't go to anyone unless I have a broken bone or something like that.♂
>
> Medical drugs only treat the symptoms of degenerative illness while the underlying causes continue unabated. Natural Health treats the underlying (lifestyle) causes and facilitates self-healing.♂

> Never saw anyone unless deep laceration which needed medical attention never for colds or illnesses, we would stay in bed until we were better.♀
>
> We only went to a GP if it was something extreme. My mum mainly treated us from home herself.♀

Use of antibiotics or natural remedies for infections

Survey participants (65.6%) said that they employed a high level of natural remedies, with 55.6% of survey participants stating that they ‘never’ used antibiotics (Table 4.8). The literature recognises the decades of antibiotic overuse internationally; as a result there is an increased prevalence of bacterial strains that are resistant to many antibiotics (Carlet, Jarlier, Harbath, Voss, Goossens and Pittet, 2012; Bugnon-Reber, Torrenté, Troillet and Genné, 2004). Individuals and the general population at large have been impacted. Patrick and Hutchinson (2009, p. 419) contended that there was ecological evidence that the sagacious use of antimicrobials would benefit populations. A majority of people raised without routine childhood vaccinations in this survey were aware of the importance of restricting antibiotic use. These findings support the notion that these unvaccinated participants have pursued responsible awareness of the implications that come with antibiotic overuse. When asked about their use of antibiotics they replied:

> I resort to drugs such as antibiotics when it is absolutely necessary.♀
>
> Would always prefer to use natural remedies and go out of my way to seek out such options.♀
>
> Would always use remedies and therapies that work in harmony with the body's natural ability to heal. They are also more likely to cure by treating the source/cause of an illness rather than quash the symptoms temporarily.♀
>
> Antibiotics totally destabilise the system and weaken the immune system. If I’ve got an imbalance in bacteria I’ll take a probiotic not an antibiotic.♂

Table 4.8 – Comparison of frequency of use between antibiotics and natural remedies and/or both

	Always	Sometimes	Never
Antibiotics	5.6%	38.9%	55.6%
Natural remedies	65.6%	29.5%	4.9%
Both	5.6%	61.1%	33.30%

Patrick and Hutchinson (2009) contemplate the similarity of individual and social effects of both vaccination and antibiotic overuse or misuse:

> Every antibiotic prescription represents a balance of benefits and risks, both to the individual and the population. The risks of antimicrobial therapy to the patient are well known and include hypersensitivity, drug interaction and disruption of normal flora. However, not all risks associated with antibiotic use may be directly experienced by the patient receiving treatment. The metaphor 'tragedy of the commons' describes an event in which individuals acting locally to benefit themselves inadvertently contribute to catastrophe at the ecological level (Patrick and Hutchinson, 2009, p. 416-417).

In addition to antibiotic avoidance, many participants mentioned that they avoid painkillers and fever-reducing pharmaceuticals. The reason for doing so was associated with the concept of least interference, where there was a preference to allow the body to manage without the use of pharmaceuticals, unless it seemed that it was failing to cope.

Preferences for use of natural remedies, compared with pharmaceuticals

Participant's use of pharmaceuticals compared with their use of natural remedies was of interest, 65.6% said they 'always' used natural remedies, compared to 5.6% that 'always' used antibiotics to treat infections, 5.6% said that they 'use both'. Table 4.9 indicates participants' use of antibiotics and/or natural remedies to treat infections.

Table 4.9 – Participants' representation of natural remedies use compared with pharmaceuticals

	Natural remedies	**Pharmaceutical**
High use	42.4%	3.1%
Some use	36.4%	6.2%
Low use	18.2%	40.0%
No use	3.0%	50.8%

It was difficult to compare this outcome with the literature, as there was a paucity of literature comparing the use of natural remedies with pharmaceuticals among the general public.

Survey participants were found to be 'quite satisfied' with their health with 54.5% nominating that they were 'very satisfied' and 36.4% 'somewhat satisfied' and only 4.5% 'dissatisfied'. Survey questionnaire participants were all keen to be somewhat involved in their own health care decisions, which was striking. Many participants preferred to have an active role in the decision-making process when considering various modes of treatment. Participants desired and were most comfortable with a substantial level of input in their own health care experience and in many cases were prepared to pay out-of-pocket for the privilege, seeking out a variety of health care practitioners depending on what they deemed necessary.

Preferences for travel vaccines

Participants were asked to describe their preferences for travel vaccinations: of the sixty-seven participants 50% were opposed to travel vaccinations compared to 9.1% who were in favour of travel vaccines (Table 4.10). The amount of people that were undecided (40.9%) was surprising. It suggests that travel vaccines may be viewed differently to vaccines for childhood contagious diseases.

Table 4.10 – Participants' preferences for and against travel vaccines

In favour of travel vaccines	Opposed to travel vaccines	Undecided
9.1%	50.0%	40.9%

When asked about any problems that they might have experienced with entering certain countries or employment issues, 76.9% said that 'no' they had not experienced problems, 15.4% said it was 'not applicable' and 7.7% indicated that 'yes', they had experienced a problem.

> Travelled extensively when younger and the only time it was an issue was when going to live in Zambia. I found a sympathetic medical practitioner who pretended to vaccinate and gave me a certificate.♀

Travel vaccines were found to fit in to the category of participants electing certain vaccines. Five of the survey participants completed compulsory vaccinations in order to travel overseas. Alternatively the reason could be that they had not yet encountered this requirement in entering countries with this specification or prerequisite.

Some participants used the comment box to explain:

Opposed to travel vaccines:

> I wouldn't go anywhere that would require me to be vaccinated.♀
>
> I would prefer to seek out alternatives such as homeopathic remedies and treat disease once contracted rather than vaccinate.♀
>
> Vaccines don't give genuine (or safe) protection against microbial diseases. Careful hygiene (according to the risks of the country you are in) and good health are the best defences.♂

Undecided regarding travel vaccines:

> Would research what was recommended before I travelled to make a decision based on available evidence, I would be looking for non-drug company evidence'.♀
>
> I am yet to be convinced that these things are necessary and I object to being 'forced' to have them because I'm told that I should.♀

> Haven’t had to look into this, but would investigate natural alternatives.♀

Vaccination choices for their own children

Adults that were raised as unvaccinated children were asked to disclose the vaccine decisions that they make for their own children. The question was divided into two, depending on whether the participant did or did not already have children. Participants that did not already have children were asked what they would choose for their potential children; 74.4% of participants who did not yet have children, were against vaccination, compared with, 74.4% of participants that already had children in the survey (Table 4.11). Hepworth (2004) found that an individual’s personal experience and family history played a significant role in health-related decision making, as was clear with the great majority making the same no-vaccination decision for their own children that was made for them.

Table 4.11 – Participants’ vaccine preferences for those who have children already and those who do not

	Participants with no children yet	Participants with children
Against vaccination	74.4%	74.4%
Undecided	15.4%	5.1%
For vaccination	10.3%	0.0%
Certain vaccines	N/A	20.5%

Some survey questionnaire participants used the comment section to explain:

> I think it’s better for the body to develop its own natural immunity to diseases. I disagree with being told how to manage my own and my children’s health by doctors; they are not gods.♀
>
> It's a constant reassessment process. I am always interested in new information and try to stay up to date. On making this decision I weighed up the likelihood of contracting the illness, the short and long term side affects of contracting the illness, against the side effects of immunisation on the WHOLE wellbeing of the child.♀

Preferences for giving there own children certain vaccines

Of the survey participants that had children, 74.4% had opted for no vaccines for their children and 20.5% said certain vaccines. Choosing certain vaccines is identified in the literature as a common choice for parents that want to avoid giving too many vaccines to their children (Freed et al., 2010; Bedford and Lansley, 2007). The literature has identified parents that choose certain vaccines as displaying concerns about 'overloading' their children's immune systems (Austin, Champion-Smith, Thomas and Ward, 2008). Furthermore, they may be more specifically concerned with certain diseases (Fredrickson, Davis, Arnold, Kennen, Humiston, Cross and Bocchini., 2004). Offit et al. (2002) highlighted that an increasing number of parents have concerns about the volume of vaccines that infants are receiving, identifying that one hundred years ago children received one vaccine, forty years ago 5 to 8 vaccines and now by the age of two, 11 to 20 routine vaccinations (Offit et al., 2002).

Children that have received certain vaccines may fit into a different category to children that are undervaccinated. Undervaccinated children have been associated with socio-economic determinants of gaining access to vaccines and facing practical barriers (McIntyre, Williams and Leask, 2003), rather than conscientious objections as reasons for choosing certain vaccines. Petts and Neimeyer (2004) found that mothers who expressed difficulties in accessing information were from a lower socio-economic background.

This study found that for those 20.5% of participants that chose certain vaccines the following vaccinations were nominated, 62.5% whooping cough, 62.5% diphtheria, 50% chose tetanus, polio, measles, mumps and rubella (MMR). Hepatitis B and chicken pox were nominated by 25% of participants. This is indicated in Table 4.12 below.

Table 4.12 – Participants' preferences for certain vaccines

Whooping cough	Diphtheria	Tetanus, Polio, MMR	Hepatitis B and Chicken pox
62.5%	62.5%	50%	25%

Children that have specifically been given certain vaccines and not other vaccines, have not been thoroughly accounted for in the literature. The public demand for separate measles, mumps and rubella vaccines (MMR), is said to be a direct response to Dr Andrew Wakefield's claims (Fitzpatrick, 2004), hypothesising a link between MMR and the development of bowel disease and autism (Casiday, 2007). However, parents with an anthroposophical worldview were found to desire separate vaccines because they believed that certain childhood diseases are essential to the development of a child (Harmsen et al., 2012).

Brownlie and Howson (2006) argued that MMR compliance issues existed prior to the Wakefield and colleagues' (1998) publication, identifying an important point, that non-compliance was seen by general practitioners as a result of 'poverty, laziness, general apathy, and being too busy'. Educated parents declining vaccination were viewed as being 'a bit precious' (Brownlie and Howson, 2006, p. 437). Despite Wakefield's research having been disproven (Elliman and Bedford, 2002), and public health attempts to reassure parents, MMR uptake remains the subject of contentious debate, with Jackson et al. (2010) study revealing that many parents were still unconvinced regarding the safety of the MMR and the information and safety statements issued by governmental agencies regarding vaccines (Baker, 2008; Niederhauser and Markowitz, 2007).

Serpell and Green (2006) noted that a growing number of parents had concerns about the safety of MMR and as a result were more commonly choosing single vaccines. In addition, well-off parents were said to have more concerns, as well as lower uptake of this vaccine (Lewis and Speers, 2003). Rogers and Pilgrim (1995) undertook some of the initial research about MMR non-compliance, interviewing nineteen mothers that had declined vaccinations for their children. They were found to be well-educated women, with concerns about the adverse effects of vaccination. In addition, they were found to have holistic views about the immune system, citing a homeopathic-orientated ethos as an influence for their rationale.

Several participants in the study wanted to be able to employ only certain vaccines for their own children. This excerpt describes participants experience with trying to make vaccine decisions for their children:

> I am disappointed that I am unable to select and choose which vaccinations.♀

> I would like to use certain vaccines. Many childhood vaccines are being combined, this does not truly allow parents and care givers to freely choose and make the best decision for their children.♀

Salathé and Bonhoeffer (2008) stated that belief systems rather than obtaining access to vaccines were the main reasons for parents declining vaccines in high-income countries. Economic factors associated with not vaccinating children were more likely related to undervaccinated children, where parents may have experienced financial, social, and physical barriers in accessing vaccines for their children, rather than conscientious objections as reasons for declining vaccinations (M^{c}Intyre et al. 2003). Fitzpatrick (2004), categorised the two groups as ‘passive defaulters’ and ‘active resisters’. ‘Passive defaulters’ refers to parents that have practical barriers, as opposed to ‘active resisters’; or parents that proactively decline vaccines. ‘Passive defaulters were characteristically low-income families experiencing various forms of deprivation or social exclusion ...The active resisters were middle-class well-educated parents, who have chosen not to have their children immunised’ (Fitzpatrick, 2004, p.15).

The access, availability and cost of health care services could be a factor for only a limited number of the participants in this study with only one person nominating socio-economic factors as one reason that they were not fully vaccinated. The literature does present a clear distinction between unvaccinated children and undervaccinated children (Smith, Chu and Barker, 2004), where ‘active’ parental opposition is evident in declining vaccinations (Bedford, 2008). This however, may only be relevant in routine childhood vaccinations, not tetanus and travel vaccines.

Emerging themes from the survey

The survey data was automatically compiled into graphs, providing percentages and outcomes, and stored in the web based (‘Survey Monkey’) database, which was password protected. A hard copy of the survey was printed off and secured.

The survey questionnaire developed emerging themes from the data, which informed the qualitative strand of the research. Statements along with formulated meanings were grouped together to form a theme. This stage of analysis resulted in several themes, which were consolidated to form eight main themes that were common to all of the participants’ descriptions of being raised without routine childhood vaccinations.

The endeavour of analysing the findings was to produce a holistic and integrated synthesis of the data. There are multiple ways of interpreting findings, these interpretations represent an exhaustive search for meaning from the findings, identifying and discussing the most important themes, while respecting the context of the study. To portray an integrated picture of the phenomenon, the themes are discussed in order of the theme relating to the significant patterns. The researcher identified significant patterns, thematically coding the categories (please see Appendix 6) to create and develop themes and categories shown in the following diagram (figure 4.1). The diagram became a framework for guiding the analysis; explaining connections, propositions, patterns and themes that were gleaned from the raw data and placed in a context of understanding.

These were:

- personal responsibility
- immunity
- least interference
- choice
- worldviews
- risk
- expert
- experienced diseases

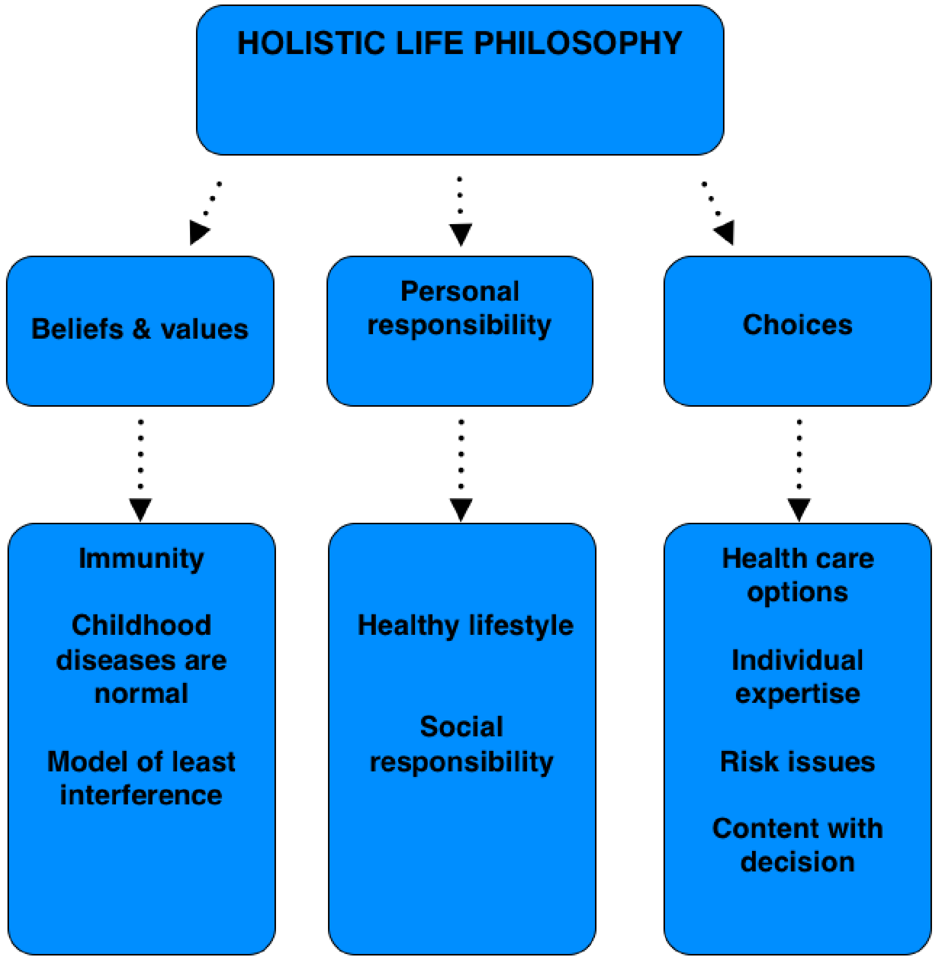

Figure 4.1 Emerging themes

Quantitative findings:

Discussion

Holistic life philosophy

The overarching theme in Figure 4.1, ‘Holistic life philosophy’ was notable in many of the participants in the study in various ways. Most obvious was the way in which they conceptualised health, disease, wellness, and treatment. This was also noted in Hildreth and Elman (2007) who found that health beliefs, including spiritual beliefs and worldviews differentiated orthodox users from heterodox users, whom they refer to as ‘alternative patients’ (Hildreth and Elman, 2007). Hildreth and Elman presented three key features of the heterodox user: a personal orientation toward a holistic worldview, a sense of health control and empowerment and personal characteristics of openness, which might include alternative health-related practices. Other researchers have come to the same conclusion, differentiating between heterodox and orthodox users and health care related decision-making, as well as attitudes and beliefs (Bishop, Yardley and Lewith, 2007; Hildreth and Elman, 2007; Caspi, Koithan, and Criddle, 2003; Barrett, Marchand, Scheder, Plane, Maberry, Appelbaum, Rakel and Rabago, 2003; Sirois and Gick, 2002; Lewith and Chan, 2002; Eisenberg and Kaptchuk, 2001; Siahpush, 1999; Astin, 1998; Kelner and Wellman, 1997; Furnham and Kirkcaldy, 1996). Holistic life philosophy was clearly linked to participants beliefs and values, which related to their perceptions and preferences for living.

Beliefs and values

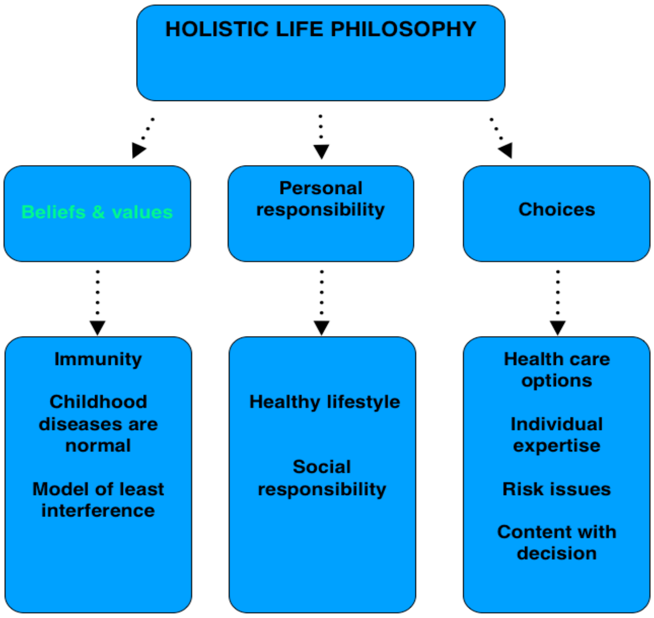

figure 4.1.1 Beliefs and values

Beliefs and Values

Theme 1 – ‘Beliefs and Values’ included the sub-theme ‘Immunity’. In heterodox medicine the emphasis is placed on supporting the body and strengthening the immune system, which is considered critical to good health. A comprehensive approach encompassing lifestyle, stress management, exercise, diet, nutritional supplementation, glandular therapy and the use of plant-based medicines are identified by well-known American naturopaths Murray and Pizzorno (1999) as the key to a well functioning immune system. Most importantly, for Murray and Pizzorno, the immune system is considered to be holistic, in that it is closely associated with other major functions of the body; psychological, neurological, nutritional, environmental, and endocrinological factors all of which affect the functioning of the immune system (Murray and Pizzorno, 1999). The participants in this study placed an emphasis on concepts associated with immunity, referring to it frequently.

In this modern era where illness of any kind could be viewed as an inconvenience, it may be difficult to comprehend that illness could be perceived as a positive experience. Illness seems to be considered by many of the unvaccinated participants in this study to be an opportunity for the further development of the immune system. The concept of illness as bringing about benefits is not new. Rudolf Steiner wrote about the benefits of certain childhood diseases and anthroposophical physicians Glöckler and Goebel (2007) described how childhood illnesses allow for the development of a more stable state of health in adulthood:

> Many of today’s adults still owe the strength and flexibility of their immune systems to the fact that as children, they were allowed to learn to cope with germs; that is, they survived symptoms of acute illness without being given fever suppressants, antibiotics, or vaccines (2007, p. 111).

Furthermore, illness may be seen as an opportunity for the body to use its inherent healing, restorative capabilities, often referred to as the ‘vital force’. Lockie, a heterodox and orthodox physician, stated that ‘[i]n most cases, the child’s vital force will enable him or her to deal with many common threats to childhood health’ (Lockie, 2000, p. 247).

Fever is said to be part of human growth and development, with the fever acknowledged by heterodox practitioners as a crucial part of the healing process (Santich and Bone, 2008). They describe a febrile response as so important that a therapeutic fever is sometimes induced with herbal medicines in cases where the body has not managed to raise a fever on its own. Low-grade chronic infections that may need resolving are provided as an example by Santich and Bone (2008) where the febrile response is used to support the individual. Therefore, the processes of illness and fever is ideally supported with rest, natural medicines and appropriate therapies, rather than suppressed with pharmaceuticals.

The following excerpts from survey participants portray this view of illness:

> I think that we need to see the benefit in illness.♀
>
> I believe childhood illnesses are there for a reason and we shouldn’t disturb the way’s our bodies work with them. I believe its part of the child’s metaphysical rite of passage to fight off illness. It strengthens both the physical body and the will.♀
>
> I think it is better for the body to develop its own natural immunities to diseases. Good nutrition assists the body to gather strength to fight disease and build immunity naturally.♀

Illness was also viewed from a philosophical perspective:

> On a more philosophic level, I do not wish to pick and choose which illnesses I may or may not face. I have been ill a number of times and each experience has led me to something that I would never have come into contact with otherwise, and thus I have felt grateful for the times I have been ill.♂

Although there is a plethora of information about the immune system, it is widely accepted in heterodox as well as orthodox medicine, that there is much to be learnt about the functioning of the immune system.

Childhood diseases as normal

The next sub-theme under Theme 1– 'Beliefs and values' that emerged from the survey and was that certain childhood diseases were normal. With this view, childhood diseases were not avoided; on the contrary they were seen as a necessary part of life. This theme was explored in detail in the interviews and is discussed in Chapter 5.

Model of least interference

The third and last sub-theme under Theme 1– 'Beliefs and values' is the concept of ‘least interference’. In an effort to adhere to the commitment associated with participants’ personal beliefs and values, a model of least interference arose as a theme in the survey. This model translated to an avoidance of orthodox medicine whenever and wherever possible. This theme was more thoroughly explored in the interviews, and is discussed in detail in Chapter 5.

Discourse of personal responsibility

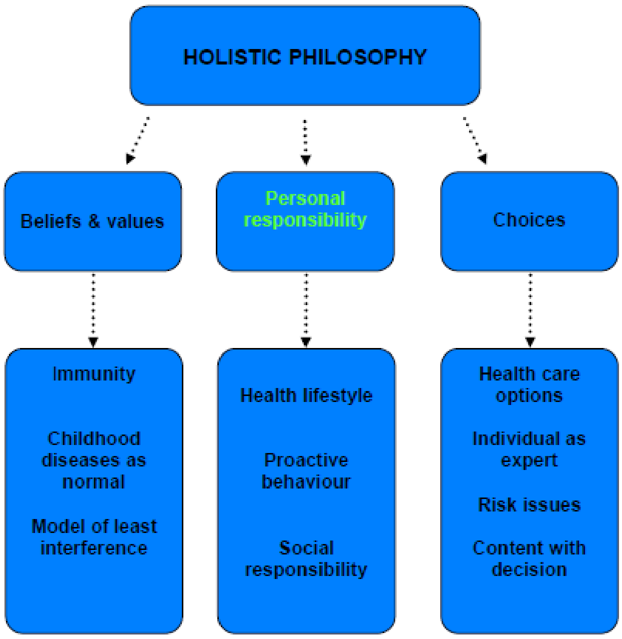

Figure 4.1.2. Personal responsibility

In the emerging themes from the survey Theme 2 – ‘Personal responsibility’ noted a marked sense of personal responsibility from participants which was evident in their summation of health outcomes and the great importance that they placed on directing health care decision-making.

The rhetoric of self-responsibility as being inextricably woven into the heterodox health paradigm has been described by Miskelly (2006), where an individual that adheres to the natural health paradigm has an expectation to exhibit some level of responsibility as well as accountability for one’s own health behaviours. This concept was also portrayed in Crawford’s (1980, p. 366) article, where he outlined that ‘holistic health encourages clients to become active participants in the healing process to exert self-responsibility’. More recently, Tesser and Barros (2008) described this as the essence of heterodox medicine, ‘firstly recognising the association between integrated health and physical, mental, social and spiritual wellbeing, and secondly, encouraging the subject to assume his or her own responsibility for his or her own health-illness, thereby increasing the sense of autonomy’ (Tesser and Barros, 2008, p. 917).

Responsibility is a contested term, described by Miskelly (2006) as a concept replete with different meaning. She defined it as being divided by individual and bureaucratic interpretation. Responsibility as defined in the *Collins Dictionary* as ‘having control, or authority or being accountable for one’s actions and decisions’ (2009, p.1398). Conversely the opposite term, irresponsible, defined as ‘not showing, or done with due care for the consequences of one’s actions or attitudes’ (*Collins Dictionary*, 2009, p. 867).

Other literature has indicated a different tone, noting that parents felt far greater responsibility when making vaccine decisions on behalf of their children (Sporton and Francis, 2001; Marfe, 2007). Bond et al. (1998) found that all of the mothers in their study considered that they had a duty of care to their children, to make good decisions that would not risk their children’s health. Interestingly, in this study, survey participants seemed to describe a high level of responsibility in terms of taking care of their own health, with many noting that they pick and chose the health care that they accept, relating to their own source of epistemology. These choices may be attributed to their upbringing, personal ideologies, and their own reading and research.

Rogers and Pilgrim (1995, p. 87) had a significant amount of insight into the impact that this individual responsibility would promote, declaring over a decade ago that mass childhood vaccinations are ‘incompatible with the notion of the health promoting patient – an informed agent actively involved in taking responsibility for their health’. They recognised the complexity of beliefs surrounding illness, healing and responsibility, as being incompatible with the vaccine rhetoric of social responsibility in participating in mass childhood vaccination, and the government surveillance of it. The patient that employed heterodox medicine was described by Kelner and Wellman (1997) as a smart consumer of health care, capable of acquiring a broad range of information on therapeutic options and then making a decision on their preferred course of treatment. Similarly, many of the survey participants in this study described their own use of health care in the same manner, resembling the competence and mark of social fitness described by Ziebland (2004).

The majority of the survey participants in this study followed a model of ‘taking responsibility’ for one’s individual health. Hobson-West (2003, p. 155) noted that a ‘vaccine critical’ group, or a group that were critical of vaccines in her study, also engaged in a discourse of ‘taking responsibility’ for one’s individual health. Hobson-West (2005) described the vaccine imperative within society where there is an expectation that everyone must vaccinate, even though vaccination is not considered compulsory in the United Kingdom or in Australia. Hobson-West also referred to a moral imperative, which was also put forward by Osborne (1997), who noted that health might no longer be a right of citizenship, but a duty of citizenship. Dew (1999) hypothesised that the state would increasingly rely on the discourse of duties of citizenship, fostering this vaccine imperative and adding to this notion of morality in vaccination. The 'social problem' of low vaccine uptake where those that do not have their children vaccinated become targets for 'moral condemnation' (Dew, 1999, p. 384) has emerged as an issue emanating from the vaccine moral imperative. This is evident with several survey participants reporting that their mothers were condemned by members of society for not vaccinating them.

The moral imperative of vaccination is clear, with participants recounting struggles with going against the recommended schedule, frequently mentioning governmentality issues that they came up against. 'Governmentality issues' refer to the policies that have been implemented by government to ensure a high uptake of vaccination in the community. Policies such as the vaccination 'blue book' that every child is expected to have, that details the vaccinations that they have acquired and is a pre-requisite in order to enter day care and primary school. In some countries/states children who cannot show proof of vaccination are banned from entering school, 'no shots, no school' (Lee, 2012, p. 4). Maternity and childcare benefit payments also tied into completing the vaccination schedule (Leask and Chapman, 2002). Although exemptions do exist, known as a 'conscientious objection', one survey participant notes that this information was not provided to her. The poor dissemination of this 'exemption' information presents issues for parents that are required to make vaccine decisions on behalf of their children.

A deeper consideration of the discourse of 'taking responsibility' is useful in understanding its affiliation with the holistic ideology of healing. Miskelly (2006, p. 55) argued that heterodox practitioners work within a holistic framework that is based on this notion of personal responsibility. Health, both physical and emotional, is recognised as a personal entity that is continuously evolving (Hobson-West, 2004). Heterodox patient have been recognised as exhibiting personal responsibility for their health, with Kelner and Wellman (1997) identifying a number of key factors in this ideology: a holistic understanding of health, incorporating mind, body and spirit, as well as an emphasis on individual and personal responsibility for all healthcare decisions. Health-seeking behaviours were identified by Crawford (1980) and described as requiring a high degree of individual responsibility. Health-seeking behaviours have also been affiliated with the ideologies of heterodox medicine.

Healthy lifestyle, proactive behaviour and social responsibility

Theme Two – ‘Personal responsibility’ had sub-themes – ‘Healthy lifestyle’, ‘Proactive behaviour’ and 'Social responsibility'. The holistic process of healing, outlined by Ventegodt, Anderson and Merrick (2003), was said to require a high degree of individual commitment. These authors suggested that a deep level of personal development, reflection and commitment was necessary for those that seek out a holistic approach to healing. The intention of healing oneself, a preparedness to relinquish negative decisions and resolve emotional difficulties that may be implicated in blockages or illnesses, are central philosophical necessities within a holistic paradigm. Everyday choices, apart from an awareness of the impact of negative attitudes and decisions, can include behaviours such as what one eats and drinks, how much activity one undertakes and other behaviours that the individual chooses. The majority of unvaccinated people in this study had a high regard for positive health-seeking behaviours, adhering to a healthy diet and lifestyle.

This next comment from a survey participant alludes to the fact that some individuals do not have the same priorities as she does and rely on the general practitioner to attend to them:

> I think a lot of people don’t take responsibility for their health, they just want to go and get a pill and continue with their unhealthy lifestyle. I don't think it's fair that we should have to deal with these effects, just as vaccinated people think we are endangering them.♀

The next excerpt gives a participant’s views about health care:

> I feel that vaccination has been a kind of quick fix and that if the time and money expended on vaccination had been devoted to public health issues and nutrition, people would have been healthier in a more proactive way.♀

The notion of the free-rider is discussed under theme two's sub-theme – 'Social responsibility'. The term ‘free-rider’ refers to a person who benefits from a good, without contributing. Although originally used as an economic concept, it is a term that is frequent in the vaccine literature. Diekema (2005) commented on ‘the problem of the free-riders’. He said, ‘parents who refuse immunization on behalf of their children are, in a sense free-riders who take advantage of the benefits created by the participation and assumption of immunization risk or burden by others while refusing to participate in the program themselves’ (Diekema, 2005, p. 1430). It is argued here that for many parents that reject mass childhood vaccination, their intention has little to do with free-riding and more to do with a variant life philosophy.

Duffell (2001) studied a Steiner community, following an outbreak of measles, and found that there was an avoidance of certain vaccines, antibiotics, and antipyretics. Hanratty et al. (2000) noted the same avoidance, concluding that it was more than just a rejection of orthodox medicine. The holistic view of the human being was philosophically aligned to favouring the development of certain contagious diseases as beneficial to the maturation of the immune system. Many of the participants in this study exhibited similar views, as represented in many of the quotes included in the discussion. Finding that the decision to decline vaccinations has encompassed more than a vaccination choice for the participants in this study, there seemed to be an overarching premise of a health and wellbeing ethos that was passed onto the children. This ethos included an awareness of the effects of diet, exercise and a consciousness about the over-use of pharmaceuticals. Asveld (2008, p. 253) affirmed that people who refuse vaccination programmes due to divergent risk perspectives are often associated with 'alternative' lifestyle ideology.

According to the unvaccinated participants in this study, individuals may feel so strongly about their views on vaccination that they are willing to leave their country of birth, or take a certain direction in life, work and/or residence because of vaccination policies and restrictions that are placed upon citizens. Relative to the theory of herd immunity, if a certain percentage of the population is vaccinated, the rest are said to have protection, or at least have a reduced 'risk' of illness. 'Free-riding' is seen by some as a way of evading responsibility and taking a free ride at the expense of the rest of the general population that have been vaccinated. Free-riding was not raised by the participants in this study as a rationale for having not been vaccinated, or not vaccinating their own children. Fredrickson et al. (2004) also found that the notion of the 'free-rider' was not raised as an issue with the participants in their study who declined vaccinations.

Serpell and Green (2006) noted that the literature provided conflicting information on free-riding as a reason for not vaccinating children, with Evans, Stoddart, Condon, Freeman, Grizzell and Mullen (2001) finding that it was not a factor, but Meszaros et al. (1996) suggested that free-riding may play a part. One could conclude that the expression 'free-rider' is used as a broad, derogatory label by vaccinating proponents that may only be applicable to a specific percentage of people that do not vaccinate their children. The term free-rider and the rhetoric along with it, has contributed to some of the hostility non-vaccinators have received from others.

These comments below and the excerpts following in the benefits of illness section, depict a different mindset to that of free-riding:

> My mother was happy for me to contract the childhood illnesses to build immunity, and exposed me to friends and acquaintances when they became ill.♀
>
> I chose not to vaccinate my children because I believe childhood illnesses have an important role in the development of the child. Not only does it strengthen their immune systems it will also have an effect on them when they become adults.♀
>
> I think it’s better for the body to develop its own natural immunity to diseases.♀

Furthermore, herd immunity was identified by many participants in the survey as an orthodox concept, with little advocacy for the theory. In fact, several participants made reference to the lack of exposure that their children had experienced, as a negative consequence of mass childhood vaccination, remarking that their children had been disadvantaged by not having the opportunity to be exposed to what are often referred to as childhood illnesses, in childhood. This finding concurred with Pilgrim and Rogers (1995) research, but refutes much of the biomedical academic literature that has implicated free-riding as a general motivation for declining vaccination (Serpell and Green, 2006; Ibuka, et al., 2014; Fine et al., 2011). In addition, this finding challenges Skea et al's. (2008) suggestion that vaccine promotional material targeted at parents should present distinctions between healthy and vulnerable children for improving vaccine uptake. This argument was not supported in this study, as discussed in the literature review, this thesis contends that people that hold holistic theories of the immune system may not consider vulnerability to be a relevant point for arguing that only certain children should be entitled to exemptions, as the perception of vulnerability may be disputed with participants discourse depicting all newborn babies and infants as vulnerable.

Several studies have also recommended appealing to the social benefits of vaccination as a means of preventing free-riding (Betsch, Bohm and Korn, 2013; Skea et al. 2008). Communicating the social benefit of vaccination may be effective in preventing free-riding if the individual's hearing the message have thoughts and beliefs that are in alignment with the public health messages. However, this is a problematic solution for those that don't have aligned views, firstly free-riding is not their intended goal and secondly, and most critically, herd immunity is not acknowledged as a public good.

Choices

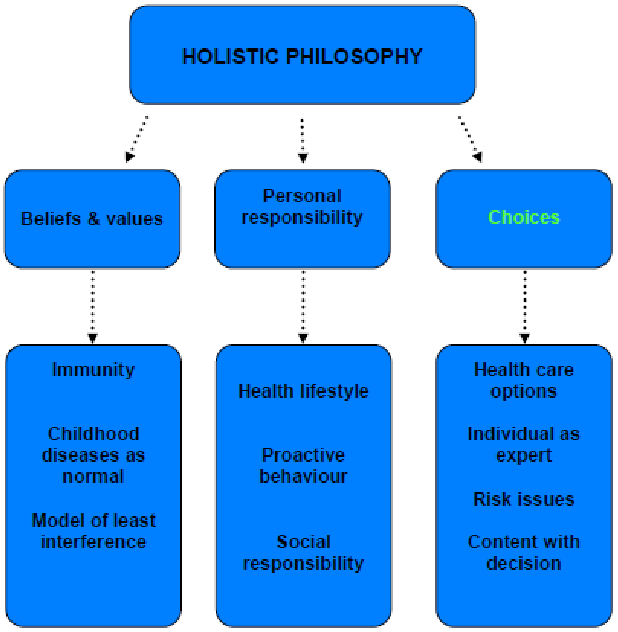

Figure 4.1.3 Choices

Theme 3 – ‘Choices’ was a common theme that developed throughout the analysis of the data and was similar to findings of other studies, that many parents are dissatisfied with the limited information they are given to make this decision on behalf of their child, with many calling for broader, more unbiased information (Sporton and Francis, 2001; Smailbegovic, Laing and Bedford, 2003; Hamilton et al., 2004; Nagaraj, 2006; Marfe, 2007; Gust et al. 2008b; Austvoll-Dahlgren and Helseth, 2010).

Health care options

'Health care options' was a sub-theme of Theme 3– 'Choices'. Health care options and in particular improvisations in health care were found to be an important factor for participants. The literature has not accounted for the improvisations that people may make, in order to follow their philosophical ideologies and attitudes towards childhood vaccinations. These individuals may relinquish certain aspects of life, in order to follow their vaccination preferences. These aspects may include moving states, or countries to avoid compulsory vaccinations, not travelling to certain countries with this requirement, the selection of certain schools, or particular educational preferences, for example homeschooling or Steiner schooling where there are less rigid criteria for entry. Some educational institutions may not accept children that have not had routine childhood vaccinations. Further improvisations may extend to electing specific health care practitioners, with a predisposition for a certain health care frame of reference; for example, birthing experiences may have some correlation with personal choices in vaccination (Poltorak et al., 2005). A preference for the holistic model in health care may carry through to birthing practices, with several participants raising the childbirth experience as a big part of their own personal worldviews and health care choices. ‘Parents who oppose immunization of their children may take their children out of public school, homeschool their children, or find other ways to avoid immunization’ (Lantos, Jackson, Opel, Marcuse, Myers, and Connelly, 2010, p. 43).

The relinquishment or giving up of something in order to follow a certain path was noted in the study and evident in Stafford’s (2008) report on two sets of Belgian parents who did not comply with a compulsory polio vaccination for their children and as a consequence received a five-month prison sentence, with each parent fined $8000. In some instances financial incentives and family payments linked to vaccinating children are relinquished because of a non-vaccination decision.

This participant explains how her family moved countries to avoid compulsory vaccination:

> At school in Canada in 1940s a medical team arrived and vaccinated all children against smallpox. My father was horrified and contacted the authorities to make his objections about the procedure known. My vaccination did not take, other children in the same situation were revaccinated I was not. Vaccination was compulsory in Canada my father was told I would be revaccinated the following year. We left Canada.♀

Other improvisations may be made. Parents are told that they are expected to keep an unvaccinated child away from school in the event of an outbreak of a childhood contagious disease. Dew (1999) noted that a Medical Officer of Health could constrain unvaccinated children from attending school, although there would be other cases where children that had been vaccinated had not seroconverted. Seroconversion means that the individual’s immune system has reacted to a vaccine in an appropriate manner, where following a vaccination, detectable antibodies are found in the blood in response to a vaccination (*Dorland’s Medical Dictionary*, 1989). Dew (1999) argued that unvaccinated children are discriminated against in terms of their education, and also parents, in that they would need to take time off work to supervise their children because they do not comply with this vaccination requirement.

Shuval and Mizrachi (2004) pointed out that orthodox and heterodox paradigms varied greatly, with differing philosophies regarding health, illness and treatment, which ultimately influenced health care decisions, including birthing decisions. Williams (1998) noted that home birthing allowed for personal empowerment, control, and individual decision-making, with hospitals viewed as 'hostile' environments where there is a perceived loss of control. Lothian (2008) also noted that choice was restricted in mainstream child birthing, with a struggle ensuing for control of autonomy, due to hospital rules and 'embodied knowledge'. Shuval and Gross (2008) studied midwives using heterodox medicine in birthing hospitals in Israel, finding that orthodox physicians varied greatly in their acceptance in allowing midwives to use heterodox medicine for women that requested it. The Shuval and Gross (2008) study found some interesting points. There was a rejection of the medicalisation of birth, and also a rejection of the over-use of technology by the midwives using heterodox medicine. The over-use of technology was also mentioned a number of times by the unvaccinated participants in the survey, with several participants commenting directly about the extensive orthodox medical intervention in birthing, with the over-use of technology said to be a concern. Several participants noted that they had a home birth:

> We have five children, all born at home except the first in a birth centre, all never vaccinated. We do not believe in experimenting with vaccinations.♂
>
> I had a home birth.♀

This participant mentions her experience at a public hospital:

> When I had my first child (and requested a couple of changes to the normal procedure e.g. no Vit.K injection to the baby, and that the cord not be cut until it stopped pulsating etc) I was approached by a doctor at that public hospital who enquired whether I would be vaccinating my baby. I said no and the next day a nurse appeared in my room with a deformed leg she started chatting and mentioned that she had polio as a child and her deformities were caused by the polio, she also mentioned how important it was to be immunised ... obviously she had been sent by that doctor.♀

Dixon-Woods, Williams, Jackson, Akkad, Kenyon and Habiba (2006) described the findings of their study of women that consented to obstetric or gynaecological surgery in a

British hospital. Power and relationships with medical staff were found to be influential in procedure decisions and informed consent. These authors say that ‘women-as-patients’ have felt that hospital environments display a social hierarchy with medical staff perceived as ‘higher’ class. Interestingly, female patients often exhibited compliant behaviour while in that hospital domain, with a subsequent unsatisfactory outcome.

Brown et al. (2010) similarly found that women felt depersonalised by the ‘system’ and were aware of an unequal power relationship, inhibiting an open dialogue in that domain. Women were also found to be more concerned about serious vaccine adverse events than men (Freed et al., 2010).

The following participant demonstrates the dissatisfaction she felt after being pressured into vaccinating her baby:

> I was bullied into having my eldest child vaccinated as a baby, something I soon came to regret and did not continue with booster vaccinations for him. My other three children were not vaccinated.♀

This variance of view has been noted as an issue in the context of birthing, as in the above excerpt, where a woman may enter an orthodox domain – the hospital – to have a baby and feel uneasy about the choices that she is expected to make. There is a vast amount of literature that recognises the disempowerment that many women have experienced in the hospital setting. In this setting they are often expected to go along with the experts that belong to the hospital institution and who impart information and knowledge to the women that are giving birth. Choice is limited by the information that is dispensed by experts and by the expectations that may be placed upon her by these ‘experts’.

Lothian (2008) argued that ‘choice is so limited it is a myth’, exploring the ways in which women’s choices are undermined in birth by the dominant orthodox model. Although vaccination has been referred to as a choice, refusing vaccines was not necessarily seen as a real option or choice in this study. It may be viewed more as a formality of consenting to have a child vaccinated with limited information, along with pressure to conform to a routine medical procedure. Lothian (2008, p. 36) asserted that what should be important is the women’s ‘knowledge of her body, her values and beliefs, what is important to her’.

Health care options and tetanus

The use of tetanus vaccines for injuries also came under the sub-theme 'Health care options'. Thirteen of the 67 survey participants noted that they had received a tetanus injection as a result of an injury. In these cases a tetanus injection had been administered promptly after stepping on a rusty or dirty object or receiving a deep puncture wound, or some other injury where the likelihood of being exposed to the tetanus bacterium was perceived to be high. In no case was it administered as the routine DPT (diphtheria, tetanus and polio) vaccine.

The question may arise as to why the tetanus vaccine was acceptable while other vaccines were not. Interestingly, the threat of tetanus seemed to be perceived differently to contagious diseases. It is important to observe that it was distinguished as an acceptable treatment when it was required as a direct result of an accident. Other reasons that may distinguish tetanus as different might include that it is not a childhood contagious disease although it is routinely given with other childhood vaccines. The tetanus bacterium enters the body through the skin, as a result of a wound, as opposed to a disease such as measles that enters the body via the respiratory system. These participants noted that they believed that the tonsils served as a barrier to infection and aided the immune system in mounting a defence against certain organisms.

This result was in keeping with participant responses in other questions where, generally speaking, participants preferred a model of least interference; health issues were dealt with as they arose. Vaccines were not given as ‘just in case’ medicine, where a child may one day be exposed, but from suspecting that they had been exposed. For these participants there was a conscious attempt to avoid what they considered to be unnecessary interference of pharmaceuticals.

> I would never consider taking a drug for anything.♂
>
> Medical drugs only treat the symptoms of degenerative illness while the underlying causes continue unabated. Natural Health treats the underlying (lifestyle) causes and facilitates self-healing.♂

Individual as expert

'Individual as expert' was a sub-theme of Theme 3 – 'Choices'. The theme was discussed in the literature review and also emerged in the survey. It was explored and developed during the in-depth interviews. The theme is discussed alongside risk issues, as the need to become expert has been associated with uncertainty. The theme is discussed extensively in chapter 5.

Risk issues

‘Risk’ was a sub-theme of Theme 3 – ‘Choices’. Risk is a word that regularly came up in the survey results and has been well identified in the literature, although some scholars offer different accounts on the weight that risk holds in vaccine decisions. Hobson-West (2005) contends that risk is an insufficient framework for understanding vaccination attitudes, demonstrating that vaccine critical groups possess ambivalent relationships with science. In contrast, O’Connor (2002, p. 64) and Siahpush (1999) found that there was no evidence suggesting that heterodox users were ‘anti-science’ despite being labelled as such. This thesis suggests some diversity in participants and their outlook on science. Several participants reported that they were pro-science, no participants reported that they were anti-science, however it should be noted that there appeared to be some deviation in their interpretation of science.

Risk is acknowledged in the literature as being a big part of vaccine decisions. Risk was found to come up in many instances, risk associated with vaccinating, risk associated with not vaccinating, and risk associated with not having the opportunity to be exposed to certain childhood contagious diseases, because of mass childhood vaccination.

These next comments depict the clear view of mothers, regarding their priority of protecting their child:

> The risk of vaccinating versus the risk of getting certain rare diseases was a no brainer. I had a number of childhood diseases and was not affected or mentally scarred by them, I feel a healthier person for not being vaccinated.♀
>
> I believe vaccinating a child causes a potential health risk to that child and in some cases can ruin their life forever.♂
>
> I believe that standard vaccines are administered when the child is far too young and being in multiple doses must be a huge shock to a delicate, newborn child. I also

> believe that these vaccinations cause a spike in the immune system resulting in the high occurrence of allergies that were not present when I was a child.♀

Risk, including a particular perception of risk, is communicated to the public by established institutions, such as the World Health Organisation. Government also influences perspectives about acceptable worldviews, where the individual is encouraged to adopt certain practices. ‘Vaccination is promoted and administered by professional experts, whose advice we are expected to passively accept’ (Hobson-West, 2005, p.187). Vaccination as described by Hobson-West (2005) was affiliated with a modern form of public health, which focused on surveillance and intervention at population level, identifying that vaccination is associated with the germ theory of disease and a preventative approach. This point is significant: as mentioned earlier many participants preferred a model of least interference, in that they did not agree with giving ‘just in case medicine’ (Hobson-West, 2005, p. 186). Casiday (2007) argued that all risks are socially constructed, with the identification of risks as being related to certain aspects. This argument certainly seemed to resonate with participants in this study who had a different view as to what a risk was and was not. For these participants the risk associated with intervention was considered far greater than the risk of the body’s contracting a childhood contagious disease.

Orthodox health messages are acknowledged as influential in the social construction of what is risky and what is not risky behaviour and may seem coercive in the way that they influence or persuade individuals regarding risk issues. Further to this, the marketing and the implementation of vaccine payments to parents once they have vaccinated their children, reinforce these health messages (Rothschild, 1999). The exchange of payments for individuals that abide by the vaccination schedule, explained by Rothschild (1999), as a fundamental marketing approach described as one individual giving up something to get something from the other. Smith, Woodward, Acharya, Beaglehole and Drager (2004) contended that on account of herd immunity, society benefits more greatly than the individual family, due to the apparent decreased exposure afforded by herd immunity. The language of individual responsibility to society as part of being a good citizen has been used persuasively in orthodox vaccination discourse. Being a ‘good citizen’ is linked to complying with the routine vaccine schedule prescribed by government. Therefore being non-compliant fosters stigmatised roles by using emotive language, ‘free-rider’, ‘free loader’, not ‘properly’ educated, further exacerbating the divide between vaccinators and non-vaccinators.

The cultural theory of risk has been nominated as being influential in why different parents interpret risk differently. Casiday (2007, p. 1068) explained that determining risk was related to ‘a cultural predisposition toward a particular kind of social outlook’. Different people view childhood vaccination in a variety of ways that range from active resistance, to passive acceptance, to active demand of vaccines for children. Risk disputes are created when this ideal does not align with the reality that individuals have differences of opinion (Casiday, 2007), with the rhetoric of ‘good citizens’ expected to go along with the majority, for the good of society (Brownlie and Howson, 2006). Brownlie and Howson noted that in the case of vaccination, the goal is to retain herd immunity. Altruism, where one conforms to do what is deemed as best for the group, is the basis of herd immunity. According to Rothschild (1999) this process involved individuals’ denying their own perceptions of self-interest, or libertarianism for the sake of paternalism, where the state is seen to know what is best for the individual as well as the group. In this manner ‘parents may be pressured into conformity so as not to put other school children 'at risk'.

Dew (1999) asserted that the germ theory of disease is often stated as undisputed fact, and representing this line of thinking, most participants in the survey did not agree with combatting germs with vaccines and antibiotics. Baer (2008, p. 183–184) provided a description of the heterodox approach:

> Naturopaths regard disease as a response to bodily toxins and imbalances in a person’s social, emotional, and spiritual environment; germs are not the cause of disease per se but rather are conceptualized as parasites that take advantage of the body when it is in a weakened state. A central tenet of naturopathy is the belief that the healing power of nature ... can restore one to health; therefore, naturopaths emphasize preventive health, education, and client responsibility.

This model was evident in this study where participants used heterodox therapies as an initial measure and only resorted to pharmaceuticals when they perceived them to be absolutely necessary. Heterodox medicine has been associated with a reverence for the body and a belief that part of health, or being healthy, included at times being sick or having an illness. This hypothesis is very much in keeping with the findings of this study, where participants referred to a holistic notion of health and wellbeing, where prevention of disease was defined as healthy diet and lifestyle rather than vaccinations which are the cornerstone of orthodox preventative medicine.

Many participants had little reliance on orthodox practitioners and detailed answers as to why they have not vaccinated their children. Survey participants described how they are expected to be able to sagaciously justify their motivation, exemplifying this competence and social fitness:

> I constantly feel like I need to justify my decision, but I am getting better at telling people to mind their own business.♀

Smith (2004) reported that individuals who search online for health information were likely to be educated and have higher incomes, with 48% having a degree compared with 18% of the whole sample in his study. Individuals proactively seeking health information were found to have a higher level of wellbeing, giving further credibility to Ende, Kazis, Ash, and Moskowitz (1989), who reported that individuals proactively involved in their own health plan had a higher satisfaction with their health. This suggests that government health services should implement more availability and access to health information via the Internet. This point is noteworthy as Petts and Neimeyer (2004) found that some participants in their study expressed frustration with gaining information from their orthodox practitioners. In addition, some participants expressed feeling uncomfortable in asking their orthodox medical practitioner questions. Relevant to this is the number of patients that do not disclose the natural remedies that they are taking (Chao, Wade, and Kronenberg, 2008). McCoy (2008, p. 785) cited that almost 60% of patients failed to disclose their use of natural remedies to their orthodox practitioners, representing a serious challenge in the communication and trust that patients have towards their orthodox medical practitioners.

> When I was younger I occasionally twisted the truth to avoid having to have the discussion with providers.♀

One could easily conclude that clear, honest information is needed, extending to acknowledging the possibility of serious adverse events from vaccinations or declining vaccination for this survey; parents prefer full disclosure about potential implications.

Content with decision

An associated sub-theme of Theme 3 – 'Choices' was contentment with decision. It was important to explore participant’s contentment with the vaccine decisions that were made on their behalf. This theme emerged from the survey findings and was more thoroughly explored during the interviews.

Summary of Chapter 4

This chapter concludes the summary findings and discussion regarding the quantitative survey questionnaire. The survey provided, as hoped and expected, a breadth of data and information. The comments section of the survey added qualitative data to the survey results. The survey questionnaire was followed by 13 in-depth interviews that provided depth, clarifying, adding and explaining further information regarding the quantitative findings.

The quantitative findings have demonstrated that survey questionnaire participants had a notable level of awareness regarding positive health behaviours, and in fact described life and health choices based on a holistic paradigm. For some participants, the personal experience of illness had meaning; in addition some people perceived that there were long-term adverse effects on the human body, associated with the use of vaccines. As was expected from the literature, the use of natural remedies was high amongst participants, but further to this, the study indicated that the use of pharmaceuticals was low, which adds new knowledge to the literature and helps to provide a more holistic view of the phenomenon.

Of particular interest, it was not unusual to observe that participants had had a tetanus injection as a direct result of an injury, with 13 survey questionnaire participants out of 67 noting this. Not yet explored in the literature, travel vaccines were observed as possibly viewed differently to childhood vaccines, with approximately 40% of participants' undecided about the use of travel vaccines. Further to this, the intergenerational insights gleaned from asking participants about vaccinating their own children offers a new contribution to the academic literature.

Chapter 5

Interview Results and Discussion

Introduction

This study explored the experiences of adults that were raised without routine childhood vaccinations by analysing the experiences and reflections of these participants using a phenomenological methodology.

Sixty-seven participants completed an on-line survey and 13 of these were invited to in-depth interviews. The purpose of the interviews was to search for deeper, more comprehensive information about adults that had been raised without routine childhood vaccinations and to give participants a chance to express and convey more about their experience. The findings are presented, with statements from participants representing all of the experiences guided by the major themes. Each statement is identified using a $\mathcal{P}$ to represent the participant and the number of the participant from 1 to 13.

This chapter further develops the major themes that emerged from the survey data (below); triangulation consolidated and validated the data that was derived from the in-depth interviews.

In-depth interviews

The interviews took place between August and November 2012. Of the sixty-seven survey questionnaire participants, twenty-three declined the interview and forty-four were willing to take part in the interview. Approximately fifteen of the forty-four people lived in other states, which was not considered ideal for in-depth interviews. In the end, thirteen were contacted and interviewed in semi-structured interviews, utilised to collect information from the participants about their life experiences related to growing up without routine childhood vaccinations.

Participation in the study

Of the thirteen interviews, eight were conducted at participants' homes; three were conducted at the researcher's home, one at a participant's place of work, and one over the phone due to the interviewee living in another state. Interviews lasted between forty-five minutes and two hours. Participants signed a consent form (please refer to Appendix 2) and, on being asked, all agreed to the interview being audio-taped. In order to protect their identity, names have been replaced with a participant number and gender sign. Ten women and three men were interviewed. The participants seemed comfortable with the interview process, they were open and communicative, with several expressing appreciation for the research.

Emerging themes from the survey chapter

The mixed method approach was particularly useful in this study as the survey identified relevant themes and the interviews explored them in further detail in an attempt to make sense of the ideas that may have been considered unorthodox or unconventional.

The survey chapter (Chapter 4) brought out the 'Emerging themes' that were explored and validated in the in-depth interviews with triangulation. The thematic model 4.1 was employed as a basis to explore the themes further in the interviews. A substantial amount of information was derived from the interviews. The ideas that emerged from the data tended to have an overarching, recurring theme that linked their somewhat different, yet consistent commentary about the research and associated topics.

Participants most commonly identified that a big part of their health care decisions and values related to their holistic life philosophy on health and illness. Beliefs and values, personal responsibility and choices were a salient issue when discussing health care in general, and vaccinations in particular; these views affected their decision making about vaccination for themselves and their own children, as well as other health care decisions.

A further theme that developed from the interviews that was less evident in the survey was the stigmatisation of participants. This variation may have been a function of the method used, as in-depth interviews are known to create more rapport with participants, where they may feel more comfortable to freely discuss personal matters.

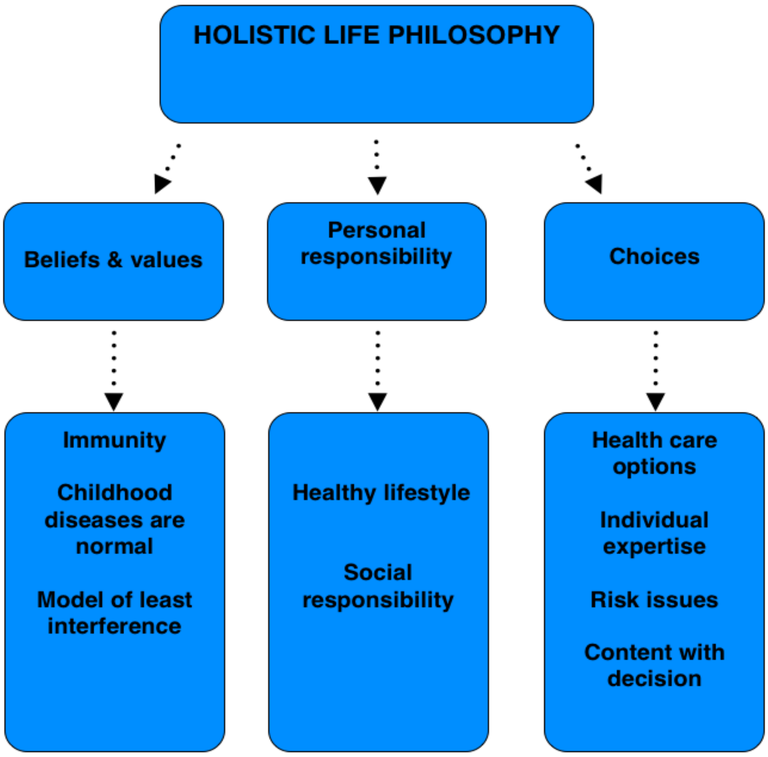

Figure 4.1 Emerging themes (reprinted)

Overarching theme - Holistic life philosophy

The holistic life philosophy was the overarching finding that permeated almost all of participants' responses. Health to them was not just about non-vaccination but a holistic philosophy, which impacted all life decisions.

Theme 1 - Beliefs and values

Participants held strong beliefs and values regarding the interconnectedness of the human body. This notion of interconnectedness meant that the body, mind and spirit are inextricably linked and that they cannot, indeed should not, be separated. Participants' thinking, reasoning and epistemology related to and reflected their wholehearted commitment to their beliefs and values regarding a holistic life and health philosophy.

The beliefs and values of participants, in reference to health and illness, very much impacted the choices that they made for themselves and their children:

> I have no conspiracy belief. It doesn't suit me, it doesn't suit my values ... I can see that it does serve society, but for me personally that doesn't suit my values at all. Bring all the marvels of modern medicine if it's needed, but give the body a chance to handle it. I'm not denying the incredible things that modern medicine can do, some of it is just remarkable. It's about picking and choosing what's needed, when it is needed and that everything out there has got value. You just have to match the value for the need. *P. 1* ♂

Participants viewed prevention of illness in terms of eating well and keeping their body in balance:

> I prefer to prevent it (by eating well) rather than just treat the sickness, so we don't actually go to the doctor very often, because number one they're rarely sick ... so do you see what I'm saying I just have a different view of sickness. *P. 11* ♀

Several participants claimed that their ability to freely choose their health care strategies or approaches was impeded by government:

> Oh they're taking privileges like you wouldn't believe, you know, it's becoming mandatory and you just won't get into the system if you are not vaccinated. *P. 4* ♀

Participant 11 was raised without routine childhood vaccinations, and now as an adult, desired to raise her own children unvaccinated, but vaccinated them out of what she described as coercion. She feels guilty about going against her beliefs. This participant was unaware of the conscientious objection form that can be signed for exemption purposes:

> I never like to feel that my choices have been taken away from me. I never like to feel like somebody is controlling me, so even like, health choices and the choices that I see as mine, for my children. I feel as though that has been taken away ... so the health of my children is not up to me, it's actually up to somebody else and I don't like that. *P. 11* ♀

> I hated it, and it used to get drummed into you. They would make these announcements that immunisation, yeah you're all doing the right thing, 'cause you won't get into day care, you won't get into pre-school, you won't get into school full stop. So it's almost like brainwashing. I was thinking, how do I get around this and I didn't know how I was going to get around it. I didn't have a choice. No, No. Fully to this moment I would say (vaccination) it is compulsory. I didn't know about that signing thing (conscientious objection form) ... I think it's a bit rude. I think it's a bit discriminatory that I have to sign something, I think it should be purely my choice umm, I don't think I should sign that away ... even then when you put it in those

> terms it’s not really a choice is it? Even though I can sign something, it’s a kind of forced choice. *P. 11* ♀
>
> I feel guilty, and I feel like I’m putting them through something utterly unnecessary, it’s painful, its stressful and they could get sick afterwards. It goes against the grain for me and there is an ethical grappling with it. *P. 11* ♀

As this participant described, some mothers experience strong feelings of guilt and responsibility in allowing someone to inflict pain on their infant. Brownlie and Leith (2011) also found that the mothers in their study expressed similar feelings of having to restrain the infant’s body and allowing someone to inflict pain on their child.

Streefland et al. (1999) predicted that the increasing vaccination schedule would bring about parental concerns that ‘experts’ are making decisions about their children’s health, without consultation or providing the option to exempt. Resisting the vaccine imperative, which is a public health programme, is considered by these authors a threat to state power and authority over individual bodies. Coercion is addressed as ‘the state’s right to coerce individuals to have themselves or their children vaccinated’ (Streefland et al., 1999, p. 1714). They argued that this level of coercion is considered acceptable to maintain herd immunity and safeguard public health. This argument raises issues of whether it is advisable to coerce individuals to go along with an invasive procedure that they do not agree with, for the sake of other people’s (orthodox) beliefs and values. People’s beliefs and values are significant in determining health belief behaviours: for example, many interview participants did not give credence to the concept of herd immunity. Hobson-West (2004, p. 89) contended that objection to vaccination was not simply about disease, ‘but a complex set of social and political responses to a political view’, the source of epistemology relating to their health care preferences.

Users of heterodox medicine were originally thought to be ‘refugees’ from orthodox medicine (Fulder, 1988, p. 30), but further research has found that many heterodox medicine users also utilise orthodox medicine if and when necessary and, most importantly, according to their own discretion (Kelner and Wellman, 1997, p. 211). Users of heterodox medicine were found to hold holistic health ideologies and employ health care alternatives because they were ‘more congruent with their own values, beliefs and philosophical orientations toward health and life’ (Astin, 1998, p. 1548).

The following quote raises the concept of the freethinking individual:

> If you're a free thinking person, there are reasons to be cautious, you know, and make that decision a personal decision, and not just go along with whatever the rage is at the time. So, I don't think that they can tell us that it doesn't have a negative impact, you know, how can they prove that? *P.* 5 ♀

Free thinkers are individuals who question vaccination, and are willing to take personal responsibility for their own health, in contrast to others that do not question what the doctor tells them to do (Hobson-West, 2005). This phenomenon has been labelled as 'passive acceptance' and contributing to high vaccine coverage rates:

> … people have their children vaccinated because everybody does so and it seems the normal thing to do. There are not necessarily deep reflections behind mothers taking their infants to the child health clinic. They do so because everyone else does, and because it is what good mothers seem to do (Streefland et al., 1999, p. 1712).

Rogers and Pilgrim (1995, p. 83) found that non-vaccinating mothers 'adhered slavishly to long periods of breast feeding' as a matter of health, emphasising healthy eating, and mental and physical components of health. Further to this, proactive health behaviours were found to be the preventative measure in which participants articulated their faith in building a strong immune system. Clark-Grill (2010) described 'alternative patients' as more health conscious than conventionally oriented people, being more careful with their diets, doing more exercise and focused on a healthier lifestyle. Mass childhood vaccination was not perceived as a means to prevent diseases. Participants considered a robust immune system to be their greatest defence and prevention against disease. Hobson-West (2004) noted that prevention is socially constructed, with the orthodox model considering vaccination an 'example of systemic preventative medicine' (Hobson-West, 2004, p. 91).

Several participants spoke about the importance of breastfeeding in developing a child's immune system. Dew (1999, p. 391) described a similar argument suggesting that 'mothers who have had "wild" measles confer immunity to their babies for some time through breast milk and/or the placenta'. This is in contrast to mothers that have been vaccinated against measles who do not pass on immunity to their babies.

Breastfeeding was viewed as a preventative, protective measure:

> I would be very worried if he (participant's baby) wasn't breastfed and unvaccinated, because umm like what would he do, he doesn't have all that stuff from me. So perhaps there is an argument for vaccinating babies that are only fed formula. *P. 2* ♀

> ... and breast milk has properties in it. I think it's a philosophy and that's kind of all linked up. what could be better for a baby than what nature designed, with the colustrum and of course then the baby is getting the immunity from the mother which maybe relates to babies that aren't breastfed and get whooping cough. *P. 5* ♀

With a desire to follow a certain holistic ethos in life and a need to fit into society, participants raised without routine childhood vaccinations, in this study, attempted to incorporate the two systems of medicine into their lives. They seemed to carefully negotiate the territory between their preferences for treatments for various conditions that supported the way that they conceptualised health and disease, and the options that were available to them. Clements, Evans, Dittman, and Reeler (1999, p. 90) declared that more people are turning to belief and value systems that support their concerns, 'mother earth, new age beliefs, homeopathy and other alternative practices'.

Hildreth and Elman (2007) found that a spiritual orientation is associated with higher use of heterodox medicine, with spirituality itself considered a very personal experience, emphasising the self (King and Koenig, 2009, p. 116), as is evident in self-reflection and meditation. 'Spirituality is the personal quest for understanding answers to ultimate questions about life, about meaning and about relationship to the sacred or transcendent' (King and Koenig, 2009, p. 116). The spiritual component in the aetiology and treatment of illness can play a significant role (Goldstein, Sutherland, Jaffe, and Wilson, 1988), and many participants associated their own experience with illness, including childhood contagious diseases, as having meaning linked to their belief and value ideology.

Fundamentally, spirituality is described as a personal search for meaning that contributes meaning to life. Williams (1998) developed insight into this meaning and value that may be related to an individual's beliefs about health and illness. These beliefs were hypothesised to dictate the type of therapy that health care consumers would ultimately choose. The holistic paradigm is noted as viewing illness as 'a disturbance of the unified functioning of the whole, not just an isolated cause and effect' (Williams, 1998, p. 1197), with ill health signifying an imbalance and taking on personal meaning for the individual

(Hobson-West, 2004). The gaining of meaning and changing lived experience were said to be a large attraction of the use of heterodox medicine (Barry, 2006).

Immunity

Immunity was an important sub-theme associated with Theme 1 – Beliefs and values, and closely linked to the main theme of Holistic life philosophy. Discourse on the developing or developed immune system was consistent throughout the survey and was raised by all thirteen of the participants that took part in the interviews. Participants believed that the immune system was capable of dealing with childhood diseases and other illnesses. Rather than trying to avoid illness, they were focused on maintaining a prime state of health, which was seen as their best defence against disease.

Participants discussed their views on immunity:

> I mean it’s kind of a whole attitude. I believe that there are negative impacts to having immunisations and obviously I think that the body needs to develop an immune system on its own *P. 5* ♀
>
> The symptoms we experience are not caused by something outside that are attacking us, but rather the body’s response to it. The immune system is sending us messages through our nervous system and causing these bodily reactions and that is a response to an outside pathogen. So, to interfere is to interfere with the body’s response to it, which is counterproductive. *P. 13* ♂

Immunity is a concern:

> Insulting the immune system by bypassing the first stage, which is via the respiratory tract; so injecting that straight into the body, I think is a bad decision. Your body never had time to prep and set the immune system up for the assault. Whereas, when a pathogen comes into the body naturally the body’s got time to build the white blood cells and form a response. *P. 1* ♂
>
> I believe that vaccines do more harm than good. The best immunity is good health. We are all carriers. We are all infected. You know most people have streptococcus throat bacteria in their bodies and most of the time don’t have sore throats, so most people are carrying all sorts of potential disease germs but don’t have the diseases. For infection to turn into disease, the body has to be in a state of physiological stress. *P. 13* ♂

Poland and Jacobson (2001) noted the results of a nationally recognised telephone survey of 1600 US parents of children under six. They reported that:

> 25% of parents believed that a child's immune system was 'weakened' by too many vaccines. Twenty-three percent believed that children got more immunizations than was good for their health, and 15% did not want their next child to get at least one of the currently recommended vaccines (Poland and Jacobson, 2001, p. 2442).

Scholarly, evidence-based, debate about immunology and the immune system is commonplace throughout the literature, the media and also within society. Various models of immune ideology exist, but the participants seemed to live by a holistic model, as opposed to the orthodox model. The orthodox model is based on the germ theory of disease (Hobson-West, 2004), described by Bedford and Elliman (1998) as viewing illness as caused by 'foreign invaders'. According to McKee (1988), the germ theory has provided a framework that promoted technology as the solution to disease. This point is significant as technology has been responsible for the development of antibiotics, vaccines and other drugs that were intended to combat pathogens (McKee, 1988). Diseased states often involve treatments that aim to 'fix' the diseased part of the body (e.g. surgery, drugs), addressing symptoms rather than the underlying cause of the disease (Hollenberg and Muzzin, 2010).

Hollenberg and Muzzin (2010) wrote about the epistemological challenges that arise from integrating orthodox and heterodox medicine. This is particularly relevant for the participants living in a society where they are negotiating between the discourses of what they are told by 'professional experts' and what is the socially acceptable standard, and what they personally believe. 'These (issues) signal important philosophical and epistemological tensions between biomedical and complementary/alternative knowledge forms' (Hollenberg and Muzzin, 2010, p. 35).

In contrast to the orthodox model, the heterodox, holistic model views the internal milieu as the most important element in achieving health. In the holistic model illness is considered an imbalance of the whole system (Williams, 1998) and treatments embody this concept. Heterodox medicine depends on this appreciation of immune competence. 'Even before the concept of an immune system was articulated, heterodox, vitalistic practitioners such as naturopathic physicians, maintained that disease should be treated by stimulating the ability of the body to heal itself rather than by treating symptoms' (Goldrosen and

Straus, 2004, p. 914). Moreover, heterodox medicine with its holistic model of vitalism – the innate energy (also called vital force, prana and Qi) – postulates that the cause of disease is a result of a lowered state of individual immunity or disease resistance, caused by an imbalance in the flow of 'life-force energy' (Tataryn, 2002, p. 885).

Fever is explained by participants as relating to the immune system function and significant in coping with childhood illness. These participants speak about the importance of allowing the body to go through illness:

> We do a lot of things to control our body's response when we need to actually let it rest. Fevers as being a transition, you know, going through a part of the development of the child you know, that they have fevers and they kind of umm ... mature through that... I think it's definitely a lot more that that too. I guess it partly comes down to having a bit more faith in the body. *P. 5* ♀

> I believe that childhood illnesses like chicken pox, measles, mumps and German measles are a rite of passage, and I think that umm the fever that happens as a result of those illnesses is really, really important. It's like a cleansing of sorts, so it's important for the child to go through it and fight through it and win the fight, rather than their symptoms being squashed by something and they don't have to fight and they sort of lay; wait dormant. *P. 2* ♀

In heterodox medicine, health is regarded as a valuable commodity, viewed as 'something holistic that can continually be improved by strengthening an individual's vital force' (Frank, 2002, p. 812). This is demonstrated in the participants who allocated considerable time and effort into their health, for the goal of wellbeing. This effort was evident in the everyday health measures that they employed to keep themselves healthy, such as purchasing organic foods, and avoiding processed foods. In addition, this effort was apparent in the self-learning that they all engaged in. All interview participants spoke about the research that they had done, in order to learn more about a particular issue, for example travel vaccines:

> So far I have only been to Europe and New Zealand, so I didn't feel they were necessary, but now I am planning a trip to India. I will look into it, although I don't think I would get it. However, I will get myself informed before I make a decision. *P. 8* ♀

The participants attested to their high levels of knowledge, but apart from holistic paradigm it was unclear exactly on what they were basing their decisions. It is important to acknowledge the large controversy between orthodox and heterodox medicine about the source of 'information' in which the knowledge has been derived. There seemed to be some suspicion amongst participants regarding orthodox information, along with describing themselves as informed about health. More research is needed to determine the true nature of this dichotomy.

Overall, survey participants exhibited an interest and knowledge about certain health issues, making comments about diet, exercise and where they had derived their health knowledge. There were several comments that indicated an awareness of what the ideal health principles were, even though admitting to not always stringently following them. They seemed knowledgeable about healthy behaviours and principles.

> I have read widely and cannot see the benefit to vaccinate – there are however many dangers with vaccinations. *P. 12* ♂
>
> I have followed the dietary guidelines of the Natural Health Society of Australia for the last 43 years. I am sure that this excellent nutrition gives me the best immunity of all. *P. 13* ♂

In terms of the research that participants engaged in, the majority mentioned books as their main source of information, also family and the Internet; a couple of participants mentioned research articles. The source of the majority of participants' information may not be considered an appropriate 'scientific' source of knowledge. Alfredsson et al. (2004) found that parents with unvaccinated children used more sources of information to expand their knowledge but interestingly also found that few parents, both with vaccinated and unvaccinated children, had acquired vaccine information from the Internet.

Several participants discussed their source of knowledge, displaying an interest in reading about health information from books:

> I love to read all about alternative health, and subscribe to great magazines and websites. I love the work of Andrew Moritz, Dr. Sandra Cabot, Mike Adams, Gerson Institute and lots of other great health experts. *P. 12* ♂

This next excerpt mentions research articles, as did a few others, but no one referred to scholarly peer reviewed journals as their main source of information.

> Started with Adele Davis – her book in the 60s – seemed logical – sensible –did further study – read many research articles – did my degrees – lectured in clinical nutrition – basic science. *P. 13* ♂

Their focus was on ensuring that the immune system was strong in order to deal with any subsequent diseases that they or the child may encounter.

The next participant talks about how she can protect her children:

> I can make sure that they're really tough. That their immune system is up and running *P. 11* ♀
>
> I meditate ... I make sure that's the first thing I do after I have a bit of fresh juice, through the juice extractor, in the morning and um and I eat clean organic food ... I exercise regularly *P. 9* ♀

Hobson-West (2003) argued that some vaccination resistance is based on a different view or understanding of health and disease, which Martin (2000, p.135) found to be related to choosing 'positive health', rather than just a refusal of vaccines. In addition, febrile illnesses were proposed by Rudolf Steiner to be related to a child's spiritual development (Hanratty et al., 2000). Six of the thirteen participants had attended a Steiner school.

Childhood diseases are normal

The next sub-theme under Theme 1 (Beliefs and values) that emerged from the survey and the in-depth interviews was that certain childhood diseases were normal. With this construct, childhood diseases were not avoided; on the contrary they were seen as a necessary part of life. For some participants the idea was profound, in that their holistic philosophy supported their ideal that diseases facilitate a maturation phase within childhood, with benefits to the immune function as well as an emotional maturation. This holistic philosophy can be likened to anthroposophical ideology, where contracting a childhood disease actually may be seen as an opportunity for the child. Other participants in this study did not have such an anthroposophical philosophical perspective, but still described believing that childhood diseases were an acceptable part of childhood. McMurray et al. (2004) also noted that parents that declined vaccinations perceived childhood diseases as 'relatively mild treatable and natural – something that the child would survive and even benefit from' (McMurray et al., 2004, p. 522).

Interview participants constructed certain childhood diseases as a normal part of childhood. Participants considered that contracting childhood diseases, such as measles and chicken pox in childhood, was an opportunity for the child's development, with all of the participants mentioning the associated immune development perspective. Rather than introducing what is perceived to be unnecessary foreign substances into a child, there is a firm belief that childhood diseases are ultimately important to a strong, effective and healthy body.

These excerpts reflect participant's views on the normality of experiencing childhood contagious diseases, in childhood:

> By the time we were grown up friends were having children and mums could see that they were getting diseases anyway, like we all had chicken pox and (brother) got mumps and measles, but it was just never a big thing. It was like the old fashioned thing was that it was good to get an illness. *P. 6* ♀

> When I was a kid we all got measles you know, my friends, my cousins that I was growing up with, and all of the people that I was growing up with, we got all of these things and you know we rested, and our parents nursed us, you know, and we got better. *P. 5* ♀

> I see sickness as just a normal part of life in terms of if you get a germ, you get a germ and it does something to you, but I still think that that can be alleviated or mitigated, so much by our general health and that includes mental health, umm so yeah, it prevents a lot of that from happening in the first place. I'm not scared of my children getting sick. I'm quite confident that they'll get over stuff because they're healthy. If they're a bit weary, they will have a rest. *P. 11* ♀

The following excerpt describes how this participant is concerned that her children will not have the chance to be exposed to childhood diseases:

> Everyone just got it, and I think that it made us stronger getting those illnesses, so umm I am concerned now that everything is being eradicated. I worry if my kids get it when they're older it could have more of a negative effect. I think it's supposed to be sort of strongest when they're older, so umm I don't know whether they'll get it and my oldest one is about to turn 10 so, probably about time he got chicken pox I think. *P. 5* ♀

This participant reflects on being raised without routine childhood vaccinations:

> To experience growing up without interference from drugs and medicine and be perfectly healthy ... gives me a perspective that it's quite possible, and normal and natural, without all of that stuff. So now as an adult and reflecting on it, I can see that there are some remarkable things there. Growing up I didn't know any difference. It was normal. *P. 1* ♂

> It was just never a big deal. At 'Lorien' (Steiner school) it was not even spoken about, it was never questioned. It was normal. *P. 6* ♀

> I've been brought up that way so that was normal to me. *P. 8* ♀

Interestingly, all but one of the interview participants had experienced a childhood contagious disease. The literature refers to parents that choose not to vaccinate their children as being unaware of what childhood contagious diseases are like, hypothesising that they have not experienced them. Several participants described three to four diseases, most commonly chicken pox, measles, mumps, rubella and/or whooping cough that they had experienced themselves. The one participant that had not had any childhood diseases was homeschooled and therefore had far less exposure to other children and other people and to childhood contagious diseases.

The adults in this study had for the great majority experienced many of the childhood diseases, including measles, mumps, rubella, whooping cough and chicken pox. However, polio and diphtheria had not been experienced.

> I did end up with chicken pox, and I did end up with measles, and I did end up with German measles (Rubella). Mind you, very mild doses. *P. 2* ♀

> Well basically we were hardly ever ill. I have had measles, I just stayed home from school, stayed in bed, kept warm, had lemon tea and you know, got rid of it. I think with all of us, when we got anything at all we rested. *P. 3* ♀

> We had chicken pox and mumps; we had that. *P. 10* ♀

> I can remember one Easter and I had whooping cough and everyone was getting Easter eggs and I had to stay in bed (laughs), feeling a bit sorry for myself. As you get older you realise that you might miss out this time, but next time it will be someone else. *P. 10* ♀

Model of least interference

The third and last sub-theme under Theme 1 (Beliefs and values) is the concept of 'least interference'. In an effort to adhere to the commitment associated with participants' personal beliefs and values, a model of least interference was followed. This model translated to an avoidance of orthodox medicine whenever and wherever possible.

Ayers and Kronenfeld (2012) found that individuals who delay seeking orthodox care are more likely to be users of heterodox medicine, which may add validity to the model of least interference. As a result of this feeling of uncertainty, many individuals would rather not interfere by taking ‘unnecessary medicines’ (Jewell, 2001, p. 875). The avoidance of vaccination in these communities was determined by Hanratty et al. (2000) to be more than a refusal to accept conventional medicine. It has been viewed, particularly in the case of measles, as a positive opportunity for the child to benefit from the illness itself. Children that were unvaccinated because of parental choice were found to have significantly lower utilisation rates of emergency department and outpatient settings, in comparison to children who were vaccinated according to the routine vaccination schedule (Glanz et al., 2013). Glanz and colleagues (2013) suggested that these results reflect the inherent health care-seeking behavioural differences between the two different groups of parents, noting that children that had not received all of the recommended vaccines appeared to have different health care utilisation patterns compared with age-appropriately vaccinated children.

In this study, orthodox medication, such as antibiotics, analgesic, anti-inflammatory medication were viewed as a disruption or a disturbance to the normal functioning of the body and health system, participants preferring to use of natural remedies, and no or minimal use of pharmaceuticals and orthodox practitioners, and no or minimal interference during birthing. This finding was noted in the survey and confirmed in the interview results.

> Whenever the doctor said, just give them some panadol, I never did and you know I probably just gave them a bit more fluid that day, but I’ve never given my children panadol or anything like that. *P. 10* ♀

> To me, I don’t like the idea of vaccinating in case. Interference or intervention for the sake of it, is crazy. Let the body do what its designed to do. *P. 5* ♀

> I think that some diseases can be a bit of a double edged sword; on the one side you have this idea that challenge builds strength, and so if we challenge our immunity, we expose it to pathogens and our immune system learns from that and develops a strong robust immune system. The other side of the sword is that when you provide a crutch for something, it weakens, so the way I tend to look at the idea of taking a drug to prevent some kind of thing happening is like a crutch. It’s like putting a perfectly healthy leg in a splint just in case you are going to break your leg. But as a

> side-effect to that, your leg atrophies, because it’s got a crutch so you actually inadvertently weaken that by trying to be over-protective *P. 1* ♂

This next excerpt describes a technique that employs wet socks to control high temperatures. It was utilised in order to bring the fever down to a safer level and therefore avoiding the need to give the child ‘panadol’:

> We’ve never had to take the kids to hospital except when my son broke his arm, but that’s what you do with something acute like that. Only one time when (daughter) had a really high temperature. I’m not sure where I even heard of it, but we put some wet socks on her. Brings the heat down from the head, changed the delirious behaviour and that’s all it needed to get it down a bit. *P. 1* ♂

All of the thirteen interview participants spoke about how they had employed natural remedies at some point and avoided pharmaceuticals:

> I’m not prepared to go down to the doctor every three months and get a prescription. *P. 12* ♂

> I use olive leaf extract and you know we give them vitamin C, zinc, echinacea and you know combinations of different remedies like that *P. 5* ♀

> There are instances when antibiotics may be called upon ... but if he gets a fever there is no chance in hell that I would give him panadol. I believe fevers are really necessary and there is a lot of ho ha oh it’s one degree over ... no it’s garbage. My resting temperature is 35.5 that’s abnormal, but it’s normal for me. I would use natural remedies. *P. 2* ♀

> My inclination if I am feeling sick, well damn it, I’ll stay in bed. I’ll let my body cope. I won’t just pop a panadol and say yea I’ve got to go to work and push on. If my body is giving me some severe headache or some severe gut problem, it’s sending me a message that I need to rest and I need to recover. *P. 1* ♂

The model of least interference included avoiding the doctor if and when possible:

> I work in health and my instructions to my staff are if I hurt myself at work, don’t send me to hospital, get me home. Pretty much, I know that sounds ridiculous but umm yeah. I accept you know, it’s not like as though I wouldn’t use conventional medicine. I just choose not to be part of it if I don’t have to be. My mother was pretty keen about not attending the doctor. She never attended the doctor and I don’t. I still don’t have a treatment doctor I’ve got to tell you, I’m 64 going on 65 and I don’t have a treating doctor. *P. 4* ♀

> I suppose the one thing that does stand out is that I've never really had a family doctor that we went to as a regular thing. Umm I know that a lot of people do have a particular doctor that they go to and rely on, umm. *P. 12* ♂

> We didn't have a family doctor and I don't remember any of us going to a family doctor. *P. 3* ♀

Interference in birthing is raised by two participants and used in their argument of avoiding orthodox interference:

> It's unusual to speak to someone that hasn't had a caesarean, which is worrying. Or some kind of interference, tearing, forceps ... a lot of women having negative birthing experiences so ... I think that's because we're not allowing the body to do what it naturally does. You know we're just trying to get in there and interfere with everything and it just leads to more and more complications in my view. So I think we need to step back a little bit and let the body do its work. Support it, you know, have a nutritious diet, have a good lifestyle, look at all of those aspects and just sort of step back and let the body have a bit of a go, before we come in and try to sort of interfere ... so I think it's a philosophy and that's kind of all linked up. *P. 5* ♀

Talking about the birth of his child, this participant's baby was born badly bruised and the medical staff wanted to administer a vitamin K injection:

> [I said] 'It's (been) five or six minutes since he was born. His bruising is less than it was when he was born. So let's just give him a few minutes, let's just give him a chance and see how he does, and if he's improving then let's just let him keep improving and not interfere' and they couldn't argue with that. It took my ability to reason with these medicos and nurses and he improved. *P. 1* ♂

This excerpt demonstrates health as a great priority for this participant. Several participants spoke about how they nursed their own children at home with childhood illnesses, however those conditions were often not medically diagnosed:

> They've been sick with various things, actually I would be really interested to have a blood test and see what they do have immunity to, because I don't really know what they've had, like you know maybe whooping cough. *P. 5* ♀

> I think the kids have all had whooping cough but we have not had it confirmed by any medical tests or anything like that. *P. 6* ♂

> He was born about there [pointing to the centre of the room], in a pool. So there was absolutely no chance I was ever going to go to hospital to have a baby unless there was a really serious medical reason. *P. 2* ♀

These participants were advised to have a tetanus injection by an orthodox practitioner following an injury:

> They wanted to give me a tetanus shot (laugh) but umm that was when we found out that whatever it is [the vaccine], was out of date and we had to go to Hornsby hospital and wait there for hours and it was out of date too. In the meantime mum was reading that they can't actually guarantee that blood borne diseases won't be transferred and she went oh right, we're going home! (laugh). *P. 8* ♀

> I had a rusty nail in my foot. I always went everywhere in barefoot and the fact that it was rusty. It might have been dad actually, he was more conservative, took me up to the doctor and I don't think there was even a question of would you like me to give you a tetanus shot it was just you had it. *P. 11* ♀

> I was walking home and one of the dogs came out hidden behind a car and it came out and just bit me and it gave me such a shock, because I had to because it was covered by work, you had to have tetanus shots. I'd better you know, in case of repercussions. I think Council has a legal right if there are any problems for people that haven't, they won't pay out and that sort of thing. *P. 10* ♀

When asked about whether there were reservations in the administration of the tetanus injection after having had an injury, one participant explained:

> No not then. Not with tetanus ... all I knew is that I had a hole in my foot and it hurt like hell and the idea of tetanus was pretty scary. *P. 1* ♂

In cases where participants may have had direct contact with the tetanus bacterium, for example an animal bite or a direct cut to the foot, the tetanus vaccine was often utilised. As discussed in the survey many participants considered the tetanus differently to other diseases. In all cases participants had sought orthodox advice following an injury and were given a tetanus injection. There seemed to be more of an acceptance of it when they considered that they had possibly been exposed to it.

It is important to explore the reasons why tetanus may be considered somewhat differently. Firstly, tetanus is not a childhood contagious disease so may be viewed differently, since many of the childhood diseases were linked to the philosophy of developing the immune system. Secondly, tetanus usually results from contamination of a wound with the spores of Clostridium tetani (Gidding, Backhouse, Burgess, and Gilbert, 2005) unlike other childhood contagious diseases, like measles, that enters via respiratory droplets (Endelson, 2012). Thirdly, unlike other diseases, tetanus is not spread from person to person, but is found in soil, and human and animal faeces (Thwaites, 2002). In anthroposophical families most children are only vaccinated against tetanus and polio (Alm, Swartz, Gunnar, Scheynius and Pershagen, 1999).

All thirteen of the interview participants expressed a preference for the model of least interference:

> Like if I've got a cough or something that's not moving, I would go through the herbs and then they could say if that doesn't work then I could see the doctor ... in the end you may have to go to the drug treatment. *P. 9* ♀
>
> People don't believe that the disease could actually be a good thing. People don't see illness and your body processing things as actually a positive thing ... but you've got to have the bad in order to appreciate the good, I think. So if people thought actually it's no big deal if my kid gets chicken pox yeah OK they're sick for a while but they work through that, and they're better, so that they don't catch more serious diseases. *P. 2* ♀
>
> It seems to me that our medical kind of attitude is more about let's get rid of the bugs. Let's kill the bugs. Not, let's make our body stronger so that it can kill the bugs. That's really the problem. Antibiotics and antibacterial everything and get rid of all the bugs in your house and all that stuff. And it's like hang on, our bodies really need to come into contact with these bugs so that we can you know ... process them and the same as panadol we take that to try and get rid of the fever as well. We do a lot of things to control our body's response when we need to actually let it rest. *P. 5* ♀

The model of least interference is commonly misunderstood as an act of being irresponsible, selfish and of rejecting orthodox medicine. Society, as well as much of the literature, has judged non-vaccinators harshly for this behaviour (Dew, 1999; Brownlie and Leith, 2011; Hodge and Gostin, 2003; Ashton, 2004). This judgement demonstrates a failure to understand the fundamental core values and beliefs of heterodox medicine that 'health and healing are individualistic processes' (Baer and Coulter, 2008, p. 334). Therefore, decisions based on health are made according to these holistic principles, which include a different view of health and illness. Participants in this study used orthodox medicine if and when necessary, but avoided it whenever possible.

Comparably, heterodox nurse midwives in the Shuval and Gross (2008) study were willing to use technology, if and when necessary, but avoided it whenever possible, '(t)hey do not deny the usefulness of orthodox medicine, but they challenge its hegemony via alternative systems of knowledge and practice', as technological control was believed to interfere with the birthing process and depersonalise women (Shuval and Gross, 2008, p. 48).

Summary of Theme 1 – Beliefs and values

This section has reviewed Theme 1 – Beliefs and values, or life philosophy, of interview participants and found that they reflected a holistic epistemology. These beliefs and values were strongly linked to the interview participants' perceptions about three important health care issues: immunity, that childhood diseases are normal and adherence to the model of least interference. Participants had been raised with this fundamental holistic ideology, as was evident in the way that they articulated their life experiences, their views on immunity and childhood diseases and in their avoidance of what they perceived to be unnecessary orthodox interventions.

In Martin's discussion 'accepting vaccination means accepting the state's power to impose a particular view about the body and the immune system – the vision developed by medical science' (Martin, 1994, p. 194). Participants' beliefs and values, or holistic epistemology, were aligned to the perception of interconnectedness of the human body, mind and spirit, and consequently determined their thought process and reasoning, which in turn impacted their sense of personal responsibility.

Theme 2 - Personal responsibility

Personal responsibility was a theme that was consistently raised and reflected upon by participants in this study. Participants felt a strong sense of responsibility for their own bodies and for what they allowed to happen to their own bodies. This responsibility extended to what they ate and drank, when they exercised and what medicines and therapies they utilised.

Participants described their personal sense of responsibility for health care decisions and choices for themselves and their children:

> I support myself. I work for myself and have all my life. I believe in personal responsibility and personal accountability, not just for my own income, but also for my own health and for my own lifestyle. So you know, whether the government does or doesn't, I don't really care to be honest with you. I'm not going to turn around and vaccinate my kids and expose them to all that risk just because I'm going to miss out on $25 a week, (laugh) who gives a crap. *P. 1* ♂

> So you kind of have to take responsibility. I think it’s an issue of people taking responsibility for their own health. In general Western society today, we rely on doctors and other health care practitioners. We think that they can actually fix us, (umm) and being unvaccinated, that’s taking responsibility for your own health … so, being aware of how my body operates and how it functions and what it does and how it reacts to certain things and noticing that and doing things.like what I eat, or what I take into my body, in order to keep the balance. *P. 2* ♀
>
> I do question, and I do like to understand what it is I’m getting involved in. I know that I am responsible for the decisions that I make. I don’t need some clown to tell me that, I know that. And so I take my decisions very seriously, right or wrong informed or not informed. I’m responsible for, and what goes into my body, I’m responsible for it, and no one can force anything on me. *P. 12* ♂

This next excerpt describes this participant feeling overwhelmed by the responsibility she felt towards the health of her own children as at the time they were living in an isolated area with few heterodox practitioners that she could turn to for support:

> There were times when I wished I was like the other people and would just go to the doctor and put all the responsibility on the doctor (laugh) because you know that is the biggest thing and especially in those days, there were very few naturopaths around ... It’s just that I believed in it myself and that made me keep on with it, because it would have been so much easier just to be like other people. *P. 9* ♀

This next participant describes that responsibility is often transferred:

> I think with a lot of things we tend to abrogate our responsibility for our children and I think we like to legislate the general population, the social conscience likes to have things legislated so that those things are no longer our responsibility. I don’t actually believe that. I believe that I’m responsible for my children. I am responsible; I take great responsibility. *P. 11* ♀
>
> They didn’t believe in relying on the medical system (speaking about his parents being responsible). *P. 12* ♂

Minkler (1999, p. 121) provides an account of the contested meaning of ‘personal responsibility for health’. Ideological and political controversies have asked whether the individual or the broader society should be held responsible for personal health behaviours. Responsibility has been differentiated between individual and social responsibility in the debate over health promotion and personal responsibility for health.

> The dominant view of health promotion in the United States today emerged in the 1970s in response to a growing disillusionment with the limits of medicine, pressures to contain health care costs, and a social and political climate emphasizing self-help and individual control over health (Minkler, 1999, p. 123).

Interestingly, at that time, Minkler notes that individual responsibility for health was the focus and was not accompanied by community or social responsibility. Modern health promotion emphasising reciprocity and social responsibility as in the notion of herd immunity is a new approach to health promotion. Both integrative medicine and heterodox medicine focus on empowering individuals to ‘actively participate in and take responsibility for their health and wellness’ (Bravewell Collaborative, 2009; National Center for Complementary and Alternative Medicine, 2009; Pelletier, Herman, Metz, and Nelson, 2009; Weil, 2009), with the acceptance of personal responsibility, an important facet of heterodox use (Nahin, Dahlhamer, Taylor, Barnes, Stussman, Simile, Blackman, Chesney, Jackson, Miller and McFann, 2007; Barrett et al., 2003; Gray, Tan, Pronk and O’Connor, 2002; Siahpush, 1999; Kelner and Wellman, 1997).

Personal responsibility was associated with participants’ sense of commitment to take care of their health. This sense of commitment and accountability has been established in the literature as fundamental in the use of heterodox medicine. As Miskelly (2006, p. 55) noted, heterodox medicine is ‘predicated on the notion of personal responsibility in relation to the patient’s role in health and illness’. Pawluch, Cain and Gillet (1994, p. 65) also found personal responsibility to be an important factor in alternative ideology, where there was ‘an emphasis on personal and individual responsibility over all health care decisions’. Personal responsibility is particularly relevant in vaccination discourse, as a high level of responsibility does not align with the model of mass childhood vaccination (Pilgrim and Rogers, 1995). Vaccination was linked with disempowerment and a ‘quick fix’ or, as Dew (1999, p. 381) noted, ‘magic bullets’, whereas the holistic approach to health was considered to be an authentic approach to personal responsibility (Hobson-West, 2007, p. 210). Participants in this study had similar perceptions on personal responsibility.

In mass childhood vaccination programmes government policies heavily influence and support the vaccination imperative within society (Hobson-West, 2005), raising ‘conflicts about where the boundaries of responsibility (and power) lie’ (Hobson-West, 2004, p. 93). This conflict of autonomy, power and personal responsibility has been challenging for participants negotiating their health care choices between heterodox and orthodox medicine.

Healthy lifestyle and proactive behaviour

A sub-theme associated with Theme 2 – Personal responsibility was healthy lifestyle. The right to make their own choices in accordance with their own moral values was paramount to participants. As proactive individuals, any action reflected on their strong sense of autonomy and personal responsibility. Lowenberg (1992, p. 37) conveyed the importance of autonomy to heterodox medicine: 'The autonomy of the patient is considered paramount and therefore it is implicit upon patients to accept responsibility for decisions they make, and the resulting impact these may have on their health' (Lowenberg, 1992, p. 37). The term wellness is defined as 'akin to health promotion and primary prevention through a healthy and natural lifestyle, and includes the variety of ways people strive to flourish in their daily lives' (Kannan et al., 2010). Further to this, O'Connor (2002, p. 55) succinctly described the priorities of an 'alternative patient' noting that:

> they have health needs that go beyond what conventional medicine does or can provide, they wish to multiply their preventive and therapeutic options, they have reasons to believe these therapies may be useful, and/or they have philosophical and experiential reasons to find them attractive and reasonable choices.

This next excerpt demonstrates how this participant feels that her ability to make choices is being minimised and silenced:

> You know, doctors are Gods and we can't take responsibility for our own health and wellbeing and I think that focus needs to be reversed. Doctors need to start listening more to their patients, and allowing them to take more responsibility for their health and not giving the impression that a doctor can fix everything because they can't. And it would be really nice if health care practitioners understood that principle, rather than saying ah I'm the doctor I know best. You shut up about your own body. *P. 2* ♀

The holistic approach to health is recognised as requiring personal effort (Kannan et al., 2010), where the state of an individual's health can always be improved (Hobson-West, 2004) and health is seen to be a state where all systems are in balance. Coulter (2004, p. 114) described this holistic approach to health, '(h)ealth is not seen as something that is given by the provider to the patient (health comes from within or not at all). It is seen as an achievement of the patient and the provider both, facilitating the body's innate ability to heal'. Therefore, health is approached as an action, rather than an inaction, unlike orthodox medicine which 'requires relatively little effort from the patient' (Kannan et al., 2010, p. 731).

Healthy lifestyle and proactive behaviours were evident in the participants in this study. This health behaviour may also be termed 'health effort'. Hildreth and Elman (2007, p. 98) referred to 'ideologically-based health efforts' associated with heterodox medicine. Health effort was described by these authors as the level of commitment required in using heterodox medicine, incorporating and adhering to certain health measures and health care strategies, such as special remedies, meditation, physical therapies, and learning special food preparation. The proactive role in maintaining health included a propensity to incorporate everyday decisions that perpetuated health, by means of a salutary diet, a commitment to exercise, meditation and positive lifestyle choices. Passive behaviour is incongruous with this proactive, holistic paradigm (Goldstein et al., 1988), although 'health communication in general assumes an audience which is ignorant and passive' (Tulloch and Lupton, 1997, p. 32).

Great importance was placed on maintaining a healthy lifestyle in order to keep the body and particularly the immune system functioning well. Participants raised the point of eating well in the survey and also in all of the interviews. This finding is in keeping with the literature. Kannan et al. (2010) noted that heterodox users were more likely to follow healthy lifestyle protocols and have a commitment to 'wellness' with several authors finding that, compared to conventional patients, these clients were more likely to engage in physical activity, monitor their diet, and recognise the importance of adequate sleep, stress reduction, and relaxation in maintaining good health (Nahin et al., 2007; Kelner and Wellman, 1997; Furnham and Forey, 1994; Furnham and Bhagrath, 1993; Furnham and Smith, 1988).

> The health of my children is more important to me. I mean we buy organic veggies, we go out and we spend money on getting good quality, organic, Australian, local produce through the local co-op, instead of going to Coles or Woollies, where we don't know where there stuff comes from or what its been sprayed with. So you know, we do take the health of our family very importantly. I mean we probably spend double what other people spend, but we're buying good quality stuff. *P. 1* ♂

> We sort of feel as though by staying healthy we give our own immune systems the best chance to fight off illness. *P. 3* ♀

Apart from following a healthy diet and lifestyle, participants carried this healthy living concept through to encompass everything that entered their bodies or to which they might be exposed. The uses of pharmaceuticals or orthodox procedures were not considered lightly and were often only employed after attempts with natural remedies.

Healthy lifestyle protocols or health promotion programs derived from ‘the rhetoric underlying neo-liberal and individualistic discourses now permeates the direction of health policies’ (Miskelly, 2006, p. iii). This healthy lifestyle protocol, common in the mainstream literature, espouses the view that patients have a responsibility to be healthy by adhering to the following protocol (Miskelly, 2006, p. 99).

1. Eating a healthy and moderate diet.
2. Not smoking or using other ‘recreational’ drugs.
3. Avoiding an excessive alcohol intake.
4. Maintaining an exercise programme.
5. Reducing stress.

Participants’ views on responsibility differed from this protocol. Participants viewed all health care matters, options, and decisions as their responsibility, emanating from these general guidelines but not exclusive to them.

Social responsibility

Social responsibility has different meanings for different people. Bunton Nettleton and Burrows (1995, p. 45) noted ‘the dominant techniques and values of health promotion and public health are congruent with capitalism in that they are elitist, individualistic and ideological’ (Rodmell and Watt, 1986; McQueen, 1989). Health promotion messages have been contradictory in that they have promoted individualism and active self-care, but more recently have imposed a discourse relying on the duties of citizenship to foster conformity to mass childhood vaccination (Dew, 1999). Poltorak and colleagues (2005) found that mothers stress the particularity of their child and because of this do not see their vaccination decisions as any one else’s business. Further to this, these authors describe that vulnerability to disease or to vaccine adverse reactions is seen as influenced by individual characteristics, including diet and hereditary factors. Hobson-West (2003) noted that this is in contrast to the way that health promotion material is presented; in epidemiological data, ‘risk is individualised or personalised’ (Hobson-West, 2007, p. 199). Luthy, Beckstrand and Peterson (2010) added that parents wanted to feel as though their child’s health care was individualised. Further to this argument, the dominant discourse consisted of ‘best interest’ decisions, which focused on what was best for the child. Parents are now expected to consider what is best for the whole community.

The new public health has employed ‘the discourse of empowerment and participatory methodologies to promote health citizenship’ (de Souza, 2011, p. 25). Critics have argued that the new public health puts pressure on individual citizens to be responsible for their own health and health care, while the role of the state in the provision of health care services and healthy environments is diminished (Zoller, 2005; Laverack, 2004; Petersen and Lupton, 1996).

Non-vaccinators have been accused of being individualistic and unconcerned for the good of the community. This may not be a fair representation of this group and may add to the stereotyping and stigma that divide communities.

Participants viewed social responsibility as depicting a different meaning when compared to mainstream notions of social responsibility. Mass childhood vaccination did not fit into their definition of social responsibility and was linked to not following the crowd.

Participants were asked how they felt about being socially responsible and the social imperative to vaccinate children.

> No, I don’t think so; it’s a lot more than vaccination. If you were going to have a social conscience about anything it should be about health, cause we like a quick fix or a tablet for something and I don’t agree with that either. *P. 11* ♀

> It sort of makes me a bit angry ... maybe some people have faith in the government, in the pharmaceutical company to just control their health, but for me I don’t really think what they are doing is in our best interest, umm and I think you have to make your own decisions and to have them sort of want to control everyone ... I don’t think that is fair and I don’t think the view that we should all be vaccinated is an objective opinion taking everything in account. *P. 4* ♀

> A friend of mine works for a pharmaceutical company and used that similar argument on me in relation to vaccinating and we got into the conversation about

> population like where a certain percentage of the population have to have vaccinations in order for it to be effective, but I just said this is totally unproven
> *P. 2* ♀

This next participant views breastfeeding and healthy diet as the responsibility of the parent:

> The diet of the parents is paramount to the health of the child. And of course breast feeding, which then protects the child. *P. 6* ♀

Much of society, government, and mainstream health have promulgated the imperative to vaccinate children. Although there is much rhetoric supporting the role of the individual in vaccination and what some might consider a social responsibility, vaccination has come under scrutiny. Social and personal responsibilities are not always in alignment, and represent varying goals that different people may view as worthy or unworthy of seeking out. The government for example, would perceive vaccine uptake to be a socially responsible action, which is for the 'common good' (Quadri-Sheriff, Hendrix, Downs, Sturm, Zimet, and Finnell, 2012). Individuals may not agree, and regard social responsibility as encompassing other factors, such as taking care of one's own health, or not overusing antibiotics (Patrick and Hutchinson, 2009). As Dew (1999, p. 383) noted orthodox medicine establishes 'goals that allow for no dissension', and sets a precedent that condemns individuals that object to a procedure that is proclaimed as good for the whole community (Dew, 1999).

Conflicts arise within society when the boundaries of 'responsibility' are not in alignment. Skea et al. (2008) discussed the role of being socially responsible to other children in the community, by ensuring that children are vaccinated and contributing to herd immunity. Skea et al. (2008) found that the idea of being socially responsible impacted some parents that participated in their study, and in turn affected their decision-making. Although avoiding harm to their children was paramount, they had a keen desire to do what was right to protect other children.

In contrast, in this study participants were asked how they felt about being socially responsible in regard to vaccination. Participants felt that social responsibility had nothing to do with vaccinating their children. Participants described responsibility as equating to being proactive about individual health in terms of making healthy lifestyle choices, rather than being about having a vaccine.

> The body does not need antibiotics or vaccines or anything else, if it gets sick it will self-heal as long as the disease is managed correctly by resting and fasting and so on and always drinking water. *P. 13* ♂
>
> Most important are diet and breastfeeding... *P. 6* ♀

Summary for Theme 2 – Personal responsibility

Personal responsibility was a tremendous influence on the participants in this study. As participants reflected upon their life experiences and choices that were made, from past to present, their strong sense of personal responsibility impacted every aspect of their lives. Autonomy, social responsibility and healthy lifestyle choices were central to this theme. Predominantly, interview participants held a strong sense of personal responsibility to make autonomous, socially responsible health care decisions and lifestyle choices. They described a proactive healthy lifestyle and spoke about their ability to navigate meaningful health care choices that they made for themselves and for their own children.

Theme 3 – Choices

Choices were observed to reflect a conscientious individual who feels personally responsible for actions and or inactions regarding the many health care options in their lives. This individual feels the need to be an expert about health care options, risks and long-term sequelae of health care decisions.

Participants said that the orthodox doctor was not their only source of information:

> I take my decisions very seriously, right or wrong informed, or not informed. One of the biggest changes that has occurred, like in my parents' generation; they looked at the doctor as the right hand man of God, but they were only given selected information. It opens up this possibility for people to select information that suits their ends and it can bias the outcome. *P. 1* ♂
>
> I mean people just blindly go into immunising their children because we're told that its eradicated all of these diseases and I'm like okay, can I have some proof of that please, can you show me some research, some documentation. I'm a person that will go looking for it for myself, being a research type person as well, I'll go looking for articles. *P. 7* ♀

These participants illustrate how they investigated for themselves:

> Vaccination is a highly emotive topic, but for me I've weighed up both sides and I think neither are wonderful options, but you've got to choose one and for me this is the one that felt most right. That I think is the way. *P. 5* ♀

> It was a difficult decision, but it's certainly one that we didn't take lightly. We took some pretty heavy consideration to it. I went out and purchased half a dozen different books, pro and against vaccination and read them all, and tried to apprise myself of the current understanding, as much as possible with an understanding from a layman's point of view. Umm so we certainly didn't make the decision blind, I read what I could and made the decision from there. *P. 1* ♂

The smart health care consumer is someone who draws on a variety of resources in the search for better health and personal growth (Kelner and Wellman, 1997). These health care consumers prefer to use their own discernment to make health decisions; their decisions are made as concerned consumers rather than compliant patients (Kelner and Wellman, 1997). Cassell et al. (2006) similarly found that mothers in their study who chose not to vaccinate, were well-informed individuals who had an interest in issues related to health. In contrast, McMurray et al. (2004) found that for parents, the decision on whether or not to vaccinate did not reflect an informed choice. These commentators described most parents in their study as having received no information prior to their scheduled second dose vaccination. Moreover, parents reported that official information was uninformative and unreal. McMurray et al's interpretation bore some resemblance to some of the participants' comments who described their feelings of frustration when trying to gain information to make an informed decision:

> … people want objective information, untarnished by any vested interests. *P. 13* ♂

> Knowledge is kept and not shared. *P. 7* ♀

> There's no education, there's no evidence. It's insidious ... government and health kind of works like ... I have this special knowledge and I am happy to share that knowledge as far as I'm prepared to share it. The whole sort of power thing ... Knowledge is power. *P. 11* ♀

One participant in this study, who had just had a home birth, mentioned the health pamphlets that she had received:

> I got a flyer from Medicare in the mail. It was information about whooping cough that the Department of Health would like parents to know. It wasn't about whooping cough at all. It was just about vaccinations, it didn't actually give any information

> about symptoms, what causes it, how you catch it, what would be the treatment, who's more likely, none of that stuff just you need to get vaccinated, so we're uninformed, we're not being given the whole picture. *P. 2* ♀

This excerpt questions the vaccine information that is provided to new parents:

> There isn't actually that information provided to anybody except to say oh it's good and we don't have polio anymore and that's because we vaccinated. Well is it? Or did something else happen. *P. 11* ♀

The same mother (participant) was concerned about vaccines before her child was even born:

> Even before I had my eldest, I was actually dreading the whole vaccination process because I just didn't like the idea. It was so drummed into you and I was like, I don't want to do this *P. 11* ♀

Cassell et al. (2006) noted that 58% of non-vaccinators of measles, mumps and rubella (MMR) reported that it was a concern for them before the birth of their child.

Trust issues came up for some participants:

> As a parent now I can see the concerns that parents have. You want to have someone that you can take your kids to that you trust. *P. 1* ♂

> I read the leaflet, I read everything on the argument for vaccinating ... it is not there, it is propaganda. *P. 2* ♀

> … they wouldn't be forthcoming about side effects because of the money. *P. 7* ♀

This participant described his dissatisfaction with the explanations that he had been given regarding vaccination:

> I don't believe in it at all, because herd immunity from my understanding is that you are trying to eliminate a pathogen by immunising 100% of the population and if 100% of the population is immune, 'herd immunity'. Then the pathogen will disappear from society; well I think that's a load of crap. Whatever causes the disease is still out there, right, and umm no one has been able to demonstrate, and it's factually known that people that have been immunised against certain diseases still contract the disease (laughs). It doesn't work (laughs). *P. 1* ♂

This next excerpt portrays the lack of trust this participant has in the vaccine statistics supplied by pharmaceutical companies:

> It’s totally unproven, like, there’s no way that you could know that for sure. That’s all just statistics, and all just numbers, and it hasn’t actually happened *P. 2* ♀

According to Brownlie and Howson (2006), health contexts characterised by uncertainty, as is the case for vaccination, raised issues about trust and the way in which information was shared. Parents in McMurray et al's. (2004) study, believed that in order to gain trust about vaccine information provided, target payments to orthodox practitioners needed to be abolished. In addition, these parents suggested that facilitating access to independent third parties, who could be trusted to provide balanced information, would help with enhancing parental trust in practitioners.

In line with existing literature, participants had trust issues and reservations about vaccinations. Any explanations that they had heard from orthodox practitioners or information that they had received had not satisfied their doubts about vaccinations. A similar theme was prevalent in Hobson-West’s (2005) study, where risk statistics were withheld or distorted when providing information to parents, in order to promote vaccine compliance. This behaviour was criticised by the participants in Hobson-West’s (2005) study and found to have long-term trust implications.

Health care options

A sub-theme of Theme 3 – Health care options involved all aspects of decision-making regarding health care and reflected the plethora of options available in contemporary society. The ability to have informed choice regarding options in health care was of great importance to participants. In addition, participants would choose whether they would see an orthodox practitioner or a heterodox practitioner. At times they would utilise both an orthodox and a heterodox practitioner, particularly if they were unsure of the condition, which meant that they could weigh up their options and make what they considered an informed health care decision.

This excerpt portrays the way this participant recognised value in a wide range of treatment modalities:

> There’s plenty of value in all modalities. I’ve had surgery four or five times, but it’s always been under my conditions, under my terms you know. I think the only time

> I've ever rocked up to a hospital is when I had a broken leg or a broken arm. Other than that it's always been I'll find the doctor that I need and I will arrange what I need and umm if it's a surgery, yep I'll pay whatever he's asking for. *P. 1* ♂

More than half of the thirteen participants interviewed spoke about the imbalance of power between orthodox medicine and heterodox medicine. They wished to see heterodox medicine more fairly represented:

> I think it's fabulous that those people (orthodox and heterodox practitioners) are there for me if I need them and I think that's their role. But, I think that I should still have that choice to be able to go and exercise responsibility myself. The stigma is still out there. There are the real health practitioners and then there are the others, and I don't think that's good. *P. 11* ♀

> Everything plays a part, there is no panacea, everything plays a part ...You want the right to choose. *P. 12* ♂

> There's not an even balance between natural health and conventional health. I'd like to see a more even balance because even when they report things in the media they'll give the naturopathic version, but the last one to come in will be the conventional and they will absolutely override it and that will be the last word on it. *P. 4* ♀

During the interviews, the issue of orthodox doctor-patient relationships came up many times. Part of health care decision-making encompassed negotiating between the option of orthodox medicine and heterodox medicine. However, most often participants chose a heterodox medical practitioner or an orthodox practitioner according to the medical condition that presented.

> I'll actually go to a naturopath before I'll go to a doctor umm and just sort of suss them out and see what they think. Usually have a conversation with mum cause she's almost as good as a naturopath. Umm yeah the doctor would be for accident style; stitches as opposed to sickness. *P. 11* ♀

Simpson (2001) and Coulter (2004) also found that patients often developed their own personal strategies for obtaining and integrating heterodox and orthodox medical care.

One of the participants in this study developed breast cancer and followed the orthodox medical advice to have radiation; although she was uncomfortable with the idea, she felt she had little choice:

> I had breast cancer; I had to decide what I was going to take and so on. I did have radiation therapy and then I was on a course of hormones, which I didn't want to have ... but I took them for a year and a half and then I decided not to. So I'm not having them at all now. I didn't think that I would take it. I would talk to my doctor but I had pretty much in my mind well I wasn't going to go that path. Even the radiation therapy was something I would rather not have done, but I did. You know it is confronting when you are told, when you first find the lump and they say yes it is breast cancer, you think oh goodness this might be the end of my life. *P. 3* ♀

Participants felt that heterodox and orthodox were not fairly represented:

> When you go to a doctor, a doctor is like, this is how it works and they're great believers in immunisation. So I confess that I have not had those conversations with my G.P, I mean she knows that I'm a little bit off the planet but umm yeah she's just kind of, do this, and I'm just like okay. *P. 6* ♀

> The problem with medicine and health is that it's looked at as an ultra profession and the people in that profession are thought to be doing the best thing for their patients, but the reality of it is very different. The situation is that they are all businesses, so there is a disparity there. *P. 12* ♂

The divergent paradigms of orthodox medicine and heterodox medicine raise various challenges in integration, due to the contradictory philosophies about health and health care (Coulter, 2004, p. 103). Determining a way of integrating both heterodox and orthodox medicine may provide some challenges for health care consumers and health care practitioners. A study on heterodox health professionals (midwives) found that these midwives struggled to integrate the two divergent paradigms in their daily work (Shuval, 2006). Shuval and Gross (2008) developed insight into modes of behaviour and explored how these nurse midwives negotiate conflicts among differing epistemologies and patterns of interaction in using both orthodox medicine and heterodox medicine. In cases where heterodox medicine has been integrated with orthodox medicine, orthodox medicine has 'maintained its epistemological superiority' (Cant, Watts and Ruston, 2011). Hunter and Grant (2005) contended that heterodox medicine was in danger of its philosophy becoming superfluous when being integrated with orthodox medicine.

Interestingly, in the majority of cases, participants were not totally against orthodox medicine, in fact, some mentioned how important it was in emergency situations, but spoke against its hegemonic position. The hegemonic position of orthodox medicine 'has silenced and devalued other forms of medicine, and their healing knowledge', creating a monolithic worldview (Hollenberg and Muzzin, 2010, p. 40), where other views are not tolerated. Therefore, individuals who decline mass childhood vaccination may be considered imprudent. Shuval (2006) observed an imbalance of power between orthodox and heterodox medicine, with orthodox medicine holding a 'monopoly on legitimacy and controlling major resources and political influence, prestige and material resources' (Shuval, 2006, p. 1786). Several participants mentioned feeling there was a lack of treatment options available to them:

> I think the best thing that could happen with the alternative health care movement is to unify under some body. The alternative medicine movement has got a huge body of knowledge but it is not coherent. It's going to take some organisation or something to sort that, but alternative options are needed. *P. 12* ♂
>
> It would be pretty cool if you could go somewhere and you had a range of traditional medicine and doctors, so you had alternatives and you could just walk in and pick and choose and it might take some of the stigma away. Lately they asked people to vote about alternative medicine in higher education. Yes, you should be able to learn it at university. Some professor from Sydney Uni absolutely slammed alternative medicine; he basically called them charlatans'. *P. 11* ♀

Zola (1972, p. 487) considered orthodox medicine to be a major institution of social control, where orthodox medical experts have finality in judgements regarding health care decisions. This ideology has influenced the medicalistation of illness, desocialising illness and explaining social phenomena in orthodox medical terms (Filc, 2004). Resistance to vaccination is an example of where the social phenomena of conscientious objection to vaccination is explained using the orthodox medical discourse of herd immunity and free-riding as a persuasive language. Government health promotion portrays vaccination as a modern medical miracle and is focused on controlling individuals, using orthodox professionals to promote vaccination and advocating the need to educate (Dew, 1999) and in some countries punish or fine (Stafford, 2008) those that resist mass childhood vaccination.

Hildreth and Elman (2007) noted that the majority of heterodox medicine users visit both orthodox and heterodox medical practitioners, with only a small portion of heterodox medicine users avoiding orthodox medical treatment completely. For participants in this study, decision-making encompassed many aspects of making everyday choices regarding behaviours and food choices, as well as health care choices, such as when and how to utilise the services of various practitioners and therapies. Of the thirteen participants interviewed, twelve did not have a regular orthodox practitioner, and would only seek one out if they required a medical diagnosis. Once they had a diagnosis, they would usually decide on the course of treatment, most frequently they would look for a natural alternative to the pharmaceutical product that the orthodox practitioner had prescribed. Participants noted that they would not disclose this decision to the orthodox practitioner.

These next excerpts illustrate participant's self-reliance:

> I didn't get the doctor down...just treated them (the kids) myself with the fruit juice and keeping them in bed they soon got over it, you know .... There was nowhere I could go to get that (natural medicines). *P. 9* ♀

> I try to avoid it (antibiotics/pharmaceuticals) when I was pregnant my iron count started off high but by the end of the pregnancy, with twins, they said that my iron was getting low. I got an iron supplement from the health food shop; I didn't like the G.P type prescription. *P. 10* ♀

> I don't really go to the doctor. Except in the last, what, twelve months. I was quite sick last year. Really low energy and all that and the naturopath said, you had better go and have an iron test and it was tested and it was really really low. The doctor gave me a prescription, which I then took to the naturopath and said what do you think and she gave me something else. *P. 8* ♀

Participants negotiated, on their own terms, the manner in which they employ heterodox medicine and/or orthodox medicine and also integrative medicine where an orthodox medical practitioner combines the two systems of medicine. Participants showed a sense of relief if they could locate an orthodox practitioner that would understand their alternative ideologies and the health care choices that were associated with this ideology.

This next excerpt depicts a sense of frustration from a participant who needs to have a conscientious objection form signed by an orthodox medical practitioner. The participant felt misunderstood and dismissed:

> I had his conscientious (exemption) form signed the other week by the doctor. This doctor was not a good doctor at all ... She just looked at me and said 'well I suppose you're not vaccinating then?' I said yeah, I have researched it and I've decided not to. She knows I am not vaccinated. I wouldn't have minded so much if I thought that she was a good doctor who would have actually listened to what I was saying and considered my opinion and tried to see where I was coming from and actually have an informed discussion about it ... as a doctor if she is so adamant about vaccination

> she should at least just go to the trouble of at least explain the ins and outs of it instead of just handing me a leaflet and going whatever *P. 2* ♀

This finding was similar to that of McMurray et al. (2004) where parents identified the need to have orthodox practitioners available for parents to openly discuss their concerns without time constraints. Most noteworthy, parents said that there was a need for written information, including case studies that they could relate to and reflect upon (McMurray et al., 2004, p. 523).

Only one participant mentioned having utilised an integrative practitioner:

> My naturopath moved to the country, so fortunately I found a good doctor umm ... I can't remember what she does, she's a medical doctor, Indian and umm she's a general practitioner; muscular skeletal medicine, acupuncture, hypnotherapy, and she has a special interest in nutritional and herbal medicine. *P. 9* ♀

Participants expressed relief when they could find an orthodox practitioner that could understand their holistic philosophy:

> I moved this year. I don't actually have a doctor in this town yet; I have to try to find one. I had a wonderful doctor on the Gold Coast when I was there. She knew me very well and would always say to me there is this available, or that available, I know you probably won't want it, but I thought I would mention it to you so that you are aware. She was very good like that, so I'd never really had any pressure. *P. 3* ♀
>
> I turned 40 this year and its only just this year that I've found myself a doctor that I'm happy with (laughs). I did five years ago, I got myself a doctor and he retired on me (laughs). *P. 1* ♂

Participants described negotiating what they wanted in health care. This was evident in the manner by which when participants attended the doctor, they would have a very specific health agenda. They were attending the doctor for a particular reason and they appeared vigilant against extraneous treatments:

> I'm pretty strong I just tell them, I just say I don't want to have it. I was having a blood test about six months ago, she was drawing blood and (the GP says) 'by the way I noticed you haven't had your cervical cancer vaccine, would you like me to give you that today?'. I just thought what, (laugh) it was like (laugh), would you like fries with that? *P. 8* ♀

> I would go to a doctor or take a vaccination as a last resort. In my mind I would want to know why a problem occurs so I could look up a more natural way. That's why it's so important to; I guess you know, to do whatever you can to learn about other ways to find a solution. *P. 12* ♂

Individual as expert

Another interesting sub-theme that developed from the interviews, associated with Theme 3 – Choices, was the expertise that participants exhibited in matters of health. In contrast to orthodox medicine, where health professionals act as the experts, heterodox medicine encourages the individual to become the expert of their own body. Becoming expert may also evolve over time, subsequent to not being reliant on orthodox practitioners.

> I have complete confidence from understanding health, from understanding disease, which medical science does not do; they do not understand health and the relation of health to part of the process of restoring health. *P. 13* ♂

> Me personally, I just know me. I know about my body, do you know what I mean? I know what works for me. *P. 4* ♀

> I find if I go to a doctor they pretty much will just prescribe me antibiotics and I don't see any point. I don't like to get my feverish child out of bed and take them to a doctor, you know, I think that they need to be in bed and as I said I don't think that the doctor can really offer me much more than antibiotics. Which, and in a lot of cases isn't what they need anyway because they probably have a virus not a bacteria and I find even if they have got say a condition that has come out of a virus, you know where you get a sinus infection or a lung infection or something like that, you know with my kids, I would just rest with them, you know. *P. 5* ♀

A level of expert behaviour is exhibited by two participants in a quest to avoid what was considered unnecessary orthodox interference:

> There would have to be pretty significant reasons why I would consider using conventional medicines. Umm if I had have been in hospital I probably would have been made to have antibiotics because I was group B strep., so what's the point I would never had had the antibiotics. But you know in hindsight and all that and you know the midwife did want me to have them and I declined. And it was absolutely fine. They just monitor and that's what we did and it was all fine. *P. 2* ♀

> If there was something really wrong with them I would know, hang on there's something not right here. But that's not something I've really felt along the way, like I can see that they're sick and that they've got a fever and I actually use wet cloths to

> keep their fevers under control, rather than using panadol, umm and I'll use a thermometer to monitor what their temperature is and say they had a really bad temperature starting to kind of, I don't know, just seem like it was an extreme temperature I might consider giving them panadol then. But I haven't had to do that. *P. 5* ♀

Further to this issue was the need that participants felt to become expert, so that they could argue their case when confronted about their choices:

> I wanted to be informed so that I had the evidence to back ME UP instead of just going oh I don't want to, but I don't know why? That's sort of a bit ... it's hard to justify that to care providers that work in the industry and you know, have seen it all, unless you have the evidence to back it, you sometimes feel a bit weak and just go along with it. *P. 2* ♀

> I don't know how many times I've handed out booklets on vaccination ... my hairdresser because she was carrying on a treat about immunisation. Until you know I gave her the full story ... I'm happy to give you all the evidence I said. Read it make an informed decision. Don't be just you know someone that's just going to follow suit. *P. 4* ♀

Brownlie and Howson (2005, p. 227) noted that parents felt shame when they felt unknowledgeable when having to make a vaccine decision on behalf of their children. The difficulty in becoming informed was also mentioned as a key issue, concluding that there was a strong '...moral imperative to be knowledgeable in order to protect their children's best interests'. Hobson-West (2005) also observed a theme in her research, whereby parents become experts in vaccination issues. Similarly, unvaccinated participants in her study displayed expertise and were able to quote and recall vast amounts of health information, related to why they follow certain health measures. Discourse from participants included dialogue about fevers, immune function, the importance of diet, exercise and organic food, and also about other health-related topics. Others mentioned issues such as fluoride in water, genetically modified foods, additives and pesticides in foods and products. Expertise was also demonstrated in terms of seeking medical help, when it was seen as necessary. Participants described decision-making about when they would get help for their sick child and/or themselves. Participants also decided when they would or would not use a prescription.

The holistic model of health and healing is aligned to individual empowerment and choice of the patient. 'Unlike the biomedical model, which has traditionally taken charge of the therapeutic process, the holistic model is decentralised and supportive of individual empowerment and choice' (Williams, 1998, p.1194), where there is 'an emphasis on the unit of body, mind and spirit' (Goldstein et al., 1988, p. 853). In this manner, clients are encouraged to do whatever is required to acquire a state of health. Since each individual is unique, each individual needs to find his/her own path to health and healing (Pawluch et al., 1994, p. 73).

Mass childhood vaccination does not allow for this freedom in health care choices. Problems may arise when negotiating the integration of orthodox medicine with heterodox medicine. The participants described how an orthodox practitioner is usually given authority in a health care interaction, as the medical expert who holds the knowledge and is obliged to adhere to vaccination policies and protocols. This is in opposition to the lay patient 'who knows nothing' about their own body because they are not experts (Mead and Bower 2000, p. 1089). Not being a medical expert and therefore not knowing much about your own body is contrary to the holistic notion, where the individual is considered the expert of their body. 'Only individuals can determine where the underlying problems lie and which therapies are effective in restoring their body's balance' (Pawluch et al., 1994, p. 73).

Risk issues

A sub-theme associated with Theme 3 – Choices was risk issues. Individuals were found to be willing to accept risk based on various forms of evidence. Parents look at evidence about vaccine risk, and talk to a variety of experts, as well as to other mothers, when making vaccine decisions (Casiday, 2007).

Risk for participants, involved the potential side effects, both long-term and short-term, of using pharmaceuticals including vaccines:

> At least the risk of getting an illness is a risk we all have and we have no control or very little control over it but ... to me, getting my child vaccinated was to ... to take on a risk that she otherwise would not take on. *P. 3* ♀

> Every single medical procedure has some risk associated with it, so it seemed to me, just unnecessary to expose my kids to all that risk. *P. 1* ♂

> Vaccination is injecting total toxins into them! Prove to me that it works. If they really worked and there wasn't all the bad stuff in them then everyone would do it.

> The fact is there's no proof. We know out of 100 children vaccinated, in only 75% it actually works anyway. Out of that 75% they can still get that disease and die ... It's like the cervical vaccine giving it to 9 and 10 year old girls, there are cases now in America where children have died from having it. So why would you give it to your child? *P. 6* ♀

Beliefs about 'nature and society' (Levidow and Carr, 2000, p. 260), have played a significant part in all types of risk debates. Risk was found to be a relevant theme in this study on exploring the experiences of adults raised without routine childhood vaccinations, but risk was also associated with other factors that were the consequences of going against the holistic model that participants believed. Risk, was signified by using a vaccine or pharmaceutical unnecessarily, with it having the potential to cause a negative reaction of some kind.

Disagreement in vaccinating children was an area of contention between many participants and their partners and, sometimes, extended families that had different views about vaccination:

> [Talking about her husband] He's very traditional, he's English.. He at first didn't like the idea of not vaccinating, because why wouldn't you do what the doctor says umm and my argument was just show me some research that beats everything that I know otherwise if you have no evidence, I'm not interested (laugh) *P. 2* ♀

> My daughter's got three girls; she actually fought very hard not to have those children vaccinated. Her in-laws and the rest of the family were so hostile to her about vaccination that in the end she said, I don't think I can do this anymore, because she was being absolutely abused, which was quite difficult. *P. 4* ♀

> Mum has sort of well, she told my father from the beginning any children, I want to bring them up with these criteria and that and they agreed with those sorts of things first off, so there were no problems. *P. 10* ♀

Skea et al. (2008) examined an online chat forum for parents. They were specifically interested in an online discussion thread about measles, mumps and rubella (MMR). Their findings revealed that participants, who did not have any significant concerns about the safety or efficacy of the MMR vaccine, were often critical and judgemental toward parents that chose not to vaccinate their healthy children. The main area of contention was the view that they were free-riding, by receiving the benefits of herd immunity without contributing to it, and that by not vaccinating they were more likely adding to the proliferation of disease. This was a common finding, here and in other studies, with hostility to so-called free-riders raised in other studies (Petts and Neimeyer, 2004; Richardson, 2005), but disputed by Evans et al. 2001 who reported that most parents were uncritical of those who chose not to vaccinate.

Two important factors raised by Dew (1999, p. 384) included the media's representation of the 'social problem' of low vaccine uptake and the moral condemnation of non-vaccinators who are portrayed as ignorant and lazy. Most importantly, parents who do not vaccinate were 'seen as selfish for resisting a procedure that is cast out as good for the whole community' (Dew, 1999, p. 387). As well as drawing a distinction between parents who act responsibly and those that do not, there is a definite label of selfishness implied towards those who do not comply with vaccine recommendations. This animosity toward non-vaccinators may be passed on to unvaccinated children, as is demonstrated in some of the excerpts below. Parental 'laziness' and 'complacency' is not considered to be an accurate portrayal of suboptimal uptake, considering that under-vaccination is 'multifactorial and complex' (Leask and Chapman, 2002, p. 455).

The media's portrayal of childhood infectious diseases has created confusion and animosity amongst vaccinators and non-vaccinators, using stereotypical and rhetorical language about disease. This portrayal of infectious disease threat has been 'conveyed using panic language, disease personification, quantification rhetoric, stories of personal tragedies and portentous tales from yesteryear' (Leask and Chapman, 2002, p. 445).

Despite the fact that participants were mostly quite confident about their position, participants spoke of instances where they have been ostracised, discriminated against or judged for not being vaccinated.

> I'm fairly confident in myself and if people ask me for something I don't want I say 'no, I'm not doing that'. As far as I'm concerned, what goes into my body I'm responsible for, and no one can force anything on me. *P. 1* ♂

> … umm I guess some people are strong minded about it and I guess, like myself I'm fairly confident in what I say but you know, I have my reasons for doing what I've done. I believe that there are negative impacts to having immunisations. *P. 5* ♂

Some participants had experienced bullying, discrimination and judgement:

> I remember one time when I was ... I would have been about 10 or 11 and I was doing like a holiday workshop thing at a drama school and umm Mum was filling out this form and the drama teacher realised that I wasn't immunised and first of all she was not going to let me do the course ... She was basically saying that she would have been at fault if the other kids picked up diseases from me and umm she told me in the class that I was going to have problems with pregnancy like, in front of everyone. *P. 7* ♀

This next participant describes how she experienced bullying when having her first baby and not wanting to vaccinate him in the hospital:

> I was a bit overwhelmed I suppose and I wasn't very old – I got married at 20 and I had my first child at 21 so although I considered myself to be umm a mature person, rearing a child was something totally new to me and I was an only child myself ... so that made it easier for me to be subjected to that bullying and you know. *P. 4* ♀

The same participant received harsh judgement from her son's school principal for not vaccinating him:

> My son was called to the principal's office and they said to me, they told me what a bad mother I was, and how irresponsible I was. Umm and I basically told them to mind their own business, the children do not belong to them. They're my children and my responsibility and I will raise them as I see fit and basically he dismissed me from his office as being an absolutely ridiculous women ... Out of that ... the teacher did actually stand my son up on the podium and said that this person is the only one that had not been vaccinated. I was absolutely livid over that. So you know I have fought a fare fight. *P. 4* ♀

Several participants mentioned keeping their vaccine status confidential to avoid confrontation or loss of employment:

> I try to steer clear of the conversation with people all together, because most people are really shocked when they hear that you haven't been vaccinated, or you're choosing not to vaccinate. *P. 2* ♀
>
> In my work, in an after school care program, nobody checked or asked me if I was vaccinated, but the ironic thing was that I had to check all the children's documents as they were not allowed to attend if they were unvaccinated. I just kept my mouth shut about the fact that I wasn't! *P. 8* ♀

This excerpt describes having to hear the judgement when out in public from individuals that felt that it is acceptable to judge:

> We were at a party and there was a mum, she was a nurse and she started talking about mothers that don't vaccinate. She was saying something about the stupid mothers, why don't they get it done and I said to her, well you know they don't take in 25% of cases and mothers think that their kids are protected but they're not and she said what do you mean? I explained it again and she said well you're right cause I have had Hep B and it hasn't taken on me. *P. 6* ♀

> You know when I was a teenager, I have a particular memory of being at school and one teacher being aware that I hadn't had a tetanus vaccine and just sort of saying to me you know you're absolutely mad and you've gotta do this, you know, despite the fact that my mother had made this decision she was telling me as a teenager this is crazy you need to get vaccinated. *P. 5* ♀

One participant who worked in health felt so strongly about her right to not have the compulsory vaccinations that she told her boss that she was prepared to fight them over it. The participant felt that the issue does linger over her:

> It's very challenging (working in health) because we have a rule that's come in where everybody in health has to be vaccinated. Don't ask me how I've managed it but I've actually said to my manager 'you force me to have a vaccination and I will make such a song and dance about this that you'll wished you'd never ever seen me or heard of me'. ... They come around all the time and we do, we've got an absolute policy from this day forward I cannot employ anybody unless they are fully vaccinated with all their Hep.Bs and so on. And yet I'm employing people with this standard and yet I don't have it myself. So ... But you know what I'm only one person but I can flap pretty loudly if I have to ... and I will if they tread on my toes you know. So they started to tread on my toes … they've backed off again. *P. 4* ♀

After having her own children and choosing not to vaccinate them, this participant lost three of her childhood friends. The participant and her former friends had opposing beliefs surrounding vaccination:

> Your child is a carrier and spreading the disease and so if you've got your child around them, then they'll catch it. Both her and Kylie told me not to come near their kids with mine, because they weren't vaccinated. You know she rung me when my brother died and asked if she could come to the funeral and I said well yeah but my kids will be there and they're still not vaccinated ... For me, the relationship had been severed. She ended our relationship because my kids weren't vaccinated, and Louise was the same. *P. 6* ♀

The marginalisation of people raised without routine childhood vaccinations is an issue that has not been addressed in the literature. The lack of understanding and knowledge about the holistic life philosophy in orthodoxy has contributed to a sense of judgement of unvaccinated people within society. This sense of judgement is escalated by the government's promulgation of vaccination, by using orthodox professionals to promote vaccination, the powerful vaccine imperative (Hobson-West, 2005) and the rhetoric of herd immunity (Dew, 1999). Dew noted that concerns over adverse reactions may also be marginalised, due to the difficulties in demonstrating causal links and the authoritative position of pharmaceutical companies and orthodox medicine that have downplayed the likelihood of side effects. As a result of marginalising non-vaccinators' concerns over side effects, the legitimacy of their concerns is trivialised.

Moreover, as has been the experience with some of the participants, the non-vaccination choice may involve the risk of a conflict, which could result in losing friends and or family members, due to the very contentious nature of vaccine beliefs. As Dew (1999, p. 393) noted: 'to oppose vaccines is to bring one into conflict with the state and with medical science'. Streefland et al. (1999) acknowledged that declining vaccination and the vaccination imperative could be difficult: 'It requires taking a stand, weighing the alternative options, and giving explanations to others – neighbours, family members, health care staff. It means taking control over the body of one's child' (1999, p. 1712).

Contentment with decision

An associated sub-theme of Theme 3 – Choices was contentment with decision. It was important to explore participant's contentment with the vaccine decisions that were made on their behalf. Speculation exists within the literature that portrays the non-vaccination decision as not in the best interest of the child. All of the thirteen participants interviewed were content with the decision:

> I am very happy with the decision that she made, I don't know whether it was reasoned, it was driven more by fear and more than most parents would ever have to go through. However, the decision she ended up making was the right decision for me. Lucky me (laughs). *P. 1* ♂

> I would say that it was in my best interest for her to make that decision. *P. 11* ♀

> It was in my best interest, no doubt. I've certainly had no negative consequences from not being vaccinated, absolutely none. *P. 13* ♂

Summary of Theme 3 – Choices

In summary, choices for participants included making informed, expert decisions regarding health care and particularly regarding vaccinations. Decision-making encompassed an ability to successfully navigate and negotiate between orthodox and heterodox medicine and understanding the risks associated with all levels of health care advice. Participants saw themselves as experts of their own bodies. They believed their expertise allowed them to adequately manage the decision-making process themselves, while remaining true to their personal beliefs and values and holistic life philosophy. In addition, the majority of participants described feelings of being ostracised, or had dealt with some form of judgement and or discrimination by a variety of friends, relatives, colleagues or health care practitioners. Finally, these interview participants were all content with their parent's decision not to vaccinate them.

Summary of Chapter 5

This chapter has presented the salient issues from the data that was collected during the in-depth interviews. The adult participants that were raised without routine childhood vaccinations had a fundamental holistic life philosophy. This holistic life philosophy influenced the way that they conceptualised both health and illness. The first theme 'beliefs and values' featured immunity as a salient component of participant' beliefs. Childhood contagious diseases were constructed as normal and an acceptable part of childhood. The participants described the importance of maintaining a high level of immunity and breastfeeding babies in particular, to assist in coping with an illness if it was to present.

A model of least interference, whereby participants avoided orthodox medicine and pharmaceuticals whenever possible was preferred. Participants described a preference for giving the body the opportunity to deal with an illness by implementing rest, a restricted diet and natural remedies.

Personal responsibility emerged as the second theme. Participants described a strong sense of personal responsibility to their own health care and health care decisions. Personal responsibility was strongly associated with the importance of healthy lifestyle and social responsibility. They describe how they felt ultimately responsible for any outcomes, and therefore needed to act in accordance with their own moral values.

Choices were identified as the third theme and of particular relevance to participants. The ability to make choices reflected back on them as autonomous, free thinking individuals who studiously sought out truthful and balanced health information in their desire to make informed health care decisions for themselves and for their children. The participant observed himself or herself as expert, as they took control of their health care and made choices for themselves and their children. They describe relying on their own knowledge, and other sources of information that they trusted, to get them through these periods. The level of effort that participants extended was apparent in the self-learning that they all described. Participants spoke about the research that they had undertaken to learn about particular issues and seemed fully aware of the risks involved with the non-vaccination decision.

Participants who took part in this study were generally not speaking against orthodox medicine, but had strong preferences for heterodox medicine as their first point of call. Participants described a desire for a more balanced system, that allowed for the utilisation of heterodox medicine and its epistemology, without the associated negative consequences of choosing other than orthodox health practitioners. Importantly, participants described disquiet with extraneous orthodox medical procedures that they perceived as invasive and unnecessary.

This chapter demonstrated that some participants have experienced discrimination regarding their unvaccinated status, that may be interlinked with their preference for another option or free choice. They perceived that those who choose other than what is recommended by the 'government' are judged and/or ostracised as a consequence of that decision. All thirteen participants reported to the researcher that they were content with having been raised without routine childhood vaccinations and, interestingly, all of them had preferences for raising their own children unvaccinated.

The findings of this study reveal that participants experienced health and illness during their childhood development and this was constructed as normal, despite any adversity that went along with the process of ill health. These findings unveil a different aspect associated with a holistic ethos, and with the experience of being raised in this way.

This current study contributes to new knowledge by revealing the way in which participants navigated between orthodox and heterodox medicine, and the intergenerational insights gleaned from exploring the vaccine choices that unvaccinated people make on behalf of their own children. Participants had genuine concerns about the long-term implications of their health care choices and felt a great sense of responsibility for making decisions that had satisfactory outcomes. As with many prior studies (Hamilton et al., 2004; Wallace et al., 2005; Smaibegovic et al., 2003; Harrington et al., 2000), participants had difficulty with gaining access to vaccine information in which to make personal health care decisions, and called for more availability of 'real' information.

The positive aspect of being raised in this manner, saw participants experiencing a sense of empowerment from the choices that they made. In addition, and in keeping with Hobson-West, faced with uncertainty, the need to show competence in health care decisions was clearly evident. Although in this study there was some contradiction between a sense of empowerment and the stigma and marginalisation that was experienced from holding incongruent beliefs and values that did not fit in with mainstream orthodox knowledge and practice.

The finding of the this chapter challenge the biomedical literature (Menzel, 1995) that failed to acknowledge the powerful role of beliefs and values in health care decisions, and the subjective lived experience of the individual; conjecture that simply surmises vaccine non-compliance at face value, without understanding the meaning behind it, or the social context, is inadequate. Moreover, this study challenges the argument of commentators such as Glanz et al., (2009) who purported that vaccine-refusing parents believed that their children were not at risk of vaccine-preventable diseases. This thesis contends that vaccine decisions are personal and complex and have broad implications to lifestyle choices that encompass ideological reasoning related to holistic life choices, and a particular approach to health care.

The next chapter will present a summary of the study's findings and the conclusions and recommendations resulting from this study.