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Understanding parents' vaccination choices: a qualitative study of parents living in eastern Norway

Å forstå foreldres vaksinasjonsvalg: en kvalitativ studie av foreldre bosatt på
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Abstract

Title: Understanding parents' vaccination choices: a qualitative study of parents living in eastern Norway.

Background: In developed countries, vaccine preventable diseases have been reduced by the use of vaccination programmes. In spite of this success, some parents question the necessity and safety of vaccination and have been seen to delay or decline vaccination for their children. Parental acceptance of childhood vaccination is crucial for maintaining herd immunity, to protect the public's health.

Aim: This project aimed to explore and understand parents' vaccination choices in Eastern Norway. No qualitative studies have explored the multifactorial reasons parents take into account when making vaccination choices for their children. This will possibly contribute to a deeper understanding of this phenomena.

Methods: A qualitative approach has been used, informed by grounded theory principles set out by . Semi-structured interviews were conducted with 8 parents of children from 5-24 months old. Analysis was guided by a 'modified' grounded theory approach.

Results: Three categories emerged from the data, and came together in one core category 'parenting as managing health risk to protect their child'. When making a choice on vaccination parents who vaccinate tend to go in faith with what is recommended. Those who chose to delay or refuse evaluate risks of vaccine preventable diseases (VPDs) and the vaccine based on their subjective views. Emotions also play a key role in vaccination choice. There was also seen a preference for the 'natural immunity' gained by diseases and vaccines were seen as an 'unnatural' way to acquire immunity.

Conclusion: The findings indicate that how parents make vaccination choices is based on many factors, and the choice is not static, it can be changed over time. Many parents have concerns about childhood vaccination, but still vaccinate, feeling they might not have made the right choice for their child; therefore these concerns should be addressed. Health care personnel are important, but more nuanced information may be needed to fit the needs of the public.

Norsk sammendrag

Tittel: Forstå foreldrenes vaksinasjon valg: en kvalitativ undersøkelse av bor på Østlandet.

Bakgrunn: I utviklede land, har sykdommer forbygget av vaksiner blitt redusert ved bruk av vaksinasjonsprogrammer. Til tross for denne suksessen, har noen foreldre spørsmål rundt nødvendigheten og sikkerheten av vaksiner og vaksinasjon. Dette har gjort at noen velger å utsette eller avslå vaksinasjon for sine barn. Det at foreldre aksepter vaksiner er avgjørende for å opprettholde flokk immuniteten, for å beskytte og ivareta folkehelsen.

Mål: Dette prosjektet var rettet mot å utforske og forstå foreldres vaksinasjon valg på Østlandet. Ingen kvalitative studier har utforsket de mange grunnene foreldre tar når de gjør vaksinasjonsvalg for sine barn. Dette vil muligens bidra til en dypere forståelse av dette fenomenet.

Metode: En kvalitativ tilnærming er brukt, informert av prinsippene fastsatt av Charmaz (2014). Semi-strukturerte intervjuer ble gjennomført av 8 foreldre med barn i alderen 5-24 måneder. Analysen ble ledet av en noe 'endret' grounded teori tilnærming.

Resultat: Tre kategorier kom ut av dataene og dannet kjerne-kategorien "foreldre som administrerende helserisiko for å beskytte sine barn". Foreldre som vaksinerer barna sine baserer ofte valget sitt på at de har tro på det som anbefales. De som valgte å utsette eller ikke gi vaksiner vurderte risikoen av vaksine-forebyggende sykdommer (VPDs) og vaksiner basert på sine subjektive synspunkter. Følelser spiller en nøkkelrolle i vaksinasjon valg. Det ble også sett en preferanse for 'naturlig immunitet' fått av sykdommer og vaksiner ble sett på som en 'unaturlig' måte å skaffe immunitet.

Konklusjon: Resultatene indikerer at hvordan foreldre gjør vaksinasjons valg er basert på mange faktorer, valget er ikke statisk og kan endres over tid. Mange foreldre har spørsmål og bekymringer rundt vaksiner og vaksiner, men velger fortsatt å vaksinere. Dette kan føre til en følelse at de ikke kanskje har gjort det riktige valget for barnet. Derfor er det viktig at disse bekymringen blir tatt opp. Helsepersonell er viktig, og behovet for mer nyansert informasjon kan være nødvendig å tilpasse behovene til publikum.

Chapter 1: Introduction

1.1 Vaccination

The idea of vaccination to prevent disease was based on an observation that some diseases give lasting immunity following an infection (Norwegian Institute of Public Health, 2016). Vaccination involves inoculating a person with a weakened microbe, parts of a microbe or something similar to stimulate the immune system to produce antibodies. The T- and B-cells of the immune system will subsequently recognize the microbe as an ‘antigen’, that is to say, something that stimulates an immune response through a process of recognition of something ‘foreign’ in the body. If a vaccinated person later becomes infected with this microbe, the immune system will provide a quicker and stronger immune response thus preventing the disease. Vaccination therefore prevents specific infectious diseases (Norwegian Institute of Public Health, 2016). The first vaccine was developed over 200 years ago, against the much feared smallpox-disease (Plotkin & Plotkin, 2007). This disease was declared eradicated by the World Health Organization (WHO) in 1980, and since then considerable progress has been made in the development and implementation of vaccination programmes and new vaccines globally (Nøkleby & Feiring, 2006; World Health Organization, 2017). Today vaccination is described as one of the ‘greatest triumphs’ of public health throughout its history, and childhood vaccinations programmes have received much of the credit for the major decline in many vaccine preventable diseases (VPD) (Dubé et al., 2015; Reich, 2016). Childhood vaccinations has also been described as one of the most effective tools for improving individual and population health, estimated to prevent about six million deaths worldwide a year (Andre et al., 2008; Ehreth, 2003). However, despite the success of vaccination programmes, an emerging trend in several countries in the developed world has been the refusal by parents of some or all vaccines for their children (Reich, 2016; P. Smith, Chu, & Barker, 2004). The success of vaccination programmes relies on high

vaccination coverage to maintain herd immunity (Brunson, 2013). In a public health way of thinking ‘herd immunity’ means according to Fine, Eames, and Heymann (2011, p. 911) that “the risk of infection among susceptible individuals in a population is reduced by the presence and proximity of immune individuals”. Although the concept of herd immunity is a lot more complex, reduced herd immunity can lead to outbreaks of VPDs (Serpell & Green, 2006). In Norway, for example, childhood vaccination has been voluntary since 1952 and there have only been two mandatory vaccinations over time. This was the smallpox vaccine, and the Bacille Calmette Guérin (BCG) against tuberculosis (Nøkleby & Feiring, 2006). Voluntary vaccination allows parents to exercise their choice in relation to childhood vaccination, which is the focus of this dissertation.

1.2 The development of vaccination programmes in a global context

From the start, development of vaccines was to a great extent inspired by public health needs of populations (Blume & Geesink, 2000). The history of vaccination started with the smallpox virus (Plotkin & Plotkin, 2007). It goes back to the 18th century, when Chinese texts describe variolation with this virus. Variolation means to take pustules from an infected individual and put it in to the skin of a healthy person to achieve immunity (Plotkin & Plotkin, 2007). Later in the century a new discovery was made; this was that by contracting cowpox (associated with the development of chicken pox) a person developed immunity against the smallpox virus. As cowpox was a rather mild disease, this was a safer way to gain immunity. In 1796 Edward Jenner started inoculating cowpox into healthy individuals, who then gained immunity from smallpox. This marks the start of the modern vaccination history (Plotkin & Plotkin, 2007).

After Jenner’s breakthrough it took almost 100 years before the next vaccine discovery. Louis Pasteur experimented with chicken cholera and anthrax in the late 1800s (Plotkin & Plotkin, 2007). Almost parallel to his discovery, researchers elsewhere had

discovered viruses, and the term killed- and –live vaccines were developed. This marked a new era of vaccinations, and in the following years after Pasteur’s discovery, several of the vaccines known today were discovered: vaccines against rabies, typhoid, and plague, for example (Plotkin & Plotkin, 2007).

In the first half of the 20th century more vaccinations were developed, such as the vaccines against Tuberculosis (BCG), pertussis, diphtheria, tetanus, yellow fever, and typhus (Plotkin & Plotkin, 2007). One of the first vaccines to create controversy over safety was that for polio. In the 2nd half of the 20th century a polio vaccine was developed by Salk in the USA, known as the inactivated Polio Vaccine (IPV) (Blume & Geesink, 2000). His work was funded by the National Foundation for Infantile Paralysis, which made it possible to carry out the largest field trials ever conducted (Blume & Geesink, 2000). In 1955 the IPV was authorized for use in the USA, and not long after for use globally. Many experts had questioned the effectiveness of Salk’s vaccine and favoured another alternative, which was made by live but ‘attenuated’ or weakened virus. This alternative vaccine was made available in 1961 and called the Oral Polio Vaccine (OPV) (Blume & Geesink, 2000). There was some controversy surrounding the use of which vaccine, to use in vaccination programmes, and questions around risk and safety emerged. One defective batch of the IPV had made six healthy children in California paralysed. The production of the IPV ceased, and the vaccination programme temporarily stopped (Blume & Geesink, 2000). In the 1960s the programme was resumed and by that time most countries had switched to the OPV. However in the 1970s a problem regarding the OPV emerged. This was that the “attenuated” virus in some cases had turned virulent again (that is to say, capable of causing disease). This led experts to argue about which of the vaccines was the safest, and how the risks and benefits of the two different vaccines could be evaluated (Blume & Geesink, 2000).

Apart from the disagreement of the experts, by the late 1970s polio was nearly eliminated in high income countries (Blume & Geesink, 2000). This gave hope to the possibility of eradication of diseases, but public health workers and politicians had concerns regarding the safety and availability of vaccines (Blume & Geesink, 2000). These issues were important from a prevention point of view as high uptake is central to herd immunity.

1.3 Vaccination statistics

Children living in Norway are offered free immunizations against 12 diseases between the ages of six weeks to 15 years. These are measles, mumps, rubella (MMR), rotavirus (RVV), diphtheria, tetanus, whooping cough (DTP), poliomyelitis (IPV), infection with haemophilus influenza type B (Hib), hepatitis-B (hep-B) (DTP-IPV-Hib-Hep-B), pneumococcal disease (PKV), and human papilloma virus (HPV). The vaccinations are usually given when children are of infant/toddler age, and booster doses are given when children are of school age (7-15 years). The first dose of RVV is given at 6 weeks of age, then at 3 and 5 months. DTP-IPV-Hib-Hep B and PVK are given at 3, 5 and 12 months, and the MMR is given at 15 months. The exception in the vaccination programme is the HPV-vaccine which is not given before 12 years of age (Norwegian Institute of Public Health, 2016). Ten of these vaccinations are given to children from 5 to 24 months, these parents were in my focus group. See table below.

Table 1: Childhood vaccination programme in Norway

Age	Vaccination against
6 weeks	Rotavirus disease
3 months	Rotavirus disease
	Diphtheria, tetanus, whooping cough, poliomyelitis, Haemophilus influenza-type B- and hepatitis B-infection (DTP-IPV-Hib-Hep B)
	Pneumococcal disease (PKV)
5 months	DTP-IPV-Hib-Hep B and PKV
12 months	DTP-IPV-Hib-Hep B and PKV
15 months	Measles, mumps, rubella (MMR)
2. Grade (ca. 7 years)	DTP-IPV
6. Grade (ca. 11 years)	MMR
7. Grade (ca. 12 years), girls	Human papilloma virus (HPV), 3 doses
10. grade (ca. 15 years)	DTP-IPV

Overall, vaccination coverage in Norway is good, and most infants and children receive the recommended vaccines (Norwegian Institute of Public Health SYSVAK, 2016). From 2011-2015 vaccination coverage on a national scale has been even with only small variations from year to year, and mainly above 91% among 2 year olds (Norgesshelsa, 2017).

The latest statistics for Hedmark County – the location for this research – shows good vaccination coverage at a county level, but with some variation across the county (Norwegian Institute of Public Health SYSVAK, 2016).

However, in 2014 the WHO Europe expressed concern about measles coverage in Norway because of the low coverage in some communities as well as other countries such as the United Kingdom, Ireland, France and Germany (Aase et al., 2015; World Health Organization, 2014b). In January, this year alone there have been 500 cases of measles, many cases in especially Italy and Romania (Norwegian Institute of Public Health, 2017). Research has indicated that the MMR has caused more concern among parents than any other vaccination (Johnson & Capdevila, 2014; Smailbegovic, Laing, & Bedford, 2003). In low and middle income countries infectious diseases are still major causes of death: measles caused nearly 115 000 deaths globally in 2014 (World Health Organization, 2016a). The implementation of new vaccines and programmes has also been difficult in these countries which is especially unfortunate because this is where the disease burden is highest (World Health Organization, 2013). In countries such as India and Nigeria efforts are made to try to ensure high coverage rates. This directs attention to inequalities in health between countries in terms of parents' and children's access to the means of prevention (Andre et al., 2008; World Health Organization, 2014a). The gap in coverage does not only exist between countries, but also within the countries own boundaries. Coverage of rural areas are known to be lower than urban areas (World Health Organization, 2013). This is of concern to high income countries such as Norway because of extensive travel and migration which generates considerable population mixing.

1.3.2 Benefits of vaccination programmes

The goal of every vaccine is to protect the individual, but vaccination-programmes usually also have goals beyond individual protection, such as eradication and elimination of

the disease (Nøkleby, 2015). An eradicated pathogen cannot emerge again, if there are no environmental reservoirs, so this is an ideal goal for vaccination programmes (Andre et al., 2008). Vaccination is also often described as a cost-efficient public-health measure next to the provision of clean water supplies (Blume & Geesink, 2000; Kennedy, Gray Brunton, & Hogg, 2014). This also relates to the fact that universal vaccination programmes, if they achieve good coverage have the potential to reduce health inequalities. As a preventive measure, they also have the potential to save health care costs through a reduction in VPD mortality and morbidity (Andre et al., 2008). Andre et al. (2008) also make the point that control, eradication or elimination of VPDs can help communities and countries save money on a big scale.

1.3.3 Vaccination coverage and herd immunity

To get an infectious disease under control, a particular level of vaccination coverage is needed. Vaccination coverage has been defined “as the number of people belonging to a certain population (i.e. one birth cohort, a group targeted by vaccination campaigns, etc.) vaccinated against a specific disease, divided by the total number of individuals belonging to the same population” (Lopalco & Carrillo Santistevé, 2014, p. 7). Maintaining high vaccination coverage is important in sustaining public and individual health. Sub-optimal uptake of vaccinations is a limitation for it to reach its full potential impact on global health (Thomson, Robinson, & Vallée-Tourangeau, 2016). If coverage is too low VPDs may start to re-emerge (Aase et al., 2015).

Vaccination does not only protect the individual, but can also provide the population with the benefit of herd immunity. Herd immunity occurs when a majority or a sufficient proportion of a population has been vaccinated against a disease, which means that fewer people will be infected thus reducing the chances of an epidemic emerging (Andre et al., 2008; Norwegian Institute of Public Health, 2016). This also protects the people in the

population who for different reasons have not or cannot get the vaccination, such as infants, people with immune deficiency or who have a diseases which means they cannot tolerate the vaccination. The vaccination coverage needed (as a percentage) varies for different diseases but a coverage between 80-95 % is usually required for herd immunity for most common vaccination programs (Norwegian Institute of Public Health, 2016). Specifically in relation to childhood vaccination programmes, for measles the coverage needed is 92-95%, for mumps 90-92 %, for rubella 85-87 % (Norwegian Institute of Public Health, 2016). This coverage rate to stop transmission depends on the average number of expected transmissions from one single case into a susceptible population (basic reproduction number) (Andre et al., 2008). Diseases such as measles have a higher basic reproduction number and require higher coverage to achieve herd immunity, than diseases with a lower basic reproduction such as rubella (Andre et al., 2008). As explained above some diseases can be eliminated without coverage of 100 % due to heard protection (Andre et al., 2008). With these facts in mind and the researcher's background as a nurse and a mother of small children, my curiosity of the subject was sparked and a research question was formed.

1.4 Ethics of vaccination programmes, mandatory or voluntary?

Vaccination was made mandatory for the first time in some European countries in the nineteenth century, due to the epidemics of smallpox that had been sweeping across Europe (Tafari et al., 2014). In Norway in 1810 the 'law on vaccination' was put into effect, with the goal to get more people vaccinated and minimize smallpox epidemic (Moseng, 2003). Only Bayern, Germany had already an existing law. Sweden agreed on a law in 1816, while England did not until 1853. At this time in Norway the 'vaccination law' created a lot of debate (Moseng, 2003). These laws of mandatory vaccination for all children limited the autonomy of parents in order to protect communities from vaccine preventable diseases. Today there is an ongoing discussion in scientific groups on mandatory vaccination.

Governments play an important role in preventing disease and protecting and improving population health. However, governments differ in the degree to which they have made vaccination compulsory. Although childhood vaccination is voluntary in Norway, in the US the vaccination programme is mandatory (with some exceptions), and has been judged to have been essential to maintain and build up needed vaccination rates in some populations (Schwartz & Caplan, 2011). In Australia some welfare benefits are related to adherence towards vaccination (Thurston, 2014). Most analysts argue that obligatory vaccination can be justified ethically, if the actions can be beneficial for the individuals and the community, but there is still a general viewpoint that policies like that should only be used in limited situations (Schwartz & Caplan, 2011; Tafuri et al., 2014). Tafuri et al. (2014) argues that public health's modern view cannot be separated from the principle that individuals have a responsibility for their own health while others differ.

1.5 Research question

The aim of this study is to understand parents' choices in relation to the vaccination of their child(ren). The main focus will be on the Measles Mumps and Rubella (MMR) vaccine, although parents' views on vaccination in the Norwegian childhood programme will be explored as well. The research question is thus: "How can we understand parents' choices relating to the vaccination of their child?" The focus is parents living in municipalities in eastern Norway.

Chapter 2: Literature review

2.1 Introduction

Parents' choice to decline vaccination for their children is acknowledged as a factor for suboptimal uptake (Samad, Butler, Peckham, & Bedford, 2006; Tickner, Leman, & Woodcock, 2006). In order to understand the current state of knowledge concerning parents' choices regarding vaccination for their children a literature search and review was carried out. This was then used to identify a gap that could be the focus of the current study. Alongside this critical review of the research and how this study fits into what is already known and not know, key concepts of relevance to the approach and perspective taken in this research are also discussed.

2.2 From success to controversy?

Since the success of smallpox eradication significant public health efforts have been made to duplicate its success with other VPDs e.g. poliomyelitis. However, although the goal is seemingly within reach, it has proven to be difficult to reach (Schwartz & Caplan, 2011). To an extent it has been demonstrated that it is difficult to maintain herd immunity as high as needed as more parents become critical towards childhood vaccinations (Bond & Nolan, 2011; Harmsen et al., 2012). Andre et al. (2008) make the point that there has been an increase in parents who chose not to vaccinate their children in high income countries over the past decade. As stated vaccinations are not mandatory in Norway, but highly recommended by the Norwegian Institute of Public Health and by professionals working in the health care system. This creates an ethical issue for public health workers and policy makers, whether the emphasis should be on protecting population health or respecting the autonomy of individual parent(s) (Schwartz & Caplan, 2011). Many parents have expressed concerns about the safety of vaccinations (Gowda, Schaffer, Kopec, Markel, & Dempsey, 2013). Even parents who support childhood vaccinations, express concerns and fear of them (Geelen, van Vliet, de

Hoogh, & Horstman, 2016). As the diseases that are prevented by vaccines become less frequent, many parents in the industrialized world appear to be more concerned about the safety and necessity of vaccines than the benefits (Leask et al., 2012). Many health workers and parents may not have experienced diseases that are preventable through vaccination programmes and thus have little or no experience of the severity of them (Bedford & Elliman, 2000; Hulsey & Bland, 2015; Kempe et al., 2011). Research also suggest that parents have created a contrast between what is ‘natural’ and ‘artificial’, in which vaccination is seen as artificial and an intrusion into the ‘natural’ perfect body of a child (Reich, 2016). There is also a belief that one can protect a child against diseases with more ‘natural’ ways, like homoeopathy (Bedford & Elliman, 2000).

At the start of the Norwegian childhood vaccination programme, vaccines have mainly been welcome by the population (Moseng, 2003), from smallpox, tuberculosis, diphtheria, whooping cough, and poliomyelitis. These diseases had been feared by most parents (Moseng, 2003). With poliomyelitis there was even a problem to obtain enough vaccinations for all (Nøkleby & Feiring, 2006). Nøkleby and Feiring (2006) show that the first debate about vaccines in Norway was related to measles. When this vaccine was to be implemented into the children vaccination programme there was a struggle to get the coverage rates up to 80%. This was probably related to the fact that many people had gone through a measles infection, and perhaps questioned the severity of it and the need for the vaccine (Nøkleby & Feiring, 2006). Nowadays in the developed world the burden of most of these diseases has much been forgotten, and other issues that may affect the coverage rates have emerged. These issues have shifted from fear of the disease to the fear of vaccine safety (Andre et al., 2008; Chatterjee & O’Keefe, 2010; World Health Organization, 2015b).

2.3 Vaccine scares

A vaccine-scare was seen in 1970 with vaccination against whooping cough with the Pertussis vaccine. The first vaccine was made of whole-cell pertussis bacteria, which had side effects such as pain and fever, and there was a suspicion that it could lead to brain damage in infants. Vaccine coverage dropped dramatically in European countries and in Sweden the vaccination rate dropped from 90 % in 1974 to 12 % in 1979, until they stopped using the vaccine completely to wait for a safer and more effective vaccine (Gangarosa et al., 1998). This decrease in the coverage rates led to an increase in epidemics among the population alongside an increase in disease mortality rate. Epidemiological research has later shown that the whole-cell pertussis vaccine is safe and that it does not lead to an increased risk of brain damage in most infants (Bedford & Elliman, 2010; Nøkleby, 2015).

Published research by a former doctor (Andrew Wakefield) in the late 1990s, suggested a link between autism, intestinal symptoms and the MMR-vaccine. The research concluded that they did not find any direct link between the MMR-vaccine and autism, and that further research was needed (Wakefield, 1998). This article however received considerable media attention especially in the UK (Johnson & Capdevila, 2014). The article was later retracted, and the link between autism and MMR-vaccine was shown not to be significant (Bedford & Elliman, 2010). Subsequently, however, there was a substantial drop in the coverage of the MMR-vaccine across Europe with concerns about safety of vaccines instead of fear of the disease (Yaqub, Castle-Clarke, Sevdalis, & Chataway, 2014).

Bedford and Elliman (2000) have argued that the media can influence parents' actions. As stated above, the concerns contribute to a drop in the coverage of the MMR-vaccine although complications of measles, mumps and rubella can be severe. Measles can have long-term consequences through neurodevelopmental sequelae, behavioral disorders, mental retardation, and epilepsy (Gans, Maldonado, Hirsch, Kaplan, & Baron, 2015). An infection often gives

fever, head cold, rash, conjunctivitis, and Koplik's spots. Measles can have severe complications and occur as often as in 30 % of the cases. The most common is diarrhea. Most deaths are caused by encephalitis or respiratory tract complications (Gans et al., 2015). Mumps often gives mild symptoms, but can have severe complications such as meningitis, encephalitis, pancreatitis and, among males, orchiditis (Albrecht, 2015). The goal of the rubella vaccine is mainly to prevent foetal damages (Nøkleby, 2015). Rubella is a mild disease in itself, but when a foetus is infected during gestation, it can cause miscarriage or permanent damage to the unborn child, this is called congenital rubella infection. The last case reported in Norway of congenital rubella infection was in 1991, but in other parts of the world such as Asia and Africa this is still a problem and reflects woman's limited access to a vaccination programme (Aase et al., 2015; Nøkleby, 2015).

The phenomenon of vaccine scares has been seen throughout history. Although it seems likely that many factors are involved, the phenomenon of vaccine safety and its connection with vaccination coverage is not new. However, in the last decade there has been an increase in the proportion of parents choosing not to vaccinate their children in some high income countries, despite efforts from international and national health authorities to maintain the level of coverage needed to sustain herd immunity (Blume, 2005; Brown et al., 2010). In Norway the topic of childhood vaccination has been debated a lot in the media in recent times, and a Norwegian actor has participated in the anti-vaccination debate in Norway, especially towards the MMR vaccination. She promoted a different view from that of the Norwegian government, and states that her views cannot be backed up by science, but she still believes that vaccination will be more harmful for her children than to vaccinate them (Hansen, 2015, February 12; Hersoug, 2014, October 5). This suggests that parents' beliefs and actions are not always (if ever) influenced by scientific evidence.

2.3 Outbreaks, concerns and risk appraisal

In England between 1970 to 1983, 270 people died from measles, 144 of these were completely healthy children without any underlying disease (Bedford & Elliman, 2000). In recent years there have been rather large outbreaks of measles in Europe. From 2001 to 2015, 10 000 cases and three deaths have been reported and worldwide it is estimated that measles causes close to 160, 000 deaths a year, and causes permanent damage to children's health (Andre et al., 2008; European Centre for Disease Prevention and Control, 2015).

In between 1999-2000 there was an epidemic of measles in Netherlands, this occurred in a group with low coverage. The result was 3000 cases, five incidents' of encephalitis and three deaths (Norwegian Institute of Public Health, 2016). Ireland also had an outbreak of measles in 2000, in a population with coverage of 75 %. There were 1200 reported cases, and most of those infected were unvaccinated children less than five years of age, two of the children died. Italy had an outbreak in 2002 in an area with low vaccination coverage. The result here was 1500 cases, four deaths and thirteen cases of encephalitis (Norwegian Institute of Public Health, 2016). In 2007, 2008 and 2011 there were outbreaks of measles in Oslo. In 2007 there was an outbreak (in Oslo) amongst 'Irish travellers' and this did not spread to the local population. The outbreak in 2008 was connected to an anthroposophical community, where the first who were ill had just returned home from a journey to Austria. The outbreak was connected to a place with low vaccination coverage. A total of 39 cases were reported: eight of the cases were too young to have received the vaccine (Norwegian Institute of Public Health, 2016; Schmid et al., 2008; Vainoi et al., 2011).

There was recently an outbreak of mumps in a student population in Trondheim (Norwegian Institute of Public Health, 2015). These outbreaks are indicative of low vaccination coverage among some population sub-groups.

Research both (quantitative and qualitative) in a variety of high income countries has shown that many parents continue to be concerned about the safety of vaccines (Brown et al., 2010; Leask et al., 2012; Samad et al., 2006; Stefanoff et al., 2010; Tickner et al., 2006). Concern about the specific effect that vaccination might have on their children's short- and long-term health, overload on infants immune systems, and uncertainty about the safety of the vaccines are reported as reasons why parents choose not to vaccinate or delay vaccination until their child is older (Brown et al., 2010; Hilton, Petticrew, & Hunt, 2006b; Smailbegovic et al., 2003; Yaqub et al., 2014). The research suggests that new vaccination are seen to cause more scepticism towards vaccination, especially when the disease the vaccination is aimed at is seen as mild (Dubé et al., 2015; Harmsen et al., 2013). Qualitative research from Netherland explored the decision-making process amongst parents who visit anthroposophical child welfare center. They identified several factors that influenced parents' vaccination choices. These were risk perception of diseases and about the effectivity of the vaccine (and its components), perception on health, lifestyle, beliefs about childhood diseases and trust in institutions. They also found that most of these factors concern parents' in general (Harmsen et al., 2012).

Smailbegovic et al. (2003) did a mixed methods study with UK parents and found that one third of the parents who decided not to vaccinate, considered the vaccine to be more harmful than the disease itself. They also found that parents perceived MMR to be more dangerous than other vaccinations. Concern about MMR was also found in a UK study by Brown et al. (2012). They found that many parents had worries about adverse events following vaccination, vaccine content, efficacy and immune overload of the three component vaccine. Stefanoff et al. (2010) conducted a quantitative study across five European countries (England, Norway, Poland, Spain and Sweden), and English parents were seen to be the most doubtful, with 28 % of parents expressing concerns about the safety of vaccines, followed by

the Norwegian and Polish parents (20 %), and then Swedish (17 %) and Spanish (12 %). Given the high degree of trust Norwegian population have in government sources (Kleven, 2016), this statistics is surprising. The most common reason expressed among the parents with doubts was: fear of adverse events of vaccination, the 'supposed' association between MMR-vaccination and autism, the safety of the vaccine and its long term effects. According to Stefanoff et al. (2010) England also had the lowest uptake of the MMR vaccine (85%) and it was reported as the vaccine that most of the 'doubters' in England expressed concerns about. Measles, mumps and rubella were also ranked as less serious diseases than other VPDs compared to all the countries in the study. However the corresponding vaccination coverage rates among 3-year-old children (2008) were 93 % in Norway, 96 % in Sweden, 98 % in Poland and 95 % in Spain (Stefanoff et al., 2010). The low coverage in England may be linked to the vaccine scare of MMR mentioned above, and the debate about it that continues in England, especially in the popular media (Bond & Nolan, 2011). This, however, may suggest that parents 'doubt' the safety of the vaccine but may still vaccinate their child as Norway still has good coverage (93%) even though 20% of parents had concerns. This shows that the phenomenon is not straightforward, and suggests that parents may evaluate things in various ways may be more fluid than is more commonly believed.

Bond and Nolan (2011) concluded in their qualitative research with Australian parents that they tended to consider their -perception of risk of the disease, and the vaccine alongside a subjective feeling of their child's robustness. This is congruent with the findings from a qualitative UK research study by Hilton et al. (2006b) that found that parents assessments of their child's immune system and their perception of how it would 'cope' with a combination of vaccines or the disease, was a factor in giving vaccination or not to their child. They explained that parents fear that infants' immune systems are not developed adequately to

handle vaccination and, relatedly that vaccines would ‘overload’ their infants’ immune system. This was also found in a Dutch study by Harmsen et al. (2013).

Gross, Hartmann, Zemp, and Merten (2015) did a qualitative study on Swiss parents who chose not to fully vaccinate their children. They found that measles, mumps and rubella was the disease that most parents reported having as a child. Many of the parents in this study described symptoms of these diseases as mild. This is congruent with findings from the study of Stefanoff et al. (2010). Bond and Nolan (2011) concluded that the risk of the disease on the other hand was often based on whether the disease was familiar or unfamiliar to the individual. This suggests that diseases that are familiar to parents tend to be seen as less severe, possibly because they survived them and their recollection of severity may be diminished by the time elapsed since contracting the disease. A qualitative UK-based study by Hilton, Hunt, and Petticrew (2006a) found that measles was the disease that most parents reported as having as a child. Parents in the study explained the symptoms of measles as having itchy spots, sore running eyes and flu-like symptoms. Tickner, Leman, and Woodcock (2010) did a qualitative study amongst parents of preschool children in the UK. They found that whether or not vaccination was perceived as important was based on personal experience of the disease or prior knowledge of adverse events of vaccination. As stated above research shows that some parents also question the efficacy of the vaccinations provided and point out that some of the vaccine preventable diseases were declining before the relevant vaccine came out (Bedford & Elliman, 2000).

A factor identified in a review by Serpell and Green (2006) is controllability of risks. This is related to the extent that parents feel like they can reduce risks through their own actions. The research suggests that parents feel they cannot control the outcome of vaccinations, hence they see VPDs as something they can control through limiting the exposure to infection risk (Smailbegovic et al., 2003). This correlates with findings from the

review of qualitative research by Brown et al. (2010) which found that parents felt that with good nutrition, minimal contact with other children (contagious), protection from other harms, and by taking relevant actions in the event of disease they could control the presence of disease in their children's life. Therefore, they viewed vaccination as unnecessary.

2.3.1 Natural VS artificial immunity

Another important concept many studies have explored is that some vaccine decliners or delayers have a strong belief in natural immunity and a naturally acquired immunity (Bystrom, Lindstrand, Likhite, Butler, & Emmelin, 2014; Dubé et al., 2015; Gross et al., 2015). In a Canadian qualitative study by Dubé et al. (2015) natural immunity was highly valued and was seen as lifelong in contrast to immunity provided by vaccines which was seen as poor and temporary. Gross et al. (2015) also found that childhood diseases were seen as a part of the natural way to strengthen the immune system, and to acquire natural immunity, and thus diseases were not perceived as a threat. Reich (2016) did a qualitative study on US parents, and found that parents tended to view their newborns as natural and perfect and vaccination as an artificial intervention entering the body in an unnatural way. This was related to their experience with birth and infants were viewed as flawless and in need of parental protection.

Research has found that some parents believed that some of the childhood diseases develop children mentally and physically after undergoing an infection. This was seen especially (but not only) in the studies done with parents with anthroposophical worldviews (Bystrom et al., 2014; Dubé et al., 2015; Harmsen et al., 2012). Bystrom et al. (2014) did a qualitative study regarding MMR-vaccine in an anthroposophical community in Sweden and also found that there was a preference for natural immunity, and a belief that an infection with measles would lead to both cognitive and physical development in the child after undergoing an infection. This is congruent with a Dutch study done with parents who used an

anthroposophical health center (Harmsen et al., 2012). Harmsen et al. (2012) found that there was a common belief amongst some of the parents in the study that the so called ‘childhood diseases’ were essential for the development of children.

2.4 Vaccine-hesitancy

The Strategic Advisory Group of Experts (SAGE) on immunization is a group established in 1999 by the WHO, to provide guidance regarding vaccination (World Health Organization, 2016b). In recognition of the issue of ‘vaccine-hesitancy’ they established The SAGE Vaccine Hesitancy Group in 2012 (Larson, Jarrett, Eckersberger, Smith, & Paterson, 2014). Vaccine-hesitancy is a term that emerged during the review of the literature. The WHO (2015, p. 1) has defined hesitancy in this way: “Vaccine hesitancy refers to delay in acceptance or refusal of vaccines despite availability of vaccination services. Vaccine hesitancy is complex and context specific varying across time, place and vaccines. It includes factors such as complacency, convenience and confidence”. The term is used for parents who are in a continuum of acceptance and refusal of vaccine for their infants; they may accept some vaccines and refuse others (Larson et al., 2014). Before this term was used the characteristics of individuals tended to be viewed as more concrete; those who were pro-vaccine or anti-vaccine. More recent research suggests that parents thinking and actions are more complex than this simple and static dichotomy suggests. Vaccine hesitancy has been identified as one of the reasons for suboptimal vaccination (Ames, Glenton, & Lewin, 2017). Dubé et al. (2015) point out that vaccine –hesitant parents may be of particular interest to public health workers. Yaqub et al. (2014) found in their review of primarily qualitative research that the phenomenon was not rare, and concluded that if the focus of public health was solely on achieving the necessary coverage rates, it would neglect the challenge of maintaining coverage rates in the future. A Cochrane Review (2017) points out that there are different factors that influence vaccine hesitancy among parents, and that they seem to fall

into three fields: individual, group and contextual influences. Contextual influences include health systems and socio-cultural factors such as media including social media, influential leaders, politics, religion, historical influences (The Sage Vaccine Hesitancy Working Group, 2013). Individual and group influences include individual evaluation of risk and benefits, and personal perceptions of a vaccine (Ames et al., 2017; The Sage Vaccine Hesitancy Working Group, 2013). The research also shows that media, including social-media, can have both positive and negative influences on parents' views of a vaccine. Social media is an open channel that allows users to comment freely on their and other people's opinions and experiences, which can facilitate social network organizations to organize themselves either for or against vaccination (The Sage Vaccine Hesitancy Working Group, 2013).

2.5 Trust in government sources and health care personnel

According to a review by Brown et al. (2010) another factor influencing choices is levels of parental distrust of health care personnel and government sources. If parents distrust the government in general, they are less likely to have trust in vaccine information provided by government sources (Serpell & Green, 2006). However, many studies have indicated that parents view health professionals as the most trusted and used source of vaccine information (Austvoll-Dahlgren & Helseth, 2010; Benin, Wisler-Scher, Colson, Shapiro, & Holmboe, 2006; Bond & Nolan, 2011; Brunson, 2013; Fadda, Depping, & Schulz, 2015; Stefanoff et al., 2010; Tickner, Leman, & Woodcock, 2007) . Public health institutions were also seen as trusted sources of information. A study from the US found that parents who considered refusing or delaying a vaccination for their child, gave credit to the child's health care personnel for changing their mind (Gust, Darling, Kennedy, & Schwartz, 2008). This indicates that health care providers play an important role in vaccination programmes, and can assist parents in making their vaccination choices. There is a need for more information on

what parents take into account when they make choices relating to vaccination for their children. This study can provide insight into parents views on this.

2.6 Other reasons for refusal and hesitancy

Research has shown that there are also other factors that influence parents' vaccine choices. Tickner, Leman, and Woodcock (2007) found that some parents vaccinate because they think it is expected of them, and not because they considered it to be important. Other research indicate that those parents who choose to vaccinate their children tend to view vaccination as the 'normal' thing to do and that not vaccinating a child tended to be linked to being a 'bad' parent (Brown et al., 2010). Some parents view themselves as not capable of making a choice regarding vaccination for their child, because they do not understand the information given by health authorities, and relied solely on health professionals to make the choice for them (Fadda et al., 2015). Others in the same research stated that they went with their 'gut feeling' when making vaccination choices for their children (Fadda et al., 2015). This suggests that there is a strong emotional element to the choices that parents make about vaccination.

One of the groups in Europe that has relatively low vaccination coverage are those communities based on Anthroposophical philosophy (Bystrom et al., 2014). Anthroposophy is a life philosophy founded by Rudolf Steiner, an Austrian philosopher in the 20th century. This philosophy includes a holistic view on health, and the lifestyles of those following this philosophy often include a biodynamic diet and restrictive use of antipyretics and antibiotics. (Bystrom et al., 2014; Harmsen et al., 2012). The philosophy of Rudolf Steiner is the basis of the pedagogy used in Waldorf-schools and anthroposophical medicine (Bystrom et al., 2014). Gypsies, Roma and Travellers are other groups with lower coverage of MMR, and higher number of Measles outbreaks (D. Smith & Newton, 2017).

A quantitative study carried out in Liverpool found lower rates of vaccine completion, in children with older siblings and children living with a lone parent (Pearson et al., 1993). The authors concluded that this reflects more of the practical issues of getting a vaccination such as geographical barriers, living far away from the health centers or being a lone parent with many responsibilities, having no car, or time to take the child to the health center. Samad et al. (2006) also found that a common reason parents gave for not being vaccinated, was that the child was sick or unwell at the time of vaccination appointment, that they had difficulties keeping an appointment or had limited access to health services. This suggests that vaccination programmes may need to be more flexible in terms of following up some parents and offering alternative appointments.

Research suggests that there are several additional factors that have been linked to incomplete immunization. For example demographic characteristics such as parents having lower income, lower educational attainment, being a single parent (Brown et al., 2010). On the other hand some studies have found associations between higher levels of socioeconomic status and being against vaccination (Hak, Schönbeck, Melker, Essen, & Sanders, 2005; P. Smith et al., 2011). This finding is consistent with findings from a study by Smith, Chu, and Barker (2004) who found that parents who refused all immunizations, were more likely to live in suburban neighborhoods, and have a high family income and were also more likely to have a college/university degree. Parents who refuse vaccines tend to believe them to be unsafe and ineffective, they also have a low perceived risk of the diseases the vaccines are given to prevent (Brown et al., 2010). This suggests that the reasons for vaccine refusal or delay might not necessarily be the same across different socio-demographic groups.

2.7 Conclusion

The research shows that how parents make choices regarding vaccination for their children is a complex issue (Brown et al., 2010). Part of this complexity also varies across

social groups, but reasons parents give for their choices may be different e.g. related to the practical aspects of being a single parent or related to the likely better information and ability to act on it among more middle class parents. As the research reviewed above suggests, influences on choices are multifactorial and not static, that is to say, can change over time and situation. The explanations that parents give are likely to be complex and unlikely to be a matter of ‘rational decisions’. In the research on this phenomenon there is a tendency to use a language that implies parents make ‘rational decisions’ based on their evaluation of statistical risk. Much of the language also suggests that parents’ choices are static and objective, common words to describe parents as: non-vaccinators, anti-vaccinators, pro-vaccinators, and hesitant reflect this issue. But parents tend to change their views over time and this needs to be seen in a broader context (Leask et al., 2012; Thurston, 2014).

2.8 The ‘gap’ and my contribution to the field

Bond and Nolan (2011) point out that to achieve high levels of childhood vaccinations, there needs to be a better understanding of how parents perceive diseases and also their consequent decisions about vaccination. This requires an in-depth qualitative approach to understand the phenomena from the worldview of the parents. To the best of the researcher’s knowledge there has not been carried out any qualitative studies on parents’ views on vaccination in Norway. If a better understanding of the factors that influence parents’ choices about vaccination, can be obtained, it can help inform the development of more acceptable and effective approaches to maintaining high vaccination coverage up to the level needed (Ames et al., 2017). Dubé et al. (2015, p. 412) point out “that qualitative studies are needed to better understand the causes and expressions of vaccine ‘hesitancy’ and parental decision in general”. Brown et al. also (2010) point out that qualitative studies may have more potential to explore the choices that parents take regarding vaccination for their children, and through that may be able to influence parental decisions, and improve uptake. But there are also the

ethical aspects of vaccination that have to be mentioned here. There is a tension in public health that relates to respecting the individual's autonomy alongside protection and improvement of population health. Determining how to weigh up the responsibility to protect the population versus the individuals autonomy is something that needs to be discussed (Schwartz & Caplan, 2011). This 'tension' may be particularly difficult to handle in countries like Norway, because, as Blume (2005, p. 639) points out, in the countries of the 'industrial north' (as he calls it) people expect to have autonomy, and with that the right to making informed choices regarding vaccination.

Chapter 3: Theoretical considerations

3.1 Introduction

This chapter relates to the theoretical background and orientation of the study. This study was informed by a ‘modified’ grounded theory approach (explained further below). Thus, in keeping with qualitative research more generally, it used a primarily inductive approach that aimed to build theory from the data generated. In qualitative research the aim is to gain an understanding of participants’ views of a particular phenomenon. The focus is on individual meaning and understanding, and the significance of the complexity of a situation from the perspective of those studied (Creswell, 2014). In this study the aim was to understand parents’ views about the vaccination choices they were making. Dunne (2011) points out that in grounded theory in particular a researcher can avoid the use of a specific theoretical framework, to make sure that the analysis is not carried out through a specific theoretical lens. Therefore this study did not make use of a specific theoretical framework. However, because extensive reading of research was carried out prior to data generation and analysis (and returned to at various points in the research process) a critical appreciation of theoretical ideas that had been used in previous research was developed. From this reading, a number of theoretical concepts were identified of potential value in the inductive theory building process, that is to say, in the development of analytic categories, as it became clearer which concepts might add explanatory power to the empirical data and therefore could usefully be incorporated at a later stage. Such concepts are often referred to as ‘sensitising concepts’ (Bryman, 2012; Charmaz, 2014). One of the advantages of using the principles of grounded theory in this study was that the researcher was better placed to avoid the use of a theoretical lens when analysing the emerging data. This leaves more room for a broader understanding of individuals’ lifeworld’s to be developed (Dubé et al., 2015).

In grounded theory the emphasis is on theory emerging from the empirical data (Bryman, 2012). Thus, the generation of data, analysis and an eventual theory stand in close relation to each other (Bryman, 2012). This raises a question on where the use of existing literature should be in grounded theory. Although the founders of grounded theory – Glaser and Strauss – argued against the use of a literature review prior to the data collection, views on this are contested (Dunne, 2011). A literature review was conducted in this dissertation on the basis of the following arguments. First of all it would not have been possible to postpone the literature review in this thesis because of the scientific and educational demand to identify a ‘gap’ in the literature and develop a rationale for the study. The points stated above also need to be in the application for the ethics approval. Dunne (2011) points out some benefits of conducting an early literature review, which include those mentioned above. In addition he argues that it can give convincing reasons for why it is worth studying and how, it can make sure the study has not been done before and at the same time find small gaps in the literature. It can also help put the study in context and simultaneously give ideas on how the phenomenon has been previously studied, and it can help the researcher in developing ‘sensitizing concepts’.

Charmaz (2014, p. 30) has referred to sensitizing concepts as something that can offer the “researcher initial but tentative ideas to pursue and questions to raise about their topic. Sensitizing concepts can provide a place to start inquiry, not to end it”. In other words, the research starts with some theoretical ideas but ends with more refined theoretical understandings that relate to the specific phenomena studied. In this regard the rest of this chapter is dedicated to some of the sensitizing concepts that have been used in research on preventive health choices in general and vaccination choices in particular as a starting point as well as a guide throughout this study. After the literature review, some concepts came out as important in parents making vaccination choices. With that said the key terms of this study are health beliefs, risk, and emotional capital which are explored briefly below.

3.2 Health beliefs

In the literature on vaccination choices, it has been common to use theoretical models such as the Health Belief model (HBM) or other similar theoretical models based on psychological constructs (Bond & Nolan, 2011; Mergler et al., 2013; Smailbegovic et al., 2003; P. Smith et al., 2011). The HBM is a model that was developed in the US in the late 1950s by Rosenstock, Derrberry and Carringner to describe and explain why parents failed to vaccinate their children with the poliomyelitis vaccine (P. Smith et al., 2011). The HBM has an attitudinal approach to behavior change in that it focuses on education, and is based on the premise that people will change their behavior if they have good information about the health intervention (Taylor, 2015). It contains a number of constructs: perceived susceptibility (person's belief of the chances of getting a disease/condition), perceived severity (person's belief of how serious a condition is and its consequences), perceived benefits and perceived barriers (person's belief in how efficient the measure is to reduce the risk of the impact, and person's belief in the substantial and psychological costs of the advised behavior). These constructs can be used to determine a person's 'readiness to act'. 'Cues to action' is another construct in the theory that refers to strategies that can activate 'readiness' to stimulate the desired behavior (in this case, for parents to choose to vaccinate their child). However, the HBM was not used deductively as a theory in this research, although some of the constructs of HBM were used as sensitizing concepts during the analysis. For example perceived susceptibility of the child and perceived severity of VPDs, and perceived benefits of vaccination were used, based on reflections during and after the interviews and an initial reading of the transcripts. However, drawing on the criticisms of this model for exploring health actions in context, additional constructs were sought. Criticisms towards this model are that it emphasizes that people (in this case parents) make conscious and rational decisions as long as they have good information to base their decision on (Taylor, 2015). Bond and Nolan

(2011) suggest that to some extent the HBM model can be used to explain vaccination choices. However, they also found that models of risk perception and decision making added more explanatory power to the understandings of these choices. With that said the concept of risk will be further explained in the next section.

3.3 The concept of risk

In general terms risk refers to the uncertainty of an event; that is to say, something that is more or less likely to occur. In contemporary society new forms of risk have arisen through technology and science (Beck, 1992), and the expansion of vaccination programmes is an example of this phenomenon. The concept of risk in public health, has often been applied to understanding particular health behaviors using a rational decision making process. This ‘objective’ view of risk indicates that a person’s health beliefs are influenced by statistical risk information, which is weighed up rationally and used to predict subsequent behavior (Thurston, 2014). For example, some parents may see more ‘risk’ in the preventative action of vaccination than the disease itself even though in objective statistical terms this is not the case (Bedford & Elliman, 2000). Numerous studies have been carried out on perception of risk in relation to vaccination, and parents ‘attitudes’ have been found to be important in their estimation of vaccination uptake (Bond & Nolan, 2011; Gowda et al., 2013; Smailbegovic et al., 2003). With that said Bond and Nolan (2011) found that parents subjective appraisal of risk relates to their emotions relating to how robust their child was seen to be, alongside disease- and vaccine risk, but also their perceptions of the controllability of risk as well as their evaluation of risk of the disease being not equally spread in the community. According to this view, the phenomenon of reduced uptake is not about parents ‘misunderstanding’ or ‘misconception’ of risk (Thurston, 2014). The subjective emotions of parents relating to their child’s robustness take us to the next sensitizing concept.

3.4 'Emotional capital'

The attention a parent gives to their child is probably one of the greater attentions that can be given to someone (Leach & Fairhead, 2007). Parents typically invest in their children, and are encouraged to do so. They are also required to evaluate risk, arrange children's opportunities, and address possible barriers to their success. Yet parents are held responsible for the outcome of these choices, mothers in particular (Reich, 2016). Choices regarding childcare can cause great anxiety, because it demands intense personal reflection, and much social interest (Leach & Fairhead, 2007). Reay's (2004) research on mothers and their involvement in their children has drawn on Bourdieu's construct 'capital', which she has taken into the field of emotions, and uses the construct of 'emotional capital' in her study. Although her paper looks at mothers' role in their children's education, the concept of 'emotional capital' was found to be useful in exploring more broadly mothering and mothers' vaccination choices. However, it does not seem to have been used in the vaccination field before, to the best of researchers' knowledge. According to Reay (2004) women engage in more 'emotional labour' than men, including responsibility for the maintenance of the emotional aspects of relationships within the family. Emotional labour is about the emotional (feelings) investment that parents – and mothers in particular – make in caring for their children. Emotional capital can be understood as the total asset of emotional resources in a family, built up over time. Reay (2004) explains further how women in her studies experienced a wealth of emotional feelings regarding their children's school experience, such as anxiety, guilt and frustration, but also encouragement and empathy. She found in her studies that positive emotions can sometimes have negative consequences' for children, although many of the emotions that women felt and communicated to their children as a way of support, could have both positive and negative outcomes. In this context and regarding the relevance of this research to this study, it refers to the emotions women experience when

having to make a choice on vaccination for their newborns. Feelings about caring interwoven with health beliefs about how to best care for their children combine to shape how they appraise various risks. Emotions women feel from the birth of their children, as something natural, and that their newborn is uncorrupted and complete as Reich (2016, p. 106) puts it. Dilemmas that can arise with this view of the newborn, is that these 'uncorrupted' babies cannot handle the potential exposures of the world, vaccination being one of these exposures (Reich, 2016) over which women have some control. To conclude this review of these sensitising concepts provide a framework for exploring the data in a way that may lead to a more refined theoretical account of how parents (predominantly mothers) make these choices. It seems to challenge psychological models that put more emphasis on rational decisions based on information as well as situating women within the social relationships of family and the wider community.

Chapter 4: Research process

4.1 Research setting

This chapter sets out the details of the study from start to end. Key steps in the research process are explained alongside strategies used to build a robust research approach. The purpose of this study was to understand parents' choices on vaccinating their child. Hedmark County was chosen foremost for practical reasons, as the researcher was living and working as a health professional in the county. However, different municipalities in Hedmark County vary in vaccination coverage of the MMR vaccine. Some of the municipalities had a lower coverage of MMR (2014) than Norway as a whole (Norwegian Institute of Public Health SYSVAK, 2016). This suggests that Hedmark is a useful place to study to get a diverse sample of women, some of whom did and did not have their children vaccinated.

4.2 Research strategy

A qualitative approach is an appropriate strategy when the goal is to understand a phenomenon in-depth in order to understand its complexity (Hilton et al., 2006b). Therefore it was suitable for the purpose of this study. An advantage of qualitative approaches over quantitative is that it provides an opportunity to explore new data continuously throughout the process, even late in the analysis. This flexibility offers a chance to gather rich data and explore subjects that may emerge during the data gathering (Charmaz, 2014). Charmaz (2014) indicates that rich data can reveal the participants' structures and contexts but also their subjective feelings, views, intentions, and actions. This was important in this study because of the complexity of the issue, as previous research indicates that parents' choices to either accept or refuse vaccination for their children is multi-factorial (Dubé et al., 2015; The Sage Vaccine Hesitancy Working Group, 2013). Qualitative research has been criticized for being subjective and impressionistic, because the research is developed on what is significant for the researcher and due to the relationship between the researcher and the participants (Bryman,

2012). The researcher tried to overcome this by asking open questions that were not too restricted as well as avoiding leading questions, in order to get a more detailed understanding of the participants' choices, as recommended by Bryman (2012)

Qualitative research is constructionist and interpretivist. The constructivist worldview or social constructivist argue that “individuals seek understanding of the world in which they live and work” (Creswell, 2014, p. 8). The epistemological position of interpretivist means that the focus is on understanding the social world through the examination and interpretation of the participants world (Bryman, 2012). Drawing on this, the interpretive understanding in this study, related to how parents make choices on vaccination for their children. The aim was to understand this process in detail.

4.2.1 Study design

The study design chosen to explore the research question was cross-sectional. This means that the data were collected at a single point of time, and gathered from more than one case (informant) (Bryman, 2012). A better design for this study might have been a longitudinal one, as it would have been useful to meet the participants before the MMR-vaccination of their child, around vaccination time and after, to explore parents' views at these different points. However due to the timescale and resources for this Master project, a longitudinal design was not feasible (Bryman, 2012). The limitation of a cross-sectional study design is discussed further in the discussion chapter.

4.2.2 Data collection method: semi-structured interviews

The research method used was semi-structured interviews. This method was chosen because it allowed the researcher to gain insight into the parents' views (Bryman, 2012). A review by Mills et al. (2005) points out that semi-structured interviews provide the most insight into the views of a participant. Semi-structured interviews are neither an open everyday conversation nor as closed as a questionnaire. In the context of this study this

flexibility was appropriate, as it was of interest to get the parents' points of view in detail about a phenomenon – choices about vaccination – they had direct experience of. It also allowed new questions to be asked in order to follow up on participants' responses. Questions and techniques such as silence, specifying, structuring, probing, indirect and direct questions were used to follow up on what the participants said, as recommended by Bryman (2012) and others. Charmaz (2014) mentions to choose questions with caution, and ask them at a slow pace so that the participant has time to reflect. The interview followed a guide with topics and question suggestions (Kvale & Brinkmann, 2009). Charmaz (2014, p. 91) says this about constructivist interviewing: “the interview becomes more than a performance. Instead it is the site of exploration, emergent understanding, legitimation of identity, and validation of experience”. Kvale and Brinkman (2009, p. 3) say of semi-structured life world interviews: “an interview with the purpose of obtaining descriptions of the life world of the interviewee in order to interpret the meaning of the described phenomena”. Although the views and experiences of the participants cannot be fully reproduced, the researcher must endeavour to enter their lifeworld. To see through the participants 'eyes' gives the researcher views that otherwise would be unobtainable (Charmaz, 2014). This was attempted by keeping the structure of the interview to a minimum, as recommended by Bryman (2012).

The original interview-guide consisted of ten questions, but after doing the pilot interview some new themes emerged that needed further exploration. Therefore, some changes were made to the interview-guide during the process. Examples of these changes were to add some sub-questions to existing questions such as “elaborate where they got information from vaccines from”, and to reformulate the questions to where the parents were in the vaccination programme, if they were considering, had delayed, refused, or given vaccination for their child. Grounded theory is a methodology that allows this flexibility and

permits the researcher to pursue issues and ideas as they emerge during the interviews (Charmaz, 2014). The original interview guide can be found in Appendix 4.

An important point when doing semi-structured interviews is the issue of involvement-detachment of the researcher (Elias, 1987). Charmaz (2014) and Denscombe (2014) mention the importance of going into a project with an 'open mind'. This means that the researcher should try to put their prior conceptions aside. However, it is unavoidable that the researcher will be influenced by prior conceptions based on their own personal and professional experience and culture (Denscombe, 2014), which includes their education. In relation to this project, the researcher has recognised that she has prior conceptions as a nurse and a mother of a young child who has been fully vaccinated, and a positive image of childhood vaccination. However, during the whole research process but particularly during interviews and analysis, efforts were made to try to view things in a detached manner so that preconceptions did not unduly 'colour' the data gathering and analysis. The researcher tried to keep an appropriate blend of involvement and detachment, to stay empathic to the interviewee and the data emerging, and to make sure that the appropriate focus of the inquiry was pursued (Perry, Thurston, & Green, 2004). It was out in the open to the research participants that the researcher was a nurse, but with no expertise on vaccination. When questioned if the researcher had any children, this was confirmed, but the vaccination status of the child was not communicated to the parents, to try to keep an appropriate blend, or to stay neutral on views on vaccination. During interviews the researcher found it to be difficult to keep the appropriate blend of involvement and detachment, for example, when similar views were expressed, it was difficult not to give support to those feelings, nor to be judgmental when opinions far from the researcher's own were expressed. However, an effort was made to listen carefully, and be alert to what was said, and not express agreement or disagreement with the interviewee, as Bryman (2012) has recommended. Denscombe (2014) also points out the

importance of remembering the effect the interviewer can have on the interviewee. People respond differently depending on how they perceive the interviewee, and this can potentially have consequences for the richness of data gathering (Perry et al., 2004). Seeing as the parents in this study was aware of the researcher role as health professional (as well as a master student) was something that could possibly influence the parents and how they responded to the interviewee, because as a 'health professional' it is unlikely that they viewed the researcher as 'neutral' to the topic of childhood vaccination. And effort was made to assure the parents of the neutral position and that it was their narratives that was interesting to the study. A deliberated naïve approach was used by the researcher to get the parents to elaborate their answer, this was used especially when the parents used terms as 'natural' or 'alternative', to get their meaning of terms. This approach is recommended by Kvale and Brinkmann (2009) to avoid predetermined questions. The interviews took place in participants' homes or in a rented room in a library in Hedmark to provide a confidential space in which participants could feel safe and secure, and to avoid interference or interruptions. Kvale and Brinkman (2009) state that an interview stage should be encouraging to the participants to make them want to describe their thoughts and worldview. An effort was made to develop rapport with the participants, and make sure they knew that the information given during the interview would be treated with respect. The researcher started by explaining how the interview would be conducted, emphasising that it was confidential.

The researcher tried to make the participants feel at ease by opening the interview with general questions such as; "Can you tell me about when you first started thinking about the childhood vaccination programme?" Participants were given time to reflect and to speak freely around the questions before next question was raised, they were also encouraged to elaborate their answers, to get detailed responses in each interview. It was also emphasized that there were no right or wrong answers, and that it was their views on the subject that were

of interest. The researcher explained that she was not an expert on vaccination, so if there were any concerns or questions about it they should take it up at the health centres. The interviews lasted approximately from twenty minutes to one hour. The interviews were audio recorded and transcribed verbatim.

4.3 Grounded theory (GT)

Grounded theory is a method that was developed in the 1960s by the sociologists Glaser and Strauss (Bowen, 2006). This research was inspired by theorists such as Glaser and Strauss (1967), Charmaz (2014), and Granheim and Lundman (2004). Primarily the study was informed by grounded theory and the principles outlined by Charmaz (2014). Grounded theory is both an inductive and deductive approach. It is inductive in the sense that it aims to generate theory from the data, but also deductive because throughout the research process concepts are used to guide and frame the study, especially in relation to the process of analysis informing the process of sampling - so called theoretical sampling (Bryman, 2012). Although the researcher wanted to sample theoretically, this was not possible due to the lack of time and resources in this research project. Grounded theory was chosen because it is appropriate for research on social relations and processes (Granskär & Höglund-Nielsen, 2012). This can be related to this study of parents making vaccination choices, and the process of making the choice can be viewed as a social process where parents interact with others, for example, when they seek advice from and discuss with other individuals, including other parents, family members, partners and health care personnel. Charmaz (2014) also points out that it is a good design when the topic has not been the source of much previous inquiry. Since the topic chosen has not been the source of any qualitative inquiries in Norway (to the best of the researcher's knowledge), this is also suitable for this study. This is because grounded theory does not demand that the methods should rigidly be determined before the generation of the data, but rather that the methods can be developed as the researcher decides

what lines of enquiry to follow in order to shed light on the research question during the data gathering process (Charmaz, 2014). This way avoids ‘forcing’ the data to fit in a predetermined theory, and instead finds data that suits the gathered data (Charmaz, 2014; Denscombe, 2014). This was applicable to this research study, with the use of sensitising concepts and going back and forth between the analysis and the data as well as the literature.

4.4 Recruitment of the sample

Parents of children from 5-24 months old, registered at health centers in Hedmark County were the target population. This age group was chosen to get parents in different stages of the vaccination programme process, and include diversity of the sample. Also, because it is when the MMR vaccine is given as well as most of the other vaccination in the programme. The parents were recruited through the public health nurses (gatekeepers) in different health centers in Hedmark county. The public health nurses agreed to be gatekeepers in the study. They gave out an information sheet about the study to the participants in the target group, that is to say, those who were parents with children in the age group from 5- to 24 months, this was given out to parents when they visited the health centres (appendix 2). The recruitment period was from December 2015 to 1st of March 2016. Those who were interested in participating in the study received a consent form, from the researcher at the time of the interview (appendix 3). Both forms are elaborated in the next section. The aim was to get some participants who were thinking about vaccination, some who had chosen to give it and some who delayed or declined vaccination for their children. The process of recruiting informants was more difficult than anticipated. All participants were welcoming, interested and polite individuals, which contributed to strengthening the researcher’s motivation to go further in this project. At the end of the recruitment period, a relatively small sample of eight informants had been recruited, seven women and one man. Four of the informants had given their children all vaccinations offered as part of the Norwegian child programme and four had

delayed or declined some or all vaccinations for their children. All of the informants spoke fluent Norwegian, and where either Norwegian or had lived in Norway for several years.

4.5 Ethical considerations

Researchers are required to consider several ethical issues when conducting interviews for research purposes. These issues go beyond just the interview, but exist through the whole inquiry process (Kvale & Brinkmann, 2009). Underlining respect for the individual human being should be the fundamental base for all social research. Principles such as avoiding harm to the participants, respecting the anonymity and confidentiality through protecting the individuals' right to privacy, and respecting consent and withdrawal at any time are of important ethical principles (Bryman, 2012). With that said research should not only be about the scientific value of the research, but, especially in public health context, should also have the purpose of improving the conditions studied if possible, as this can further increase the ethical value of the research.

In this study, the informants were given a participant information sheet about the study through the public health nurses in the health centres. The sheet had information about voluntary participation and explained that they could withdraw from the study at any time without giving any further reasons. It also explained that their participation in the study would not in any way interfere with their relationship with the health centres or health care provider. It also explained that the interviews were audio-recorded and subsequently transcribed verbatim (appendix 2). Data were anonymized- so that none of the informants could be recognized in the study. All data were destroyed at the end of the project. A 'fremleggsvurdering' was sent to REK, the Regional committee for medical and health professional research ethics, because the researcher was uncertain if this study would be under the category of medical research. However, it was not (appendix 6). An application was sent to NSD and approval to go through with the study was given. All the informants signed a

consent form indicating their willingness to participate in the study (appendix 3). The approval from NSD can be found in (appendix 5).

4.6 Data analysis

One of the main challenges in qualitative research is the analysis, because of the large volume of generated data that can be gathered through transcription of interviews, and notes (Bryman, 2012). The main purpose of the analysis is to uncover significant ways of understanding the participants life views in the large volume of gathered data, and ultimately contribute to the existing literature of the phenomenon studied (Bryman, 2012). Data analysis was carried out according to grounded theory principles outlined by Charmaz (2014) using, initial coding, focused coding and theoretical coding/development of categories. In grounded theory the researcher is not interested in the testing of hypotheses of existing data, but rather aims to develop new theories or concepts (Dunne, 2011). That is to say, in this study, it related to how parents make choices regarding vaccination for their children. Thus it is important to mention that this is not a grounded theory study, but a qualitative study informed by grounded theory principles.

There has been some debate about what attributes a study needs in order to be classified as a grounded theory study (Sbaraini, Carter, Evans, & Blinkhorn, 2011). This study lacks some of these attributes and can therefore not be called a grounded theory study. Sbaraini et al. (2011) point to some fundamental components that have to be in a study for it to be called grounded theory. These are: openness, immediate analysis, coding and comparing, memo-writing, theoretical sampling, theoretical saturation, production of a substantive theory. The concept of openness refers to the inductive process, and that the study may develop during the process when the researcher understands what is of importance for the participants. This allowed the researcher to gain ideas from the interviews, to pursue in following interviews. Immediate analysis is also important in grounded theory, and the

analysis should begin as soon as possible and at the same time as further data collection. This was done to the extent possible, and will be further elaborated in the next section. Data analysis is dependent on coding. In this process, the data is fractured into smaller pieces and labelled, then compared with other data-fragments, to ensure that nothing gets overlooked. Memos were written by hand during the study; this was about specific events, non-verbal communication, and categories to follow up. The constant comparison allowed the researcher to constant compare data with data to find differences or similarities. This was useful in the development of categories (Bryman, 2012; Charmaz, 2014).

4.6.1 Transcription and memo-writing

Initially, transcription took place the same day as the interview had been conducted, and preliminary analysis was carried out. However, it was not possible to do this after every interview, because most interviews had to be in the afternoon after children had gone to bed. However, interviews were transcribed as soon as possible after the interview had taken place. This turned out to be advantageous, because it meant the researcher became very well acquainted with the data during the whole process. Transcription is not a simple process according to Kvale and Brinkmann (2009), but rather an interpretative process that can lead to some practical and principal issues when the oral text is transcribed into words. This was also the experience of the researcher, that when participants used Norwegian sayings to illustrate a point, some of this got lost in the translation. The interviews were transcribed in Norwegian standard form, although some of the informants had dialects. This was done to help to maintain the anonymity of the informants as well as making it easier for the researcher to translate into English. The interviews were translated into English to focus on one language throughout the rest of the process, and to allow discussions with the British supervisor. Since transcripts lose the non-verbal language and it becomes a weakened rendering of the verbal interview conversations, the researcher found it helpful to write memos, as recommended by

Charmaz (2014) and others. One example of a memo written, was that parents put emphasis on natural acquired immunity; this helped in the development of categories. Memos were written after interviews and during transcription. According to Charmaz (2014) memo-writing is a central aspect in grounded theory, because it helps the researcher discover new ideas, hunches or codes. It also introduces the process of analyzing the data and starting the coding process early in the research. An advantage with this whole process was that the researcher got the opportunity to become increasingly familiar with the gathered data, and every new aspect/subject that emerged could possibly be further explored in continuous data gathering (Malterud, 2011). This was done to some extent in this study. With the use of the constant comparative method the researcher started comparing data with data and statements from the different interviews at an early point in the gathering of data through to the end; this was helpful in finding similarities and contrasts in the data, and helped develop codes and categories. Denscombe (2014) points out by using the constant comparative method the researcher remains close to the data, and keeps the analysis close to the participants' reality. This is an important aspect of how the researcher tried to control her own impressions and assumptions in this study.

4.6.2 Coding, categories and discovering concepts

Charmaz (2014) states that theoretical sensitivity can bring an analytic exactness to a study, whether one is in pursuit of constructing a theory or not. Theoretical sensitivity and codes are influenced by each other. Charmaz (2014, p. 161) also states that “theoretical sensitivity is the ability to understand and define phenomena in abstract terms to demonstrate abstract relationships between studied phenomena”. As elaborated earlier sensitizing concepts were drawn from the existing literature, and used throughout the analysis of the generated data to describe key elements in this study. The researcher went back and forth between the

literature and the analysis to help elaborate the categories as recommended by Charmaz (2014). The sensitizing concepts turned out to be helpful in the development of categories.

The first step the researcher took was to read through the transcripts several times to become familiar with the data, and to make sure the translation from Norwegian to English was valid. As Denscombe (2014) suggests reading and re-reading develops a feel for the data, and makes it easier to absorb the details of what has been said and done. Parallel to doing this, the process of initial coding started. According to (Charmaz, 2014, 2015) this is the first step in an analytic process. This was done by coding line-by-line to stay close to the data (Charmaz, 2014). Charmaz (2015) also points out that line-by-line coding is especially useful when it comes to interviews. With the initial coding the researcher can inductively generate ideas from the data. Some codes and ideas were developed in this process by the use of the sensitizing concepts described in chapter 3. These ideas and initial codes from the interviews were put into different tables and printed out to give some structure to the initial codes, to move forward to the next process.

The second step conducted was to move towards the focused coding which according to Charmaz (2014) is usually the second phase in coding. In focused coding, some of the main codes in the dataset were pursued. This required decisions to be made about which of the initial codes seemed most important for further analysis. This process was not linear, and involved moving between the data and the literature, a process which helped to elaborate the categories. During this process, the researcher printed out all of the initial codes from the interviews, colour coded them and put them into different boxes, to get an overview and structure of the material. For example, one box contained similar codes regarding parents' views on natural immunity, and the importance of naturally building an immune system. This was further developed into one of the main categories later on.

The third step was the production of categories; this was done by connecting the different codes to each other, to further refine the categories. By using Charmaz (2014)'s method of focused coding, one core category, and four additional categories were developed during the analysis. Below you can see an example of the analytic process.

Table 2: Example of coding and categorization of the text

Quotation	Initial codes	Focused codes	Category	Core category
<p>“I live with that kind of peace in mind, that I knew I could protect them through breastfeeding...”</p> <p>“There is one thing that I believe in that it is better for my children to let them build up their immune system their own way”</p>	<p>Breastfeeding is important</p> <p>Naturally building an immune system</p>	<p>The protective role of breastfeeding</p> <p>The belief that children having a childhood infection can give them the immunity they need</p>	<p>Letting ‘nature’ run its course</p>	<p>Parenting as managing health risks to protect their child (this is about acting to protect where they can)</p>

Chapter 5: Findings

5.1 Introduction

In line with grounded theory principles of analysis (Charmaz, 2014), as stated in the previous chapter, three categories, and one core-category were developed. The three categories that emerged through the analysis were: making choices to protect their children; evaluating risks; and letting 'nature' run its course. The core-category that brings these three categories together is: parenting as managing health risks to protect their child. Quotations are used to illustrate key aspects of the categories and have been anonymised through use of a pseudonym. In order to contextualize the analysis, the chapter starts with a brief description of the sample of interviewees.

5.2 The participants

In total eight parents were interviewed: seven mothers and one father. All parents had at least one child, with the majority having two or more children. All of the parents with unvaccinated children had two or more children, all unvaccinated, but only one child in the age group between 5-24 months. One of the female participants was under 30 years old, and the rest were between 30-45 years old. All but one (who was a student) of the informants had a bachelor degree or higher, and half of the participants were working as health professionals, others in different services. Some details are not given to protect the anonymity of the participants. Three of the parents were currently on maternity leave. Half of the participants had chosen to give vaccines for their children and the other half had chosen to either delay or refuse vaccination for their children. Three of those in the latter group were concerned with the fact that they did not want to be put in an 'anti-vaccination box'; their choice was seen as one that was constantly evaluated and one that they could reconsider at any time.

5.3 Making choices to protect their child

This category emerged through the data, as parents talked about their choices regarding vaccination and actions that were taken to protect their children. It is worth mentioning that the setting is in a Norwegian context where ‘choice’ is a possibility and where the perceived risks are fewer than in other countries. Health care services are also freely available to all if children develop VPDs. This category includes parents’ choices relating to vaccination, to not have it or to delay it or reject it completely. All of these varied actions could be understood in terms of parents making choices to protect their children. What actions they took, however, varied in terms of how they thought they could best protect their children: that is to say, by either having their child vaccinated, delaying vaccination or declining vaccination: all were seen as protective actions.

Parents either viewed vaccines as good for those who needed them but not for ‘us’, or as very necessary and safe. Parents who had chosen to have their child vaccinated referred to it as a ‘natural choice’ to follow the recommended childhood programme. When asked about why this was seen as a ‘natural choice’, most mentioned intergenerational beliefs as one of the reasons, trust in the public recommendations and those behind the recommendations were also mentioned. While parents who delayed or rejected vaccination had some scepticism about the current recommendations from the health authorities. This scepticism centred on why they recommended vaccines for *all* children, alongside the timing of vaccination.

Furthermore, parents’ inter-generational beliefs, health beliefs are developed through intergenerational mechanisms such as informal socialization through the process of parenting. Those parents who delayed or refused vaccination for their children was all brought up in (different) anthroposophical communities and the way in which processes of socialization develops particular kinds of beliefs about what is natural and appropriate up-bringing with

vaccination or up-bringing without or with some vaccinations or in an anthroposophical environment were influential for their choice.

Parents who vaccinated their children were also generally positive towards the vaccination-programme and saw it as important to protect their children from these diseases because they considered them dangerous. One mother who had chosen to have her child vaccinated explained that subsequently her child had experienced a bad reaction to the MMR-vaccine, but she would still choose to have it again if she had another child because she saw the risk of measles, mumps and rubella as more harmful than the reaction to the vaccine. This example illustrates how this mother is weighting up her beliefs about the risk of the vaccine against the risk of the diseases. However, it also shows her apparent strong beliefs in the value of the Norwegian health care system and the vaccination programme in particular. Ann said this regarding vaccination. “.. *protect children from what we can protect them against, especially diseases anyhow.*”

Although some of the participants felt positive towards the current vaccination programme and the policies, the findings suggest that most of the parents did not feel or think that vaccination was presented as a choice from the health centres and most felt constrained in their choice, and felt they ‘had to’ follow the recommendations although vaccination was voluntary. Heidi was a mother who vaccinated her children and said this regardless:

I do not feel it is presented as a choice, it might not be that they (public health nurses) would have reacted if I said no, but it’s not like, “Do you want this vaccine?”. I mean it’s already lying there, ready!.

Notwithstanding feeling of constraint to conform to the expectations of health care professionals and the wider health care system (in other words to feel constraint by social norms relating to childhood vaccination), parents who had rejected or delayed vaccinations for their children talked about a number of actions they did take to protect them, actions that

they felt or thought might influence positively or negatively the health of their children. Actions such as delaying the starting of kindergarten were mentioned by parents. This was explained as allowing their children the time to develop their immune-system 'undisturbed' by foreign vaccines and become stronger before they were exposed to risk of disease or the vaccine in those that delayed vaccination. These actions illustrate how the parenting of young children involves 'emotional capital'. Thus mothers' involvement in their children's health and wellbeing necessitates, making choices to protect their health as best they see it. Their actions can be understood as reflecting interweaving of accumulated health beliefs with the emotional capital associated with parenting, which influence how they evaluate the risks of disease and the risks of vaccination in a young developing and somewhat vulnerable young child. Another reason for delaying vaccination was to wait until the child was older and stronger and their immune system was 'naturally developed', with no 'unnatural interferences'. Parents who had delayed/rejected vaccines mentioned that they would not give any vaccination to a child under two years old. This indicates that these parents viewed children under two as particularly vulnerable and delaying vaccinations was judged to be an action that could protect their best interests.

When it came to the MMR-vaccines one mother (who had declined vaccination for her child) talked about how she would reconsider giving single antigens if that was an option in Norway (which currently it is not). This mother had persistent doubts about the safety of the MMR, and the alleged link with autism. This example show how health beliefs and the anxiety that those beliefs can provoke and influence how parents appraise the risk associated with vaccination, which gives rise to them making particular kinds of choices. However, strong beliefs regarding MMR, Liv said she would reconsider her choice about vaccination if someone in her near family or acquaintances got an illness that made them vulnerable to VDPs. *"If I had someone in my family or acquaintance that couldn't handle the disease or*

vaccination, I would have reconsidered vaccinating my children that is how I feel". This illustrates how a mother who has declined vaccination for her children continue to evaluate the risk of vaccine up against risk of disease, and if circumstances alters, possibly make a different choice to protect her children or family.

Parents actions for reducing risk and protecting their children included not going abroad (for holiday or for other reasons) to what they viewed as a 'less' safe country where disease rates were higher and therefore the risk of exposure was greater. Or, if a new epidemic emerged in Norway they would reconsider vaccination. These examples illustrate how those parents who decline vaccination continue to evaluate risks and courses of action in order to best protect their children if circumstances change. Diseases such as poliomyelitis and hepatitis were specifically identified as possible risks when travelling outside Norway, and were seen as more severe. They were not, however viewed as relevant when living in Norway. Some parents explained that they had postponed travelling or decided to travel to destinations that were perceived to be 'safer' in order to minimize the risk to their children from these kinds of diseases. The findings indicate that parents who have declined the vaccine tend to view living in Norway as providing a low perceived risk of the disease and a higher perceived risk of the vaccine. This evaluation of risk, however, can shift depending on context.

Parents in the study talked about their upbringing and how they were influenced by their backgrounds, and that many of their beliefs on vaccination had been transmitted. All talked about the way their upbringing with or without vaccinations had influenced the choices they made with regard to the vaccination (or not) of their own children. In this study, all of those who delayed or refused vaccination had attended Waldorf-schools (in Norway referred to as Steiner schools). These parents did not think that this was an influential factor in the vaccination choices they made. Thus some of those who delayed or rejected vaccination

explained specifically that they had had some guidance from an anthroposophical doctor to help them decide which vaccines they might choose and when to have them for their children. However, it seems likely that guidance from such a doctor is likely to be more significant and accepted by parents who have similar beliefs because they have been brought up in a similar way.

Parents talked specifically about their emotions relating to their children and vaccination choices, such as anxiety, gut feelings, uncertainty about what to do, and the feelings that go with trying to weigh things up over time to reach the ‘right’ decision for their child. Parents who delayed or rejected vaccination tended to explain that they had followed their ‘gut-feeling’ when it came to the choice on vaccination, suggesting that emotions played an important role in their choice. For example, one mom who had declined vaccination elaborated how she felt when their child was due for vaccination.

We had a very round and nice boy, but due to the fact that he was still so small and new in this world, we wanted him to get to know this world and the environment he was in, so first we really went on our gut-feeling, that we do not want to interfere with the development now, and inject artificial diseases.

This quotation from Maria suggest an emotional subjective feeling of how she evaluates risk, and what she believes to be ‘natural’ is considered to be better for her child at this moment in time, and that vaccines are something artificial that could upset his normal development. Vaccines in this case are believed to be an intrusion into the body of an infant and therefore should be avoided.

5.4 Evaluating risks

This category relates to seeing how parents subjectively evaluated the risk of vaccination. The parents, who chose to delay or not to vaccinate their children generally viewed childhood diseases as mild. They also had full confidence that they would receive the

necessary medical treatment if they needed it, and none of the parents communicated any fear that VPDs could possibly cause death, illness or sequela. Parents who delayed or refused vaccinations viewed their children as very 'healthy', so they had faith that they would cope with a childhood disease. Parents who delayed- or refused vaccination for their children questioned why there was so much reliance on vaccines rather than other more 'natural' methods of protecting children from infectious diseases, such as for example homeopathy. Their questioning of vaccination suggests that their appraisal of risk was influenced by their beliefs about the lower risk of the disease relative to the high risk of the vaccine.

Mumps was generally viewed as more dangerous for boys, because it was associated with infertility later in life. Rubella was only considered relevant for girls, and parents talked about the importance of giving it before puberty. These discussions illustrate that parents' appreciation of risks involve both established scientific 'facts' about diseases as well as are personal beliefs (for which there may be no 'evidence' as such) relation to disease severity. Measles was also believed to be more severe if contracted as an adult. Regarding MMR, parents explained that if the child had not contracted the disease by a particular age, they would reconsider giving the vaccination at some point. Parents explained that they felt the risk of these diseases and their possible outcomes were more severe in adolescents and adulthood. This reveals the underpinning 'logic' to parents' actions. This can be related to their health beliefs, in that, based on their beliefs about vaccination and the disease, they evaluated the risk of both to be greater than the risk of doing nothing. Their appraisal of risk shows subjectivity, as they view vaccination as unnecessary and almost 'strange' why so many would want to give vaccination to their children.

Parents who delayed or refused also expressed how they found it strange that so many parents seem to accept that a child could get a reaction after a vaccine, such as fever. This reaction was mentioned as 'proof' of vaccine risk and something that should be avoided. The

likelihood of such an outcome from vaccination was not, however, seemingly rooted in ‘factual’ information from health care personnel, rather their subjective risk appraisal that vaccines are bad and health beliefs about the risk of the vaccine.

It was also mentioned by those who delayed or refused vaccination that they felt there was an overuse of painkillers, antibiotics in our society. Their evaluation of risk associated to vaccination seems to reflect a wider view of the risk of other medical ‘interventions’ that seem to ‘disrupt’ natural development, and are therefore viewed as a risk. Maria said:

If you go through different diseases, the immune system will learn how to master things that want to go in, that's not supposed to go in (microorganisms) the body, and maybe be stronger against more severe diseases that can come later in life as opposed to never take the time for it. Instead try to have healthy children all the time or apparently healthy all the time, and as quick as possible, using antibiotics. Painless- and fever-free as quick as possible. If we cut away all the time, one gets so weak in the fight against disease

Those parents who delayed or rejected vaccination felt they had made an informed and responsible choice by looking up information from different sources, unbiased, and taking different ‘what if’ scenarios into account, however, they believed that their responsibility was to protect their children from the vaccine. But the extreme scenario – of a child dying – was referred to by one parent, suggesting a willingness to accept responsibility for the difficult decisions that sometimes have to be made in these situations.

“...if something should break out (VPD) and one of my kids die from it, that's okay. That is also something you have to take into account...”

On the other hand, parents who had given vaccinations to their children, did so to protect their children from the diseases, and believed the vaccines to be safe to use, based on the fact that they had been in the programme for a long time. They had a deep trust in the

vaccination-programme and the experts who recommended them. At least to them, their choice to vaccinate their children was almost obvious. This suggests that they believe that it is their responsibility to protect their children from VDPs. This also reflects their apparent strong trust their beliefs regarding the Norwegian government and the health care system.

Those parents who had chosen to give vaccinations to their children believed the childhood vaccination programme to be safe and expressed more concern regarding the risk VPDs. Those parents who had delayed or refused vaccinations vaccination for their children were evaluating specific risks, at least in part, in relation to questioning the effectiveness of the vaccine, and were more sceptical towards possible adverse events associated with the vaccines than the threat of the diseases. Some specific safety concerns were identified by those not vaccinating their children, and this was the concern that vaccines might lead to a higher risk of asthma, allergies, Alzheimer's disease and autism. Parents also questioned whether enough is known about the long term side effects in particular. This concern was regarding if enough research on vaccination in today's society, given how well-nourished the population is, living a 'healthy' life and a relatively 'risk' free society. These parents also had reservations and doubts about the components of the vaccines, such as egg white, thiomersal, and also the live virus vaccines. They also believed that combination vaccines were particularly risky.

Furthermore, all parents had reservations regarding the new vaccines being introduced into the programme, such as HPV and rotavirus vaccine and were sceptical about eventual additional new vaccination should be implemented to the programme. (There was an ongoing discussion among politicians whether vaccination against hepatitis B should be entered in to the programme, and since the time of the interviews, hepatitis b vaccination has been implemented in the children vaccination programme). This suggests that both parents who vaccinated and those who delayed or refused were generally more concerned with risks of

new vaccines. However, parents who vaccinated their children identified some positive aspects of expanding the number of vaccines in the programme, such as improving the safety in travelling, both in and out of the country and better protection from immigration (from countries with assumed lower vaccination coverage).

Participants varied in the degree of trust they had in the health care system, which went from high level of trust to distrust. Parents who delayed- or refused vaccination for their children felt that there was too little information about the positive sides of not vaccinating, and generally missed information about the side effects or possible negative outcomes of vaccination from what they viewed as a non-biased source. Health care personnel were seen as biased towards vaccines. These parents also questioned whether the information given by the health authorities could be trusted. Another dimension of parents' scepticism related to the perceived influence of the pharmaceutical industry. Parents who had chosen to delay or not to have their children vaccinated expressed a concern that pharmaceutical companies were behind the recommendations.

Parents who delayed or refused vaccines were also suspicious of why vaccination was pushed by as the norm. Some parents questioned the societal motives for promoting vaccines, such as financial benefits for the ones recommending vaccines. Parents tended to see society's use of vaccines as due to cultural and economic reasons, as well as due to changes in family structure that made it more difficult for families to be able to care for sick children. Another common belief among the parents who had delayed or refused vaccination was that vaccination was promoted by the government due to keep up the good economy in our society. This was due to the fact that parents would need prolonged sick leave to take care of a child with a childhood disease.

5.6 Letting 'nature' run its course

This category was developed to describe and explain the importance of 'natural' development of their children's immune system and the acquirement of natural immunity. Many of the parents who delayed or rejected viewed this as their most important argument against vaccination. As Siri put it: *"There is one thing that I believe that it is better (without vaccines), and for my children to naturally build up their immune system in its own way"*

There was some consensus among the parents who delayed or refused vaccination that some of the diseases were named childhood diseases for a reason; that is to say, they believed that children were meant to have them as children. Half of the informants had a view that vaccines were artificial and more of an intrusion into a child's natural development of the immune system. For example, one mother argued that vaccines were unnecessary and that a healthy child with a normal immune system could overcome childhood diseases without the need for vaccines. Nina put it this way; *"I think we're good enough from nature's side and I think we have to go other ways (than to vaccinate), thus nature can!"*

All the informants viewed diseases as a natural and necessary part of a child's life, and diseases such as the influenza and chickenpox were mentioned as something that was normal to go through, and something the parents would not vaccinate their children against if they were healthy. However, parents believed that vaccination (against influenza and chickenpox) was good for the people who needed it. Some of the parents who delayed or rejected vaccination had either gone through or had close experience with someone who had gone through a childhood disease such as measles, mumps, rubella or whooping cough. They generally viewed these diseases as mild and not as a threat. They also shared the belief that children having a childhood infection could provide them with needed immunity, and that they would recover and be stronger both mentally and physically as a result. The belief that natural immunity through undergoing an infection was superior to the immunity given

through vaccination was common. Generally, the parents in this study did not see mortality as a likely outcome of their actions. They therefore, choose natural immunity over vaccination.

Parents who delayed or refused also mentioned the importance allowing the ‘natural’ development of the immune system, letting it unfold and become strong without interference from something ‘unnatural’ (such as a vaccine). This was seen as something that could disrupt the ‘natural’ process in the child’s body.

Further, parents who made the choice to delay or reject were in their minds, supporting the development of well-nourished children who were able to resist infection (and recover better) because of it. In relation to this the importance of breastfeeding was discussed, and viewed as particularly beneficial if carried out over a long period. There was a belief that it was an adequate measure to protect infants, especially in the first year. Parents who delayed- or rejected vaccination perceived their infants to be at very low risk of getting a disease as long as they were breastfeed.

The importance of eating food that had not been exposed to pesticides was also seen as important for protecting children. Thus, VPDs were not perceived as a risk, if certain precautions were taken to protect the ‘naturalness’ of your children’s development. This can also be seen as these parents feeling that they can control the risks their children are exposed to, and in so doing the need for vaccination disappear.

Parents who delayed or refused vaccines fundamentally viewed them as undesirable and unnatural. They explained how vaccination was a different route for introducing the antigens into the body compared what happens in when a natural immune response occurs. Almost all vaccinations in the Norwegian childhood programme are injected intramuscularly or subcutaneously, depending on the components of the vaccine (Norwegian Institute of Public Health, 2016). Thus, this was an ‘unnatural’ route of entering the body. For example, Maria expressed some lingering concerns about this in relation to the tetanus vaccination:

The problem (with tetanus) is that you inject foreign egg-white that is very unnatural. You eat it of course, but you don't usually get it directly in your bloodstream, and then it can pass through your blood/brain barrier, and that can be seen in the context of a high percentage of those with Alzheimer disease.

Parents who delayed or refused vaccination also had a belief that high herd immunity meant that children were not exposed to infections, which limited the extent to which they could develop 'natural immunity'. Parents who delayed or refused vaccines expressed the idea that they felt like a victim of herd immunity due to the fact the childhood diseases have become so rare. Heidi put it this way: *"When it comes to childhood diseases I almost feel like a victim of herd immunity because the children don't get the childhood diseases anymore when they are children, and suddenly they get them as adults and that's no good"*.

5.6 Parenting as managing health risks to protect their child

This was developed as the core category in the study. All of the eight parents in this study had a goal to protect their children, however how each of them did this was based on their own subjective beliefs, thoughts and feelings on what was best for their own child. The categories are each important and linked to each other, the exception is the category 'letting nature run its course' that is somewhat more relevant to those parents who delay or refuse vaccination for their children. How parents make the choice to vaccinate or not, can be understood as reflecting their subjective beliefs and emotions towards their child(ren), which influence how they evaluate the risks they encounter (whether the risk of the vaccine or the risk of diseases). Their choice is also fluent, and can alter if a situation changes. Parenting as managing health risks to protect their child is therefore the core category of this dissertation.

This research project has developed a grounded theory of how parents in eastern Norway make choices on vaccination for their children. This theory was developed by the use of principles set out by Charmaz (2014).

A theoretical model has been developed to further explain the three categories and the core category. The three categories on the left hand side are important to answer the research question. The category 'Letting nature run its course' mostly applied to the parents who delayed or refused vaccination for their children and can be of value to explain their choices regarding vaccination, (parents who chose to vaccinate also saw some diseases as a 'natural' part of life). The two remaining categories 'making choices to protect their child' and 'evaluating risks', are equally important categories to explain how parents make vaccination choices. The three categories come together in the core category and can explain how parents in this study make vaccination choices for their children. The figure shows the process parents go through, making vaccination choices, emotions and beliefs play a key role in this process. The categories relate both to actions to vaccinate and not, it depends on how they are weighed up and interpreted by parents, but the considerations are the same. It diagrams how parents evaluate risk (subjectively and influenced by their personal beliefs) and how their 'emotional labour' (feelings) influence their vaccination choices. 'Emotional labour' is used to describe the wealth of emotions (especially mothers) feel taking responsibility for their children, in this case on vaccination choices.

Figure 1: Theoretical model to explain how parents make vaccination choices for their children.

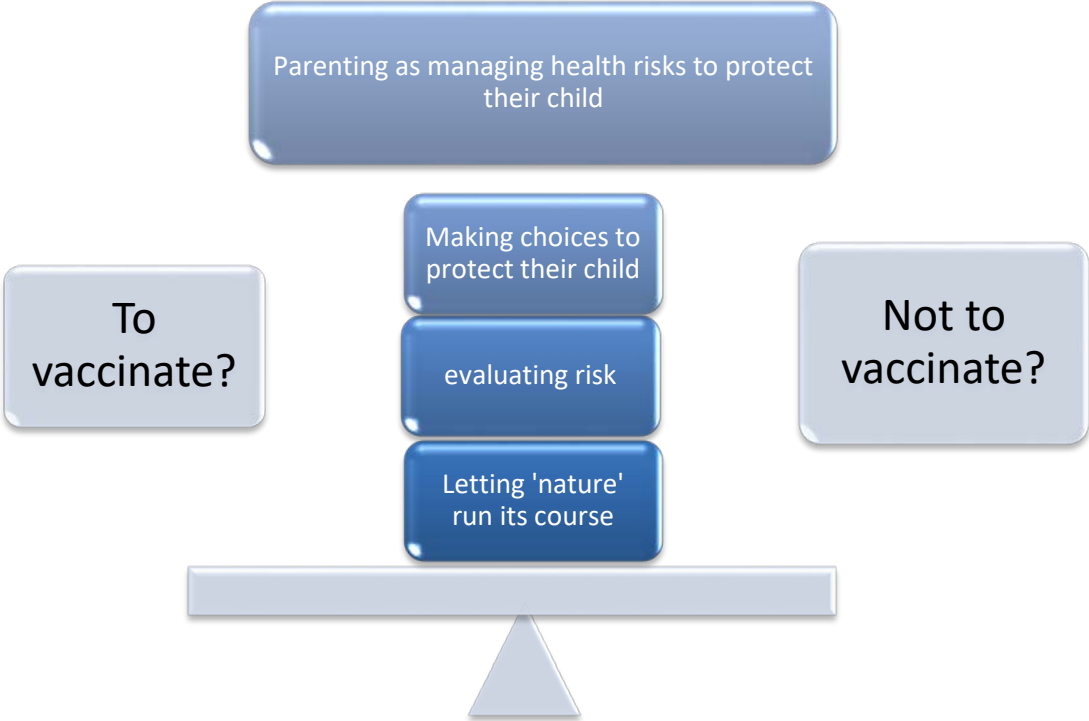


Figure 1: Theoretical model

Chapter 6: Discussion

6.1 Introduction

The aim of this study was to explore and understand how parents make vaccination choices for their children. Previous research has focused on many different topics on how parents make choices relating to the vaccination of their children (Hilton et al., 2006b; Serpell & Green, 2006; P. Smith et al., 2011). The findings of this study add to the existing literature, demonstrating the complexity of this issue. The findings are also consistent with previous research from developed countries, although this is the first qualitative study (to the researchers knowledge) to explore this issue in this way in Norway. This chapter starts with a presentation of the limitations of the research. It then discusses the findings in relation to previous research presented earlier in the study in order to illustrate what this study has added in terms of our understanding of parental choice relating to vaccination in general and in Norway in particular.

6.2 Limitations

The limitations of this study are many, and they are important to discuss in order to consider the extent to which they have reduced the integrity and validity of the research. In part, the limitations reflect the fact that this is the first time the researcher has taken on a study with a methodological scientific approach as is required in the Masters in Public Health. Thus, the experience has involved considerable learning about research. A critical reflection on the study's strengths and weaknesses is thus an important part of the conclusion to this study.

As a novice researcher, there were several limiting factors. A particularly important factor to consider is the interview technique. The first interview was characterized by a nervous researcher, which made it difficult to develop rapport with the interviewee and put them at their ease, which is important if rich detailed responses are to be generated (Charmaz, 2014). Thus this was reflected in the interview, which lacked some follow-up questions. Due to the

stress and the unfamiliar situation, it was difficult to both listen to the parent, but also consider follow-up questions. This might have led to the loss of some valuable information during interviews. Reading the transcript from the first interview and having supervision, helped this process because it was talked through where and how to ask follow-up questions. After the first couple of interviews the researcher felt less nervous and more competent to better put the respondents at their ease as well as to ask follow-up questions.

Another factor to consider is that the respondents might have been influenced by the researcher's background as a health professional (which they knew about, as well as the researcher's role as a master student in Public health), and might not have considered the researcher as 'neutral' in the topic of 'childhood vaccination'. It was noticed that when the respondents were to explain 'medical things' that they had some reservations explaining it, and referred to the researcher "as you probably know as a nurse" or "this might be explained bad or wrong...etc.". Another limitation connected to the role as a health care professional, (with a positive attitude towards vaccination), is the possible effect these personal perspectives might have had to the collection of data as well as the analysis.

Some limitations are also linked to the sample and the sampling process. The first issue was the composition of the sample. Thus the sample turned out to be a relatively similar group of people, regarding their socio-demographic backgrounds, such as age, ethnicity and level of education. There were also seven women and one man. Including participants' with different socio-demographics (age and sex in particular) and cultural backgrounds including different ethnicities, income levels, and from outside Hedmark may have generated different world views from those revealed by the seven participants in this study. This is, perhaps, likely given the way in which culture seemed to be important in shaping beliefs and values, which in turn shaped emotional response and gave rise to particular actions. This is worth taking into account if it were to be further researched in the future. Furthermore, it is worth

mentioning that the outcome might have been different by choosing different methodological tools or approaches, or if the research was conducted at another time (for example after a high media coverage of a vaccine issue). In terms of the latter point, this might be expected given that this study showed the importance of the role of the emotions in decisions relating to vaccination choices. At the time the research took place, there were no high-profile vaccine scares reported in the Norwegian media.

A third factor relating to the sample is that the parents who agreed to participate in the study might be those who are most interested in discussing the topic of childhood vaccination, whether in favour of vaccination or against it. In other words, the sample is biased in favour of those who have something to say about it. Nonetheless, these views are still important to explore. Also parents who were more trusting of the Norwegian health care system and government might have been more likely to participate. However, it was evident in the parents' responses that this was not the case for all the respondents.

As mentioned earlier in the study a valuable design for this study might have been longitudinal, to meet the parents at different points in time, to see how their views developed as they moved through the process of making choices about vaccination and in relation to what kinds of events and issues. The timescale and resources for the Master project did not make this possible but it could be carried out in further research.

Another interesting issue to study would have been the interactions between mothers and fathers during making choices about vaccination. A future study could try to interview parents together to try to explore how parents together (or not) negotiate these types of choices or if fathers tend to leave it with mothers.

The second issue related to the sampling process. In order to align the process more closely to that recommended by Charmaz (2014), the sample should have been a theoretical sample. Although this is a form of purposive sampling (not selected randomly) it adopts a

different process. A theoretical sample requires analysis to parallel sampling so that participants can be purposively selected on the basis of pursuing emerging lines of enquiry and categories of meaning. This was not possible to do, both due to time and problems to recruit more parents. With theoretical sampling the interviews should be carried on until there were no new information emerging from the category, a situation described as theoretical saturation (Bryman, 2012). This also turned out to be difficult due to time and resources limitations, a small sample size and lack of time to do more interviews. It was also challenging to get more informants and the researcher had to stop before theoretical saturation was reached. Charmaz (2014) states that when new theoretical understandings no longer can be stimulated by new data, the categories are saturated. This suggests that the categories presented as part of the grounded theory in this study are unlikely to be fully theoretically saturated and this is a major threat to the validity of the study.

In qualitative research the aim is not to generalize in the statistical sense (from a random sample to a wider population), but to theoretically generalize. However, as explained above, notwithstanding the limitations due to the theoretical categories which were derived from a narrow sample in which theoretical saturation was not likely to achieve, the study might have some transfer value to other similar places.

6.3 Discussion of main findings

The findings of this study show that the choice to vaccinate children or not, is not a straight forward 'decision' made by parents based on weighing objective facts about the disease or vaccination. This study identifies several aspects parents take into account when making choices regarding vaccination for their children, including beliefs about the vaccines, beliefs and emotions of their child, risks appraisal of the vaccine and VPDs and also actions parents' do to protect their children from 'risk'. Thus the aim was to build theory from the lifeworld's of the parents generated through interviews, in line with grounded theory

principles (Charmaz, 2014). The findings chapter presented the different categories, but the discussion will be presented by the core category ‘parenting as managing health risk to protect their child’, which is explored further below as the main theoretical contribution for understand and explaining parent’s choices.

6.3.1 ‘Parenting as managing health risk to protect their child’

It seems that parents feel they are utterly responsible for their children’s health and health outcomes, and do not take lightly on their choices regarding vaccination. As reported previously the finding suggests that those choices are made with their own subjective interpretations, perceptions of their child’s health, values, beliefs, and risk appraisal, consistent with findings from Bond and Nolan (2011). Parents use their emotions when making vaccination choices. This important finding was explored using the term ‘emotional labour’, and can explain feelings parents have (especially women) in caring for their children. This concept was found useful in explaining parents vaccination choices. However, earlier studies have made the point of the gender issue and the expectations mothers have of themselves, to protect the health of their children (Reich, 2014). Although not using terms as ‘emotional labour’. But mothers often feel exclusively qualified for the job. This can exacerbate concerns that women have, because they feel they are personally accountable for their children’s health and health outcomes (Reich, 2014).

A particularly important factor related to this in this study was related to ‘controllability’. Mothers felt very confident to reject some or all vaccination for their children, because they were confident they could keep their children healthy through their actions or living situations. The findings revealed actions that parents who delayed or refused vaccination took to reduce the risks of their child being exposed to the risk of disease. These actions were not based on statistical facts or factual risk assessments, but rather subjective feelings of what was ‘risky’ and what a child would need protection from and ‘suitable’

actions adjusted the risks. Behind these ‘risk assessments’ lie emotions towards their child and evaluations about what their child could handle or not. The actions parents take show how they feel they can control the risk their child is exposed (example VPDs) to by their own actions. This finding indicate that parents who delayed or refused vaccination for their children viewed the outcome of vaccination as something uncontrollable, whilst they felt they could control the exposure of VPDs. This is consistent with other findings (Bond & Nolan, 2011; Serpell & Green, 2006).

The findings of this research also support research by Bystrom et al. (2014) and Reich (2016) who also found that parents who delayed or refused vaccination questioned the timing of it; the choice was made on the assumption that when a child is older it is presumed stronger and more able to handle ‘unnatural’ interferences such as a vaccine was perceived to be. Parents who delayed or refused vaccination would not give any vaccine to a child under two years old, and viewed children under two as vulnerable. In contrast the schedule of vaccination is justified as safe and evidence-based, at the same time very effective in reducing VPDs in a global setting (Edwards, Maldonado, Byington, Jefferson, & Demicheli, 2016). But the rationale behind these recommendations are not normally known to parents (Gross et al., 2015), and would possibly not make a difference considering what it is known of how parents make choices on vaccination.

Parents mentioned intergenerational beliefs as an influential factor for their vaccination choice whether it was to vaccinate or not. All those who chose to delay or refuse vaccination for their children were brought up in anthroposophical environments. This can be explained in terms of socialization through early childhood experiences, which leads to the internalization of beliefs that come to reflect a particular ‘world view’ in such a way that it is a part of sub-conscious and is often not examined or questioned. Furthermore, it cannot be seen how they have been formed. Previous research has indicated that anthroposophical

environments are linked to lower vaccination coverage especially of measles and there have been outbreaks across Europe in recent years (Bystrom et al., 2014; Harmsen et al., 2012; Schmid et al., 2008).

Another interesting finding was that parents in this study seem to feel that vaccination was not presented as a choice. This may be linked to the training of health care personnel, which emphasises that one shall assume that parents want vaccination for their children (Norwegian Institute of Public Health, 2016). Previous research showed that many Norwegian parents have 'doubts' about vaccination, but still chose to vaccinate their children (Stefanoff et al., 2010). This is an interesting finding because Norwegians tend to have a high trust in public institutions (Kleven, 2016). This can be linked to the findings of previous research that found that parents vaccinated their children, because it was expected of them, and that it was the 'normal' thing to do (Brown et al., 2010; Tickner et al., 2007). Findings showed that parents who vaccinate often rely on the vaccination advice from health centres, because they trust the recommended programme or they see themselves as unable to make the choice, because they do not understand the information about vaccination. This was also found by Fadda et al. (2015). The parents in this study who delayed or refused vaccination emphasised the importance of making an informed decision and choice regarding vaccination, and not just going along in 'blind faith' with what the authorities recommended, which they stated they felt many parents did. Yaqub et al. (2014) mentions that the parents who follow the recommendations from government in 'blind faith' can be seen disparagingly due to the responsibility one should have over personal health. Blume (2005, p. 639) asks "Isn't a critical stance toward vaccination, and hence the possibility of alternative viewpoints, a logical consequence of this ideological shift?" (towards the encouragement of individual rights). When the childhood vaccination programme is voluntary the parent is given a choice to either vaccinate or not their children. Therefore vaccination strategies will have to respect

this individual choice. However, responsibilities for individual health (or in this case children's health), if or when outbreaks of VPDs occur and people are infected, the consequences are a severe reminder that a single person is not solitary in their choice.

Findings from this study also found that some parents who vaccinate follow the recommendations in this 'blind faith', which are related to their trust in health authorities, and faith in the recommendations being safe. This was also seen in research by Fadda et al. (2015). Previous research has pointed out that distrust in government, health care personnel or pharmaceutical companies as key factors for parental delaying or refusal of vaccination for their children (Brown et al., 2010; Yaqub et al., 2014). This study did not find distrust to be a key factor for delaying or refusing vaccination, though some parents had some reservations against pharmaceutical companies. Findings of this study suggests that most parents had trust in the health care services and the government, and half the parents in this study worked in the health care services (parents who chose to vaccinate and those who delayed or refused are represented here). However, some of them still decided not to follow the recommended vaccination programme. Some of the parents who delayed or refused vaccination, also reflected a wider view of risk related to other 'medical interventions' in our society, such as antibiotics and painkillers to mention some. This can be linked to another of the main findings in this research. Parents that delayed or refused vaccination mentioned a strong preference for 'natural' immunity instead of the 'artificial' immunity gained from vaccination, which was seen as superior- and more long-lasting than the one gained from vaccination. This is consistent with findings from previous research (Bystrom et al., 2014; Gross et al., 2015; Harmsen et al., 2012; Reich, 2016). Reich (2016) has pointed out that whether one gets a vaccination or an infection, it is the body's own immune system that sets the immune response (natural), however, parents who delayed or refused vaccination in this study had a belief that herd immunity meant that their children were not exposed to childhood diseases,

which limited the extent to which they could develop ‘natural immunity’. Similar findings have been seen in previous research, as many parents were seen to seek out places with outbreaks of VPDs to insure natural immunity for their children (Reich, 2016). Although the gaining of ‘natural’ immunity sometimes can be better, gaining immunity from a VPD may have severe outcomes, even deadly. As explained in the findings chapter these parents also valued breastfeeding as it was seen as a natural way to enhance infants’ immunity and it was seen as an adequate measure to protect children from VPDs especially during their first year. This is supported by previous research, and is often seen in a commitment with natural living, and ‘healthy’ lifestyle, by eating superior food, living in ‘healthy’ neighbourhoods (Gross et al., 2015; Reich, 2016; Tickner et al., 2007). This was also congruent with findings from this study, that some parents who delayed or refused vaccination found it important not to eat food that had been sprayed with pesticides. This ‘belief’ that ‘natural’ is better is unexpected as these were educated parents some working in the health sector. Previous research has suggested that lower vaccination rates are often connected with lower income and lower education in parents (Brown et al., 2010).

Furthermore, one important finding is that parents regardless what vaccination choice they had made, expressed more concerns about new vaccines in the childhood vaccination programme. These concerns were about long-term effects, and possible adverse events. This is nothing new and concordant with previous research (Brown et al., 2010; Dubé et al., 2015; Kennedy et al., 2014). It is an important aspect to mention considering that there is likely to be more vaccinations developed and implemented as time passes (Chatterjee & O’Keefe, 2010; Nøkleby & Feiring, 2006). Only since the time of the interviews, hepatitis B vaccination has now become a part of the standard childhood vaccination programme (Norwegian Institute of Public Health, 2016).

6.4 Implications for policy and practice

The findings of this study have given insights in how some parents in eastern Norway make vaccination choices. What this study can contribute to the consisting body of research; is the importance of emotions in vaccination choices. and that parents use ‘subjective risk appraisal’ and ‘emotional labour’ when they are making vaccination choices. Much research points towards health care personnel being an important source of information when it comes to vaccination (Austvoll-Dahlgren & Helseth, 2010; Benin et al., 2006; Fadda et al., 2015; Gust et al., 2008; Mergler et al., 2013; Stefanoff et al., 2010; Tickner et al., 2007), and they can have a crucial role in helping parents in their vaccination choices. To support parents in making their choices about vaccination, it is important to understand how they come to their choice. A Cochrane review has found that poor communication or relationships with a health care personnel, can be an influential for vaccination choices (Ames et al., 2017). In Norway the public health nurses based at health centres (well baby clinics) have the important role of assisting parents with their vaccination choices. It is very important that the health care personnel do not address vaccine refusal or delay as ignorance or misconceptions and dismiss them, but listen to parents concerns and not try to persuade them by giving information (Bond & Nolan, 2011; Leask et al., 2012). Public health nurses could benefit from a more individualized approach to vaccination, since parents have different needs regarding vaccination. Since parents choices on vaccination are complex, and can be based on subjective feelings and emotions towards their child; can mean that a universal approach to reach parents would possible be useless. To challenge the worldviews of these parents would most likely be ineffective, instead it might be useful to try and meet parents at their terms and possible offer a ‘flexible’ vaccination schedule for some parents. These measures might help address parental concerns regarding vaccination and possibly maintain or increase vaccination coverage on levels needed. To date many researchers have tried to find suitable interventions

for 'helping' parents' who refuse vaccination for their children into vaccinating, but policy makers could possibly benefit from building on this (and existing research) when making public health messages. Another important aspect is related to herd immunity and the public health; future strategies should consider how to relate these individual choices up to the responsibility to the community. As the Ottawa Charter for Promoting Health (1986, p. 2) says; "Reorienting health services also requires stronger attention to health research as well as changes in professional education and training. This must lead to a change of attitude and organization of health services which refocuses on the total needs of the individual as a whole person"

Chapter 7: Conclusion

7.1 'Still not done'

The purpose of this study was to explore how parents living in eastern Norway make vaccination choices for their children. This study adds to some extent the understanding of how some parents make choices regarding vaccination for their children. The findings of this study are building on the existing literature of the complexity of this issue. One important aspect to remember is that most parents aim to make the best choices for their children, and to optimise their health no matter what choice they take on vaccination. Another important factor is that the choice that parents make can be a transitory and can change for various reasons, previous research points to health care personnel as a possible cause for changing their mind (Gust et al., 2008). Sophie explained how she felt regarding the decision to delay vaccination for her child and how she would continue her research to find the choice.

The road I've gone to reach a decision has been a little crooked, and I feel am still not done

Although there is high vaccination coverage in Norway, this cannot be taken for granted. The success to vaccination programmes requires maintenance of the herd immunity. This again depends on parents continuing to vaccinate their children. As a Dutch study by Geelen et al. (2016) point out that high vaccination rates cannot only be interpreted as high trust and loyalty in the vaccination programmes, and that in the long run the high vaccination rate may not be considered as robust. Previous research has shown that many Norwegians have concerns about vaccination, but still chose to vaccinate (Stefanoff et al., 2010). To maintain a high vaccination coverage, and protect the communities we might have to address these concerns.

Seeing this is the first qualitative study done on this subject in Eastern Norway (to the best of the researchers knowledge), this will hopefully inspire others to continue research into

the lifeworld of parents with children in vaccination age. Further research with a different design and more participant with different backgrounds would have been interesting.

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Appendices

Appendix 1 literature search strategy

I started the search strategy with a PICO-form, to find search terms/mesh-terms and then do a systematic search strategy.

P: Parental attitudes, views, beliefs (theme), Health knowledge attitudes & decision making (mesh-term), Parents psychology (mesh-term), patient acceptance of health care (mesh-term), attitude to health (mesh-term) .

I: Infant

I: MMR, Measles Mumps & Rubella vaccine

C: non vaccination (this was not used as a search word, because it is implicit in the research question).

O:

Based on this I did a systematic literature search in Cochrane (1 review), Chinal (54 results, 34 from 2006 up to date), Pubmed/Medline (68 results), Embase (119 results). I also search trough Oria and google scholar. After finding relevant literature I also applied “snowballing”, to find relevant articles from the articles found.

Appendix 2 participant information

Hva er grunnene til at noen velger å vaksinere spebarna sine og at andre ikke gjør det?

Jeg er sykepleier under videreutdanning, for tiden jobber jeg med min masteroppgave i Folkehelsevitenskap med fokus på livsstilsendringer ved Høgskolen i Hedmark. Målet med denne studien er å oppdage foreldres syn på vaksiner og deres grunner for å vaksinere eller ikke vaksinere.

For å finne ut av dette vil jeg spørre foreldre med spebarn i alderen 6-24 måneder som har kontakt med en helsestasjon i Hedmark om å være med på et intervju, begge foreldre må gjerne delta hvis ønskelig. Det blir en uformell samtale med åpne spørsmål om vaksiner, med hovedvekt på meslinger, kusma og rubella vaksinen (MMR). Det blir også noen spørsmål om livsstil og litt bakgrunnsinformasjon til slutt. Samtalen vil vare fra 30-45 min. intervju blir tatt opp og transkribert.

Intervjuet vil bli anonymisert og alle personopplysninger vil bli behandlet konfidensielt. Etter endt studie vil alt materialet bli slettet. Det vil ikke være mulig å gjenkjenne den enkeltes svar i studien. Forskningsprosjektet skal etter planen være ferdig i mai 2016.

Det er helt frivillig å delta i studien. Du kan når som helst trekke deg, uten å oppgi noen grunn. Intervjuet vil foregå hjemme hos deg eller på helsestasjon etter ditt ønske.

Dersom du har spørsmål angående forskningsprosjektet, ta kontakt med ansvarlige

Kari Fallet

Tlf: 95143074 E-mail: kariirene@hotmail.com

Studien er meld og godkjent av Personvernforbundet for forskning, Norsk Samfunnsvitenskapelige datatjeneste AS

Appendix 3 consent form

Forespørsel om deltakelse i forskningsprosjektet

Til alle informanter

”Å forstå foreldres vaksinasjon valg: En kvalitativ studie”

Bakgrunn og formål

Formålet med dette mastergradstudiet er å undersøke foreldres syn og grunner til å vaksinere eller ikke å vaksinere spebarna sine med barnevaksiner spesielt MMR vaksinen. Studien gjennomføres ved Høgskolen i Hedmark.

Foreldre med spebarn i alderen 6-24 mnd. med tilknytning til en helsestasjonen i Hedmark vil bli spurt om å delta.

Hva innebærer deltakelse i studien?

Det jeg lurer på er om du kunne tenkt deg å være med på en uformell samtale rundt barnevaksinering? Spørsmålene vil omhandle ditt syn på barnevaksiner, følelser rundt vaksinering og litt om ditt forhold til sykdommer og livsstil det vil også bli stilt noen bakgrunn spørsmål som alder, kjønn, yrke, utdanning og hvor mange barn du har. Jeg ønsker å starte med de første intervjuene egentlig så snart som mulig og vil gjennomføre de ettersom når det måtte passe for informantene utover vinteren. Om du kunne tenkt deg å delta, blir vi sammen enig om tid og sted.

Tidsbruken på samtalen er litt vanskelig å si noe konkret om nå, men jeg antar at det vil ligge på rundt 30 minutter til en time. Under intervjuet kommer jeg til å ta notater samt å benytte lydopptak.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Kun prosjektleder og veileder har tilgang til datamaterialet. Data blir lagret på prosjektlederens data med beskyttet med passord. Deltakere vil ikke bli gjenkjent i publikasjoner.

Prosjektet skal etter planen avsluttes 20. Mai. 2016. Frem til juli 2016 som er etter muntlig høring av masteroppgaven vil personopplysninger være anonymisert og lagret elektronisk.

Frivillig deltakelse

Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Dersom du trekker deg, vil alle opplysninger om deg bli anonymisert. Alle opplysninger som kommer frem under intervjuet vil bli behandlet konfidensielt i tråd med Personopplysningsloven. Studien er godkjent av Personvernombudet for forskning (NSD), Norsk samfunnsvitenskapelig datatjeneste AS.

Dersom du ønsker å delta eller har spørsmål til studien, ta kontakt med prosjektleder Kari Fallet på telefon 95143074 eller mail: kariirene@hotmail.com eller med veileder Miranda Thurston på mail: miranda.thurston@hihm.no

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta

(Signert av prosjektdeltaker, dato)

Appendix 4 interview guide

1. Kan du begynne med å fortelle meg om når du først begynte å tenke på barnevaksinasjonsprogrammet? (Can you start by telling me when you first started to think about the childhood vaccination programme?)
2. Snakket du med noen om det? (Did you talk about it with anyone?)
3. Hvilke tanker og følelser hadde du/har du om barnevaksinasjonsprogrammet? (What kinds of thoughts and feelings did you have about the programme?)
4. Hva vet du om meslinger, kuma og rubella vaksinen (MMR)? (What do you know about the MMR vaccination?)
5. Kan du fortelle meg hvordan du/dere kom fram til avgjørelsen om MMR-vaksinen? (Can you talk me through how you decide what action to take?)

Evt. Kan du utdype hvor du fikk informasjon fra? (Can you elaborate where you got that information from?)
6. Hvilke tanker og følelser har du nå? (How do you feel about things now?)
7. Ville du ha gjort det samme med et evt. neste barn? (If you had another child would you do the same thing?)

Bakgrunnsopplysninger/backgroundinformation:

Kjønn (gender), alder (age), sivilstatus (marital status), utdanning/yrke (education/occupation), hvor mange barn har du (number of children)?

Appendix 5 NSD document

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
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nsd@nsd.uib.no
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Postboks 400
2418 ELVERUM

Vår dato: 04.12.2015

Vår ref: 45506 / 3 / AH

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 04.11.2015. Meldingen gjelder prosjektet:

45506	<i>Exploring parents views on childhood vaccination</i>
Behandlingsansvarlig	<i>Høgskolen i Hedmark, ved institusjonens øverste leder</i>
Daglig ansvarlig	<i>Miranda Thurston</i>
Student	<i>Kari Irene Fallet</i>

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 20.05.2016, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Åsne Halskau

Kontaktperson: Åsne Halskau tlf: 55 58 21 88

Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

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Appendix 6 REK document

Emne: Sv: Foreldres syn på barnevaksiner
Fra: post@helseforskning.etikkom.no
Dato: 27.11.2015 13:04
Til: kariirene@hotmail.com
Kopi:

Vår ref.nr.: 2015/2219 C

Hei.

Vi viser til innsendt skjema for fremleggingsvurdering av ovennevnte prosjekt, mottatt 04.11.2015.

Det angis i skjemaet følgende om formålet: *Ønsker å se på syn på foreldres syn på barnevaksiner (spesielt MMR). Jeg vil ha et mangfold av deltagelse, både de som velger å vaksinere og de som ikke vaksinere, og med forskjellig bakgrunn (utdanningsnivå, alder, flere barn/første barn, minoritetsbakgrunn/norsk) disse blir rekrutert gjennom helsesøtier.*

Datainnsamling vil skje gjennom semistrukturerte intervjuer med foreldre.

Helseforskningslovens gjelder for medisinsk og helsefaglig forskning, forstått som virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom, jf. helseforskningslovens § 4.

REK sør-øst C mener dette prosjektet har til hensikt å skaffe kunnskap om foreldres egne tanker og holdninger til et innført helsetjenestetilbud, og at formålet dermed ikke er å skaffe til veie ny kunnskap om helse eller sykdom *per se*.

Prosjektet faller derfor ikke inn under bestemmelsene i helseforskningsloven, jf. § 2 og 4.

Prosjektet kan gjennomføres uten REK-godkjenning.

Vi antar for øvrig at prosjektet kommer inn under de interne regler for behandling av opplysninger som gjelder ved ansvarlig virksomhet. Søker bør derfor ta kontakt med enten forskerstøtteavdeling eller personvernombud for å avklare hvilke retningslinjer som er gjeldende

Vi gjør videre oppmerksom på at konklusjonen er å anse som veiledende jfr. forvaltningsloven § 11.

Dersom dere likevel ønsker å søke REK, vil søknaden bli behandlet i komitémøte, og det vil bli fattet et enkeltvedtak etter forvaltningsloven.

Med vennlig hilsen
Tor Even Svanes
seniorrådgiver
post@helseforskning.etikkom.no
T: 22845521

**Regional komité for medisinsk og helsefaglig
forskningsetikk REK sør-øst-Norge (REK sør-øst)**
<http://helseforskning.etikkom.no>