Is the choice to vaccinate informed? A qualitative study on information exchange in the vaccination encounter in Dhaka, Bangladesh

Heather Melanie R Ames

April 2011

UiO University of Oslo

Faculty of Medicine
Institute of Health and Society
Department of Community Medicine

Supervisor: Per Nortvedt, Centre for Medical Ethics, University of Oslo, Norway
Co-Supervisor: Mette Sagbakken, Institute of Health and Society, Section for International Health, University of Oslo, Norway

Thesis submitted as partial fulfilment of Masters of Philosophy Degree in International Community Health

Is the choice to vaccinate informed? A qualitative study on information exchange in the vaccination encounter in Dhaka, Bangladesh

Heather Ames

Dedication

First and foremost this thesis is dedicated to the participants of the study in Dhaka City, Bangladesh. Without them the study would not exist.

Secondly, I would like to dedicate this master's to Noelle McHolm, a great friend who passed away during the preliminary phase of this project from meningitis. She was the inspiration for this study.

A client receiving her Tetanus Toxoid vaccination in the vaccination room at the International Centre for Diarrhoeal Disease Research, Bangladesh.

Is the choice to vaccinate informed? A qualitative study on information exchange in the vaccination encounter in Dhaka, Bangladesh

Table of Contents

Table of Images

Abstract

Vaccination is a globally accepted public health initiative. Recently, there has been a new push to vaccinate children to meet the millennium development goal four. This push for mass vaccination has undeniable benefits however, it is unclear if ethical and human rights standards are being met concerning guardian access to information and consent. In some countries where vaccination is voluntary express informed consent procedures have been implemented to protect the autonomy of those involved. Bangladesh has a voluntary immunization program without a consent policy. Vaccination levels are low and many studies link these low rates to a lack of vaccination information and a lack of communication inside the vaccination clinic.

The first objective of this study is to explore the vaccination encounter in two Bengali vaccination clinics with a focus on information exchange and communication. The second objective is to identify the decision making process of guardians around vaccination and to see if they feel their decision to vaccinate is informed.

This was a qualitative study. Observations were done in the vaccination clinics during the vaccination encounter. Interviews were done with eight vaccinators and twenty-two guardians. Six workshops were done at the International Centre for Diarrhoeal Disease Research, Bangladesh to gain further insight into the perceptions of vaccinators. Finally, material analysis was done on five group vaccination talks and vaccination teaching aids.

Four main factors were found to effect communication and information exchange during the vaccination encounter. These were the environment of the vaccination clinic, the job satisfaction of the vaccinators, the source from which guardians received their information, and power, trust and respect during the vaccination encounter. The majority of parents wanted more information about vaccination before making their decision.

In conclusion, various ethical and human rights standards in vaccination have yet to be achieved in Bangladesh. The implementation of informed decision making and informed consent during the vaccination encounter would help to increase communication and information exchange leading to a more informed decision on the part of the guardian.

Acknowledgements

I would first like to acknowledge the support of my supervisors Per Nortvedt and Mette Sagbakken for their continued patience during what has come to be a very long masters. Their guidance and input have been invaluable. I would also like to thank Line Løw and Ane Haaland for their continued support throughout this project. Their support and ideas have been very appreciated.

In Bangladesh, I would like to thank my supervisor at ICDDR, B, Dr. Azharul Islam Khan. His help in organizing the Health Workers for Change workshop and the use of his office facilitated the research process. I would also like to thank Dr. Mark Pietroni and the other staff at ICDDR, B for their help. Thank you to Dr. Shariar at Paedicare Hospital for allowing me to do research in his hospital. Thanks also to my research assistants and Bimala Rai.

Part of what made my time in Bangladesh so enjoyable was the opportunity to teach at the International University of Business Agriculture and Technology. My students in Introduction to Nursing Research helped with cultural insights and ideas. Thanks also to Dr. Karen Lund, Alex Berland and Deidre Evans for making my trip to Bangladesh not only possible, but enjoyable. Thanks to Musa in the nursing office for helping me to organize transportation.

Finally, I would not have been able to complete this thesis without the loving support of my family, Gail, Nelson and Amanda, and friends. A special thanks to Alex Quin who was always there to help me solve a problem or just make me laugh. I would not have made it through without you.

Note to the reader

In this thesis I refer to those bringing children for vaccination as guardians. In the majority of cases in this study it was the parent who brought the child for vaccination however, it is quite common for an older sibling or other relative to bring a child to be immunized.

Similarly, the health workers working with vaccination will be referred to as vaccinators. In this study vaccinators included nurses, health assistants and health workers. I feel that this will help to simplify the reading of this thesis.

Finally, the author took all of the photographs in this thesis. Oral consent was given from all of those photographed.

Abbreviations:

BCG	Bacillus of Calmette and Guerin (Name of the Tuberculosis Vaccine)
CIOMS	Council for International Organization of Medical Sciences
DPT	Diphtheria, Pertussis, Tetanus
DPT3	Diphtheria, Pertussis, Tetanus: Series of three shots
EPI	Extended Program of Immunization
GAVI	The Global Alliance for Vaccines and Immunization
Hep B	Hepatitis B
HiB	Haemopholous Influenza B
HWFC	Health Workers for Change
ICDDR, B	International Centre for Diarrhoeal Disease Research, Bangladesh
MDG	Millennium Development Goals
MMR	Measles, Mumps, and Rubella
NGO	Non-Governmental Organisation
NID	National Immunisation Day
OPV	Oral Polio Vaccine
REK	Norwegian Regional Ethics Committees
UNICEF	The United Nations Children’s Fund
WHO	World Health Organisation
φ	A course of action or treatment

Chapter 1: Introduction

"It is estimated that 3 million children are saved annually by vaccination, but 2 million still die because they are not immunized...Data from Bangladesh show that full implementation of EPI vaccines has the potential of reducing mortality by almost one half in children aged 1-4 years."

Bonanni, P. Demographic impact of vaccination: A review. Vaccine. 1999 Oct 29;17 Suppl 3:S120-5. (1)

Vaccines are second only to potable water in the reduction of mortality and morbidity in the world.(2) Vaccination is a relatively new public health intervention. Most countries have had routine immunization programmes with a similar basic set of vaccines since 1974.(3) Immunizing a child has many positive indirect effects on other causes of death, such as malnutrition. Most of the world now takes vaccination for granted. It is a service that most people know about and the vast majority of citizens take advantage of. The majority of people understand that vaccines prevent illness, that they may have some side effects and that there is an immunization schedule to be followed. However, in some situations the basic vaccine knowledge that most people take for granted is missing.

The United Nations Children’s Fund (UNICEF) defines immunization as the whole process of delivery of a vaccine and the immunity it generates in an individual and population. A vaccine is defined as a special form of a disease-causing agent (e.g. a virus or bacteria) that has been developed to protect against that disease. Since Edward Jenner created the first vaccine against small pox in 1792 there has been a push to immunize whole populations against disease with the majority of the focus being placed on children.(4) In 1974, the World Health Organization (WHO) established the Extended Program of Immunization (EPI) with the goal of achieving universal coverage of childhood immunization for six diseases.(3) These are tuberculosis (BCG), polio (OPV), diphtheria, pertussis, tetanus (DPT) and measles. In 2000, the Global Alliance for Vaccines and Immunization (GAVI) was founded. GAVI has the goal to increase access to immunization.(5) However, at present there are nearly thirty million children who do not complete their immunization schedule every year.(4)

In 2000, the Millennium Development Goals (MDG) were formulated based on a fifteen-year plan. MDG 4 deals with child health. One of the stated measures to achieve MDG 4 is to ensure the full coverage of immunization programs. The MDG measles initiative began in 2001. Since then the initiative has helped reduce global measles mortality by 68% and has vaccinated over 500 million children.(6) This push for mass immunization of children around the world has had positive effects on child survival. There has been a sixty percent drop in the rate of child mortality since 1960.(6) However, there is a continuing disparity in both child mortality and immunization rates between the developed and developing world. Vaccination is one of the central proposals to decrease the disparity in child mortality and the results are looking promising.

This massive push towards global immunization has positive effects, as mentioned above, but ethical questions are beginning to be raised about how the immunization process is implemented and the information that is, or is not, being disseminated to those involved.(7)(8)(9) In most countries law does not require childhood immunization. It is voluntary. This said it is socially required in many contexts. A child may require a complete immunization card to be accepted to school, to receive treatment in a medical clinic or to apply for a passport.(3) In the end it is still the choice of the guardian whether are not to immunize their children. It is crucial that guardians receive enough information to make this decision to the best of their ability. The rights of both the child and the guardian need to be protected throughout the immunization process. In my research I want to investigate whether the decision of guardians in Dhaka City, Bangladesh, to immunize is informed, if they are being given adequate information around the vaccinations, and finally if they are giving their full and informed consent to the immunizations.

In Bangladesh, the EPI vaccination schedule starts at birth with the BCG vaccine. The child returns to the vaccination program at six, ten and fourteen weeks for the pentavalent vaccine. This new vaccine combines diphtheria, pertussis, and tetanus (DPT), haemopholous influenza B (HiB) and hepatitis B (Hep B). At thirty-eight weeks the child returns to the clinic to receive measles and vitamin A. The oral polio vaccine (OPV) is given at six, ten, fourteen and thirty eight weeks. The EPI immunization program also includes the tetanus toxoid (TT) vaccine given to women aged 15-49. They receive five injections. Ideally, the woman will receive her first injection when she turns 15. She will receive further injections at plus one month, plus six months, plus one year and finally plus another year. The whole TT series takes two years and seven months.(10)

This thesis will explore the current debate around the ethics of informed consent in voluntary childhood immunization. This study is very relevant to the current state of vaccination programs around the world. In many parts of the world it is assumed that parents understand immunization and the decision they are making to immunize their child. In many cases studies have shown that guardians may not fully understand what immunization is.(11)(12) It has even been recorded that children have been vaccinated without their parent’s knowledge.(13) At the core of the debate lie some central questions; Do parents have a right to be informed? Do they feel they are receiving enough information to make the decision to immunize? Where are they receiving their information from? What are the vaccinators’ perceptions of the importance of information in vaccination? These questions became the central research questions for this thesis.

To investigate these questions I travelled to Dhaka City, Bangladesh to study the perceptions of the importance of information for both guardians and vaccinators in childhood EPI immunization. Bangladesh is a good example of a country where vaccination is not required by law but is still socially required as a child cannot enter public school or obtain a passport without having a completed EPI vaccination card. (Knowledge gained from interviews) I interviewed both vaccinators and guardians at two separate hospitals, one private and one public. I observed over 200 vaccinations during my fieldwork to see how communication and information exchange occurred in the vaccination encounter. I also observed and analysed the transcripts of vaccination information talks (tikka talks) at the International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR, B). I employed material analysis to study the information that was available to parents and vaccinators concerning vaccinations at the clinics included in this study. Finally, I conducted six workshops with the vaccinators at ICDDR, B using the Health Workers for Change (HWFC) workshop series. These workshops explore women's status in society and how it effects their health seeking behaviour, how health workers felt they were perceived by their clients, communication barriers and facilitators in their work, and barriers and facilitators to doing their work well.

The first part of this thesis, chapter 2, will address the ethical debate surrounding voluntary childhood vaccination. The concepts of informed consent and informed decision making will be explored. There will also be a discussion on communication between health workers and clients about healthcare. The chapter will end with a brief presentation of existing immunization policies and practices from around the world.

In the second part of this thesis, chapters 3-11, I will present the study I conducted in Bangladesh. This will begin with a literature review of the current state of vaccination in Bangladesh, followed by a discussion on the methodology of the study. Finally, the results of the qualitative study will be presented.

In the third part of this thesis, chapters 12 and 13, I will present some thoughts on how informed consent and informed decision-making could be bridged in the vaccination process. Finally, conclusions and recommendations will be presented.

Chapter 2: The ethics of vaccination and informed consent: A literature Review

“In developing countries the pursuit of high quality standards, particularly though not only in the way clients are treated, should always characterise vaccination campaigns and routine vaccination. In practice this means that informed consent is an obligation, as is the strict avoidance of rudeness and intimidation by health professionals.”

Streefland PH. Public doubts about vaccination safety and resistance against vaccination. Health Policy. 2001 Mar;55(3):159-172 (3)

Immunization is a provider driven public health initiative. In every country, governments, various Non-Governmental Organisations (NGOs) and Health Organizations promote immunization. The remarkable stability of vaccination programs is rooted in their wide public acceptance.(3) Vaccination serves a greater good to the community than to the individual to which it is given. This is a quality unique to population health initiatives. This public acceptance of vaccination is partly based on trust in the health system. In order to maintain the public's trust in vaccination it is important that guardians are informed about the vaccinations their children are receiving. Under the Universal Declaration of Human Rights,(14) each person has the right to information and education. If we combine this with the right to safe and affordable health care each person has the right to be informed about the different medical procedures that they undergo. These human rights also contribute to the ethical guidelines surrounding vaccination and health care in general. Vaccination is saving millions of lives every year but are the practices employed around the world ethical? Do they follow accepted human rights guidelines?

This chapter will explore the ethical debate surrounding childhood vaccinations and informed consent. There will be a discussion on what informed consent is. Following the discussion on informed consent I will present the argument for a movement towards informed decision making. Communication within the immunization process will be discussed. Finally, there will be a presentation of four existing vaccination policies concerning information in immunization from Canada, Norway, the USA and Bangladesh.

2.1 Literature Search

Literature for this study was found on Pub Med and Google Scholar. I also used the websites of the WHO, UN and GAVI to search for information and statistics relevant to Bangladesh. The curriculum of the Masters course, along with suggested articles from people involved with the study and the bibliographies of the articles and books found originally were used to expand the search. Keywords used included, vaccination, immunization, ethics, Bangladesh, consent, informed decision making, EPI, informed consent, autonomy, and communication. Different combinations of these words were used in the search engine. Literature about vaccination in Bangladesh will be presented in chapter three.

2.2 Discussion of the ethics of vaccination

It was an unexpected outcome that this Masters has a focus in biomedical ethics. When I entered the Masters of Philosophy in International Community Health at the University of Oslo I had a passion for human rights but little experience in biomedical ethics. As the project developed I realised that there was no way to discuss information exchange in vaccination without entering into an ethical discussion around power and the right to information. Biomedical ethics is based in principles of autonomy, beneficence, non-malfeasance and justice. Most people relate biomedical ethics to medical research and research ethics committees. It is true that these play a central role in biomedical ethics today however, biomedical ethics principals are also being applied to the everyday encounters between health workers and patients. Paternalism in these everyday health care interactions is still present, especially in highly stratified and hierarchical cultures and health systems. There has been a movement towards a more equal doctor patient relationship in many parts of the world. However, there are still places where the doctor\patient relationship is based in an ubalanced power relationship where doctors can make decisions for patients without consultation.

I am interested in the role of ethics in the everyday practice of childhood immunization. In many countries law no longer requires these immunizations. From an ethical perspective, if law does not require immunization then the health workers have a responsibility to inform guardians about basic vaccination information and side effects. In countries where immunizations are required by law the health worker has a moral responsibility to inform. I wanted to see how or if communication occurred in vaccination in a developing world setting with voluntary vaccination where health workers still hold a position of authority. In this hierarchical structure patients often do not feel able to question the decisions being made for them or ask about the procedures that are occurring.(11) This is the micro perspective of ethics in vaccination. At the macro level the arguments are different.

Verweij and Dawson (2004) raise two groups of macro ethical concerns surrounding vaccination. The first concerns the development, testing, introduction and availability of new vaccines. The second deals with the implementation of vaccination programs. This includes the means used to achieve high vaccination levels and the information and communication process. They question which standards of information disclosure need to be adopted.(7) The problems concerning the ethics of vaccination research are well documented. This thesis will focus on the second area presented by Verweij and Dawson, information and communication in vaccination program implementation.

On a global scale there are not many people concerned with the right to information of people in the developing world when it comes to vaccination. We can all agree that the benefits of vaccination, especially in the developing world where the diseases are still prevalent, far outweigh the costs. However, I find it paternalistic of western societies to fund vaccination of children in the developing world without informing the parents about what the vaccination is for, what the side effects are and what the vaccination schedule entails.

The debate around the ethics of vaccination is growing. Over the past decade the amount of published material has increased. Nevertheless, I feel that this debate still has a long way to go before all the different voices are heard and we gain a more accurate insight into the real vaccination practices in use around the world. At this point in time the majority of the discourse around this topic is based in the developed world. We need to ask if people's rights are being respected all over the world in one of the largest public health interventions currently being implemented.

There is increasing debate on the world stage around ethical standardisation within medical care. One of the debates within this larger scenario is including informed consent as part of the immunization procedure. Many researchers are starting to question the ethical implications of mass vaccination programs. In their article, Ethical principles for collective immunization programmes, Verweij and Dawson argue that, "*analysis and discussion of ethical issues should be part of any justification of collective vaccination programmes.*"(7) They identify two built in assumptions that exist in vaccination. The first is the substantive assumption that government has the obligation to protect the public's health and welfare. The second is the basic assumption that the individual human is not just a member of the public but above all a person whose rights should be respected.(7) This raises the dilemma of greater public good over individual benefit that is at the heart of the immunization debate. In order for these benefits to balance the authors suggest seven ethical principles for collective vaccination programmes;

1- Programmes should target serious diseases that are a public health problem.

2- Each vaccine and the program as a whole must be effective and safe.

3- The burdens and inconveniences for participants should be as small as possible.

4- The programme's burden to benefit ratio should be favourable in comparison to alternative vaccination schemes or prevention options.

5- Collective vaccination programmes should involve a just distribution of benefits and burdens.

6- Participation should generally be voluntary unless compulsory vaccination is essential to prevent concrete and serious harm.

7- The public trust in the vaccination program should be honoured and protected.(7)

This gold standard for vaccination programs is difficult to achieve. However, these seven ethical ideals should be the standard that programs strive to meet.

Vaccination is an interesting medical intervention because the benefit to the community is far greater than the potential benefit to the individual who is vaccinated. In order for a community to be protected by vaccination a certain percentage of community members must participate. This is known as herd immunity and should be around 80% in order for the community to be protected from a disease outbreak. This coverage percentage changes depending on the specific vaccination.(15)

Reluga, Bauch and Galvani (2006), use mathematical games in their article, Evolving public perceptions and stability in vaccine uptake, to predict how different community levels of acceptance of vaccination will affect vaccination and disease levels. They found that the effectivenes of mass vaccination is goverened by the public’s perception of vaccination. However, once a community is no longer threatened by the disease being vaccinated for, people begin to make decisions on the basis of self interest. If this happens it can lead to suboptimal levels of vaccination and may destabilize vaccination programs. This can also happen if there is a shift in the community perception of vaccination for religious reasons or if an adverse reaction is experienced. Reluga, Bauch and Galvani predict that if the supply of vaccines is limited then the uptake will be stable. In contrast, if the vaccine supply is stable then individual decisions will play a bigger role based on the person’s ‘perceived utility’ of vaccination as well as the prevalence of the infection in the community.(16)

The amount of trust a community has in their health system and individual health workers can also influence vaccination levels. However, this trust in the moral integrity of health workers to do no harm can also limit a patient’s freedom to choose. Castillo (2002) argues that hospitals are not the patient’s domain. They are not a place where the patient feels comfortable or in control. Family and/or community support is also limited. Hospitals are unfamiliar, impersonal, overwhelming environments for patients. This is particularly so, she argues, for the poor and uneducated.(17) I believe that the same can be applied to health clinics. Clinics and vaccination rooms are the domain of the health worker. When guardians bring their children for vaccination they leave their comfort zone and enter an arena where they have limited power and knowledge. It is up to the vaccinator to create a welcoming and secure environment, to invite questions and initiate communication.

Onora O'Neill (2002) argues in her book, Autonomy and trust in bioethics that, "*Doctors, like many other professionals, find themselves pressed to be accountable rather than to be communicative, to conform to regulations rather than enter into a relationship of trust.*" (p. 39, 18) Informed consent has been proposed as a method to standardize the immunization information given to guardians. It could also help in opening the lines of communication between the vaccinator and guardian. Streefland (2001) stresses the importance of both informed consent and communication when he argues, "*In developing countries the pursuit of high quality standards, particularly though of course not only in the way clients are treated, should always characterize vaccination campaigns and routine vaccination. In practice this means that informed consent is an obligation, as is the strict avoidance of rudeness and intimidation by health professionals*."(3) However, this proposition of incorporating informed consent into vaccination faces challenges of it's own. These challenges will be discussed in the next two sections.

2.3 Informed Consent

Informed consent is now a recognized and established part of medical research and medical practice. The development of the concept of informed consent began after the Second World War in response to the atrocities committed in Nazi concentration camps where prisoners were forced to participate in medical and other research. After the war ended there was a movement towards guaranteeing an autonomous and informed option to participate in research through both the Nuremburg Code and the Universal Declaration of Human Rights.(19)

The concept of informed consent began as a concept of voluntary consent. Voluntary consent, as an ethical concept in medical research, was first raised in the Nuremberg Code of 1947.(20) It states, "*The voluntary consent of the human subject is absolutely essential."*(21) However, the legal status of the Nuremberg Code was never clear and the idea of consent remained an abstract concept. It was not until the 1970's that the term informed consent received a detailed examination.(22) Since then its importance in research ethics has grown. Beginning in the mid 80's the concept of informed consent has been expanded.(20) It is no longer only concerned with those participating in medical research. The term informed consent has now been introduced into medical procedures.

More recently, there has been an ethical shift in care from a doctor centred approach to a patient centred approach, from consent based in disclosure to consent based in understanding.(20) It is no longer enough that a health worker discloses the necessary information but they must also check that the patient or participant understands the information that has been disclosed. This change has only been applied in some countries and cultural settings. The importance of informed consent is still highly linked to a less hierarchical, less paternalistic medical and research system. In many parts of the world this focus on informed consent is just beginning or, as of yet, has not been addressed within health systems.(17)

The latest revision of the Declaration of Helsinki, approved in 2004, sets out the strongest requirements to date for explicit and specific consent.(20) However, the focus is still on medical research and not day-to-day interactions between patients and health workers. Most ethicists would now argue that the term informed consent is inseparable from medical research and some medical procedures. However, this argument has yet to find ground on a completely global scale.

So what is informed consent? In general it is argued that informed consent shows respect for a person's autonomy. It provides an effective way of waiving requirements and expectations of the patient or society for the purpose of a medical procedure or research. Without this consent the intervention could be constituted as an assault.(20) The participant should make an autonomous decision to participate in the medical research or procedure.

Beauchamp and Childress argue that there are two conditions, which are essential for autonomy; liberty and agency. They analyze autonomous action based on normal choosers who act intentionally, with understanding and are free from controlling influences.(22) It can be argued that the action of giving informed consent can be autonomous by degree. This is especially relevant in healthcare where there can be an inherent power imbalance between the patient and the health worker and where decisions are often influenced by family and friends. The patient is dependant on the health worker for the information needed to make the decision. This hierarchy may limit the patient's consenting capacity, as they may feel unable to ask questions or to clarify information given to them by health workers. In some cases patients may not feel comfortable asking for any information and may just accept whatever the health worker proposes.

John Kleining (2009) discusses the grammar of consent in his chapter, The nature of consent in, The ethics of consent. "*Consent is a three-place transaction in which consent to do something -φ- is always given to another party or agent, to whom we will refer to as B. So, 'A consented (to B) to φ.*" (p. 5,(23) He argues that the central act of consent is communication that alters the moral relationship between A and B. There are some qualifications that need to be met for consent to take place. For example for A to be able to consent they must have reached a certain level of maturity. A's consent is an individual action. B, to whom A gives their consent, must be an agent of some kind (a person, or group etc).(23)

B initiates the action of seeking consent from A on a certain matter. B is seeking from A their permission to do something, or their agreement to do something that B, without this consent, would have no moral right to do. If we place this is in the context of a medical intervention A may have initiated the intervention by making an appointment with B but will still be asked to sign a consent form. This is because a decision to have the medical procedure is assumed to have been made after consultation with B during which B must present information about the medical intervention. If A consents to the terms presented by B then the medical intervention may take place.

φ is most often the proposed course of action. The course of action for which A's authorization is required. This course of action may be pursued and initiated by B, for example in medical research, or initiated by A, for example for immunization. If A consents then this will form or change the moral relationship between A and B. The commitment formed, in most cases, will be ongoing. The moral relationship between A and B can only change if the consent is given through a communicative act. In order for the consent to be valid A and B must have had some sort of communication.(23)

Miller and Werheimer also present this application of a transformation of a moral relationship through consent. For them the central question of consent is, "*Whether a consent transaction between A and B is morally transformative and, in particular, whether a consent transaction renders it permissible for B to proceed."* (p. 79, (23) They present a fair transaction model of consent. This model proposes that "*B is morally permitted to proceed on the basis of a consent transaction if they have treated A fairly and if they have responded in a reasonable manner to A's expression or token of consent or what B reasonably believes is A's token or expression of consent.*" (p. 79, (23) This consent procedure is a bilateral transaction where both parties are involved. If the focus is put on the consent only or the fact that A is consenting then the notion of communication and transaction at the heart of consent are lost. Within this understanding of consent, consent and consent transactions, serve two base values. The first is the well-being or the agent's interest. The second is that of autonomy and self-determination. These two base values of well-being and autonomy can be served through a protective or negative function. When an intervention is done without the agents consent their negative autonomy is violated. These base values can also be served through a facilitative or positive function. This occurs when a person's positive autonomy is violated when they are not allowed to follow through with what they have consented to.(23)

Kleining argues that we have to be careful to distinguish approval from consent. This distinction is important even if, "*our consent to something is often contingent on our approval of it*." (p.10, (23) In order for approval to become consent some sort of authorization must also be given. The author argues that a feeling of approval is not morally transformative but an act of consent is. Consent needs to be formally recognized and/or recorded whereas approval does not. He characterizes coerced consent as assent. This assent does not allow B to φ or obligate A to φ. As with other ethicists Kleining concludes by saying that A's consent is valid if A is competent, and the consent is voluntary (free from coercion), based on understanding, appropriately informed and finally, it must be intentional. Consent is not valid if coerced. (23)

Consent is an intentional act. A intentionally consents to φ after hearing a certain description, understanding this description and then deciding to proceed based on the information received.(23) Consent can also take place between governments and the collective groups that they rule. However, this thesis will focus on the individual consent in the vaccination room. I will focus on the individual process, as the vaccinator is the representative of government policy in the community. The guardian who brings their child for immunization probably does not feel as if they are entering into a commitment with the government.

I personally think that when it comes to making decisions regarding a person's health care, a notion of relational autonomy comes into play. This concept, from an ethics of care, places a person's individual autonomy into the social web of their interactions and the complex social determinants of their life. Everything and everyone who surrounds them affects their decisions. However, the basic requirements of autonomy must still be met.(22)

The principle of autonomy can be viewed as implying both a negative and positive obligation. Beauchamp and Childress define this negative duty simply. Controlling constraints should not impact on autonomous actions. The positive obligation requires respectful treatment during the disclosure of information and actions, which encourage an autonomous choice. This respect for autonomy obligates health care professionals and researchers to disclose information, to probe and ensure understanding, to make sure the decision to participate is voluntary and to encourage adequate decision-making. With this positive view of autonomy it is important that patients are given the right to choose but not a mandatory duty to choose.(22) It is important that health workers inquire about their patients needs and wants concerning information for the procedure they have come for. The fact that a patient will consent to treatment should never be assumed.

This leads to the various forms of consent that exist. The gold standard of informed consent is express consent. The participant/patient is given information and makes an autonomous decision surrounding their participation. Tacit consent is expressed silently or by omission. Implicit or implied consent is believed to be inferable from actions. Presumed consent is present if a decision is made on the basis of what we know about a particular persons values and or choices. Presumed consent will always be problematic. However, presumed consent is important in scenarios where a patient cannot decide for himself or herself and a decision about treatment needs to be taken.(22) I think that if the patient is competent, consent should refer to an individual person's actual choices and should not be based on presumptions made from their behaviour or beliefs. If you do not ask a person then you will never know if they are consenting to participate. Some patients/participants may believe that they actually don't have a choice. Their unwavering and complete faith in the health workers makes implicit or tacit consent problematic as the patients may feel like they have no choice but to follow the instructions of the health worker because of the authority of the position this person holds.

Beauchamp and Childress set out two meanings of informed consent. In the first sense informed consent can be analyzed through the account of autonomous choice. This informed consent is "*an individual's autonomous authorization of a medical intervention or participation in research. This occurs only if a patient or subject, with substantial understanding and in absence of substantial control by others, intentionally authorizes a professional to do something quite specific*." (22)

In its second sense informed consent is analyzable in terms of the social rules of consent that maintain that, "*one must obtain legally or institutionally valid consent from patients or subjects before proceeding with diagnostic, therapeutic or research procedures. Informed consent in this case refers only to an institutionally or legally effective authorization, as determined by prevailing social rules*." (22)

Both of these definitions are important. In the first sense the focus is on the choice of the individual. In the second sense the focus is placed on the institutional level to fulfil the requirements of society. It is with a combination of these two senses that the consent of a person is truly respected. The institution provides the person with the right to choose and the autonomous individual uses this right to make their decision.

Now that the different definitions of consent have been explored we can move onto the elements that make up informed consent itself. At its core informed consent is an exchange of information between two parties. However, as ethics has progressed the elements of informed consent have expanded. Beauchamp and Childress use a seven-step definition with three main elements.

I. **Threshold elements (preconditions)**
   1. Competence (to understanding and deciding)
   2. Voluntariness (in deciding)
II. **Information Elements**
   3. Disclosure (of material information)
   4. Recommendation (of a plan)
   5. Understanding (of 3 and 4)
III. **Consent Elements**
   6. Decision (in favour of a plan)
   7. Authorization (of the chosen plan)(22)

The three elements represent the parts to obtaining consent; making sure the person is able to give consent, exchanging the necessary information, and obtaining consent. The above list of seven points could be read as a checklist for a consent interaction.

When a health worker meets a patient they must first check that the patient is able to give consent. If the patient is not able to give consent due to age or mental capacity then another person must be present who is legally able to consent for the patient such as a parent, guardian, or executor. After competency has been determined the health worker must ensure that the patient's choice is voluntary. In the case of relational autonomy, and if the patient is competent, this would mean that no one other than the patient himself or a person authorized by the patient is making the decision. Next the health worker must disclose the relevant information to the participant/patient. Too much information can be just as much of a problem as too little. The challenge of the health worker is to provide enough information for the patient to make a choice but not so much to scare the patient into compliance. The way this information is given also needs to be taken into consideration. The health worker must exchange the information in a language and vocabulary that the patient understands. If necessary the health worker will then recommend a plan or course of treatment. Next a check will be performed to make sure that the patient has understood the information that has been presented. The patient should feel free to ask questions and make comments throughout the process. The patient will then decide on a course of action. Finally the patient will authorize this course of action or treatment. Therefore, an informed consent can occur only if the participant/patient has a substantial understanding of the information, is free from control by others and intentionally authorizes the health worker to do something.(23)

In a perfect world this is how an informed consent interaction would take place. However, this is rarely the case. Steps are quite often skipped altogether. Frequently the decision on a plan may be taken for consent to treatment. Informed consent is based on a mutual trust between the investigator/health worker and the patient/participant. However, this trust is asymmetrical in information and steeped in power relations. Judicially the obligation of informed consent is met when the participant signs the informed consent form. However, the ethical validation of informed consent is not based on the signing of a document but is based on the quality of the information exchange and interaction between the two parties.(24)

The concept of informed consent was originally developed only to address participation in medical research. Its transition into medical practice has been difficult.(20) Often, in medical practice, the health worker is dealing with patients who are lacking in competence to make a decision either momentarily or permanently. Health workers are dealing with the uninformed, sick and mentally ill. They also face emergency situations and time pressures.

I believe it is important to mention in the closing of this section that there is a field of research on informed consent. Many ethicists and researchers have been examining informed consent since the origin of the doctrine. What has frustrated them has been the apparent difficulty of attaining meaningful consent from research participants, consent that would truly fulfil the expectations of the informed consent doctrine. This field of research uses both qualitative and quantitative methodology to explore the perceptions and understandings of those signing the informed consent forms, of the content of the form, as well as the consent interaction. The goal of this research into informed consent is to improve the assessment of the quality of consent, of patient understanding, and ways in which to enhance and improve information sharing between the parties involved. Some of these researchers have now started to study the interactions between the health worker/researcher and the patient/participant.(23) Linguistic techniques along with interviews, surveys and tape and video recordings are used to study this interaction. Those interactions that were the most successful left genuine openings for discussion and questioning between the two parties. Research has found that different groups approach consent in different ways.(23)

Candilis and Lidz state, "*many professionals view informed consent simply as part of routine clinical explanations. These routine discussions are often paternalistic monologues rather than collaborative decision-making processes. For many consent discussions are still not an ongoing exchange of information and values but a method for ensuring a desired outcome.*" (p.

336, (23) This has lead to a common outcome that patients may not fully understand the research or medical procedure they are participating in. This is especially true when it come to therapeutic misconception. A therapeutic misconception is a research subject's belief that their individual needs will determine their treatment even though they may be participating in an intervention where they could receive a placebo. It can also be understood as the patients believing that the benefit will be greater than is actually the case.(23)

It is clear from the research on informed consent that the communicative and interactive aspects of this process have been left to the side in favour of one-sided information disclosure. In the next section this aspect will be explored further.

2.4 Informed Decision Making

Some ethicists, researchers and legalists now believe that the disclosure for decision-making model of informed consent based on autonomy does not go far enough to ensure a patient/participants right to fully understand what they are consenting to. Some propose changing to a concept of informed decision-making. I first came across the concept of informed decision making in an article from the Philippines. In the article entitled, Limiting factors impacting on voluntary first person informed consent in the Philippines (17) Dr. Rachel Cook presents the concept of informed decision-making. The concept of informed decision-making interested me as an alternative to informed consent. It can be seen from the arguments presented above that the focus in informed consent is on disclosure. I see it as a static process in which consent is given, not exchanged, at one time point and then left. I think the term informed decision-making puts a greater focus on the interaction process. It also emphasizes that this process takes time. Informed decision-making is similar to the concept of shared decision-making. Both are terms with multiple and fluctuating definitions. Both terms will often mean different things to different people.(17)

To try and delve deeper into the idea of informed decision making presented by Cook and Dickens I emailed her. She sent me four articles to read. None of these went much further in defining the concept of informed decisions making. The articles concern reproductive health and human rights. They look into the ability of minors to make decision about their own reproductive health. They argue that the term informed consent is dysfunctional because it's aim is to induce consent. The term informed consent, they propose, should be replaced by informed decision-making or informed choice. They feel the emphasis would then be placed on the health workers duty to disclose information rather than having the focus on obtaining consent. The legal duty of the health worker is to present the information needed to make a choice in a form that the user can understand. The purpose of giving them the information is to help them to exercise their choice or to review a choice that was already made. They state that this should be an ongoing practice of disclosure, not just at one time point.(25) I think that Cook and Dickens' proposed model of informed decision making does not go far enough. The focus is still on information disclosure rather than communication.

When referring to informed decision-making and shared-decision making in this thesis I will be using the definitions set forth by Charles, Gafni and Whelan.(26) They describe the informed decision-making model as deriving from the informational asymmetry present between the patient and physician. Physicians hold technical knowledge whereas patients hold personal preferences. The informed decision-making model aims to increase patient's knowledge of their medical options so that the patients can make a treatment decision for themselves. This model is based on information sharing and communication between the patient and physician. Control is clearly placed in the hands of the patient. The physician's role is limited to exchanging information and communicating technical knowledge to the patient.(26)

When defining shared decision-making, Charles, Gafni and Whelan, suggest four key characteristics, which should be present. Firstly, that there are at least two participants involved i.e. a doctor and a patient. Secondly, that information is shared between the two parties. Thirdly, that both people involved take steps towards reaching a consensus to decide on the preferred course of action. Finally, that an agreement is reached on which treatment will be implemented.(26)

Communication is a rich and complicated two-way process. Many now think that the modern informed consent procedures ignore two-way dynamic communication and simply focus on giving information to a participant. Manson and O'Neill demonstrate this in their book, Rethinking informed consent in bioethics. They argue that the autonomy based justifications of consent requirements are problematic.(20) In this book they discuss two theories of information exchange. The first is the conduit and container model. This is based on the assumption that informed consent stresses the conveyance or transfer of information from one party to another. This model sees this information as the means by which the individual will make their decision, and insists that this individual, autonomous, decision-making ought to be respected. The conduit container model views information as the content of communication. Information is something to be acquired, exchanged, concealed and possessed. Informed consent in this respect requires the transfer of information from one person to another. This information is communicated through various speech acts and is in this sense semantic. This information is about things that A wants B to know in order to consent to φ. The information needs to be communicated in a way that both parties understand. Manson and O'Neil argue that this form of communication hides too much. The person disclosing, or giving the information, has full control over the situation.(20) In sum, Manson and O'Neil's criticism of the conduit and container model is that information is being transferred between people who are though of as originating, or receiving messages. The content of what is transmitted is highlighted but the communication act is hidden.

Beauchamp comes up with a similar criticism of the focus on information disclosure in informed consent in the chapter, Autonomy and consent in, The ethics of consent. He argues that disclosure is not a necessary condition of informed consent. Furthermore he states that information disclosure is only remotely connected to consent per se. He feels that this focus on information disclosure has led to the neglect of voluntary consent. The concept of voluntariness he feels has been neglected in discussions and research surrounding informed consent.(23)

Manson and O'Neil's second model, the agency or agency-based model, is grounded in individual epistemic agency where the two agents exchange information while questioning each other. Agency involves two different commitments. The first are practical commitments that come from the agent's desires, needs, wishes, etc. The second are cognitive needs. Agents take certain things to be the case, others to be likely, and others to be impossible. These cognitive commitments try to fit the way the world is whereas practical commitments aim to fit the world to our commitments. This allows agents to grasp inferential relations in order to view the potential action as something worth doing in accordance to their cognitive and practical commitments. This allows the agent to understand how the commitment will fit into their world and to put their commitments into action. In order for the agency model to work both parties must engage in intentional communication. To do this they must speak the same language, share similar background knowledge of their society and the rules that govern it, they must be able to draw on this knowledge to understand inferences made in the conversation, and they must have some knowledge of each other's commitments and competences in relation to the desired action. The agency model requires two-way communication where the two parties trust each other. This model explicitly highlights aspects of information and communication that are hidden in the conduit/container model.(20)

In this model it is accepted that the communication is context based and dependent on a complex implicit understanding of societal norms. If we accept this as true then there are feasibility constraints on the amount of information that can be exchanged. If it is accepted that all communication is partial, rooted in background knowledge and inferential competences we can no longer accept that fully explicit consent exists. It is not possible to actively communicate all of the information about a certain procedure or idea. Manson and O'Neil argue that too much information can also be detrimental to ethically adequate communication i.e. giving the patient information on all the potential side effects from a surgery, even the most rare.(20) Relevant communication always involves the withholding of some details that could potentially be disclosed. In summary, in the agency model the focus is not only on the content of the speech, what is said, but also what is done, the speech act. It recognizes the transactional, interactive quality of successful communication.

The authors argue that the agency-based model will lead to a transactional account of informed consent. This would go one step further than the information disclosure form of informed consent. The information disclosure version of informed consent sees the autonomy and consent of research subjects and patients as merely responsive. Leaving only a choose or refuse option; a dichotomous choice to accept the procedure or refuse with no middle ground. The scope of informed consent is not set by autonomy but by ethical and legal norms which must be waived or set aside for the procedure or research to proceed. Informed consent allows a procedure or research to proceed by the patient/participant giving permission to in fact potentially be harmed in some way even if this harm is for a long term good. Without consent the procedure or research would not be able to continue. But how do we make the decision to consent? There have been two studies done in the UK looking into how parents decided to immunize their children and if this decision was informed. They provide insight into the practical ways in which parents make their decisions.

McMurray et al. (2004) studied how parents decided to immunise their children for measles, mumps and rubella (MMR) in the United Kingdom in their study entitled, Managing controversy through consultation: A qualitative study of communication and trust around MMR vaccination decisions.(27) The authors found that in most cases the decision to immunize, or not, was not informed. Contributing factors to the result of a non informed decision were, a rushed General Practitioner who did not want to be asked questions, practitioners who were unwilling to engage with parents, or were dismissive, condescending or coercive. Parents obtained their information through their everyday contacts and experiential knowledge. The official government immunization information was felt not to have any bearing on real life situations and lacked in emotional appeal. It did not discuss the impact of the immunisation or the disease. Parents did identify many factors that would support informed decision making on the MMR vaccine. These included, drop in sessions to answer concerns and discuss controversies without time limits, increased written information with case studies and photos that parents could relate to, and the want for the practitioner to ask and encourage questions during the vaccination. This last point was seen as especially relevant as parents felt that pracitioners took their appearance at the clinic as an indication of informed consent.(27)

In their article Choosing to immunize: Are parents making informed decisions?(9) Sporton and Francis explore how parents make the choice to immunize in the United Kingdom and whether or not it is informed. It was a qualitative study using semi-structured interviews. In the United Kingdom vaccination is voluntary so consent has to be obtained before a child is immunized. Health workers were seen as providing unbalanced information that became an obstacle to the parent’s decision making. They also found that some parents immunized their children even when they were unsure so as to not upset their relationship with their General Practitioner. They identified a lengthy five-stage process parents went through in making the decision whether or not to immunize their child. First, there was a trigger event that caused them to question the vaccination. Second, they went through a questioning stage. Third, they thought about what they knew about immunization and then went hunting for information. Fourth, they considered the dilemma in front of them. Finally, the decision was made by reflecting on the previous four stages. The parents were performing their own risk benefit analysis about the their child’s vaccination. However, even though parents had gone through the five steps it did not mean that their decision to immunize was informed. This depended on where they got their information concerning immunization and how accurate it was. Many parents found understanding the medical information difficult. They wished that the information given were more relevant to their everyday situation. Those parents who felt like they had made their decision in a systematic way felt that it was informed. Interestingly, it was discovered that when parents were informed that they had a choice when it came to immunization this made them anxious. They began to worry if they were making the right choice.(9)

In both the study by McMurray et al. and Sporton and Francis the main barrier to making an informed decision was a lack of interactive two-way communication, which was relevant to the guardian’s situations. Guardians felt like they could not identify with the information they were receiving from their health care provider. A transactional model of information exchange as discussed in informed decision making was not present.

Tenrreiro (2005) found that it was statements that emphasized the seriousness of the disease that were most likely to influence a parent's decision. Arguments such as social responsibility, a child's right to be protected, the value of prevention or what the practitioner had done for their own children were less effective.(28) This shows the importance of giving parents information that is related to their everyday lives and is relevant to their direct situation.

In this section I have presented various rebuttal arguments to the traditional informed consent model. Studies have also been presented that show the importance of information in decision-making. Too much information can be as harmful and ethically wrong as giving too little. I do not think that the current understanding of informed decision-making goes far enough to ensure informed consent unless it addresses the arguments raised by Manson and O'Neill around communication. The legal requirement to disclose does not address the open two-way communication needed for real informed decision-making nor does it address the huge role that the trust in the health system plays when guardians are deciding to immunize. In the western world shared decision making with a balanced amount of information from both physician and guardian would be the ideal ethical standard. This model would still involve an informed decision on the part of the parent. However, in many parts of the world a concept of shared decision making where patient and doctor work as a team can be a far way off. This is why I am focusing on informed decision-making in this thesis. This focus on communication and interaction in order for the parent to make an informed decision can pave the way towards a model of shared decision-making.

2.5 To Inform or not? The debate in vaccination

Whether or not to inform parents about routine immunization is an ongoing debate in childhood vaccination.(3) Policies vary from non disclosure to disclosure with conversation to confirm understanding. If we follow ethical and human rights policy then a policy of non-disclosure is unacceptable. However, non-disclosure may be more common than we would like to think. There have not been many studies done on this topic and even fewer in the developing world. In this section, I will present the debate in vaccination about whether or not to inform guardians about the vaccines their children are receiving and if we do inform how much information do we give?

Voluntary immunization programs are based in social demand for vaccination. This social demand is important. It represents a community requesting that the authorities or health system provide vaccinations or improve the quality of vaccination services. Nichter makes a distinction between active demand and passive acceptance. He defines these as follows, "*active* *demand entails adherence to vaccination programs by an informed public which perceives the benefits and need for specific vaccinations. Passive acceptance denotes compliance: passive acceptance by a public, which yields to the recommendations and social pressure, if not prodding of health workers and community leaders."*(29) As discussed above the persuasive techniques of health workers need to be limited when convincing parents to immunize. Nichter goes on to explain that widespread acceptance of vaccination may or may not be rooted in an informed knowledgeable vaccination culture.(29)

In the west we have the option to gain knowledge about vaccination through a variety of sources and like to think that we are knowledgeable about health issues that affect us. In contrast, in the developing world access to independent vaccination material is limited. There is often little to no Internet access and this combined with low levels of literacy limit access. However, in the developing world I think that people have a better grasp of what the diseases are that they are immunized against. The diseases are still present in the community or have been witnessed by the children's parents. I am not sure that this is the case in the western world. How many parents would be able to name the signs and symptoms of tetanus in Norway or Canada?

Verweij and Dawson argue that if you have a policy based on parental autonomy then you must have adequate disclosure of information of the benefits and possible side effects. They argue that it is also very important to set limits on the persuasive techniques health workers are allowed to use when they are supplying information. They believe that it is essential that it be made clear that it is the child and not the parent who runs the risk of harm if not vaccinated. The authors argue that in some cases small amounts of persuasion may be allowed. " *As long as parents are well informed and are given a choice in the matter, governments and public health professionals may take reasonable steps to persuade them to participate in the program."*(7) The difficulty lies in determining what is reasonable and by whose standards.

The strong base of any successful immunization program is the trust in the health care system and health workers by guardians. This trust, where it exists, needs to be protected and promoted through information campaigns and communication. It must not just be expected from the community but earned through the actions of those who work for the health system.(7) I believe that guardians expect their concerns to be taken seriously when they are dealing with the health of their children. Health workers need to address these concerns and be open about the information parents are requesting. Health workers also need to correct unrealistic expectations of parents concerning immunization if and where they exist. Immunization programs should be structured to secure this public trust. There should be sufficient time for communication and information exchange. Their should be no coercion and as little persuasion used as possible.

In their article from 2005, Paul and Dawson discuss the debate and ethical issues surrounding the policy of non-disclosure in the Indian polio eradication campaign.(13) The article focuses on the WHO polio eradication campaign, which is conducted by the National Polio Surveillance Project under the guidance of UNICEF and with the support of Rotary International and the Indian Academy of Paediatrics. Even though the project is taking place in India the policies are formulated at the WHO in Geneva. India uses the oral polio vaccine (OPV) in their eradication campaign. OPV contains a live but weakened virus. Three doses are recommended. It is given orally through liquid drops. The authors found that as a result of the various campaigns children were receiving up to ten doses in endemic areas. OPV can occasionally cause Polio as it is shed in the faeces. The alternative injectable polio vaccine (IPV) is not shed in the faeces and as such cannot infect others.(13)

They found that there was little, or no attempt to inform participants or parents about the possible risks of OPV. Advocates of the programme believe that if the parents were to be informed they would choose not to allow their children to participate. Doctors in India are advised not to inform the public of the fact that OPV can transmit polio. The WHO documents focus on the importance of advocacy but make no mention of informed consent. The overarching debate in the author's opinions is, "*whether this sacrifice of parental autonomy, due to the absence of informed consent, is worth making for the greater good?*" Paul and Dawson conclude that the only ethical reason for withholding consent and information is if the greater good for the public outweighs the risk from the Oral Polio Vaccine. If this is the case then they argue that a compensation program should be in place to help those harmed by the vaccine.(13) I would argue that a compensation program is not enough. Parents have the right to be informed about the vaccinations their children are receiving. Optimal information procedures should be implemented to help educate everyone and secure the participation of those involved.

This case raises two ethical dilemmas. The first is if it is ethical to continue using the OPV vaccine in non endemic areas or if the programme should switch to the IPV vaccine which is harder and more time consuming to administer but cannot transmit the disease. The second ethical issue is the policy of non-disclosure. The authors fear that if this policy of non-disclosure continues there is a risk that public trust in the programme will collapse.(13) If the public find out about the adverse side effects of OPV in a way that erodes their trust in the health system, i.e.

through a sensationalized media report, the long term consequences to the polio eradication campaign could be devastating.

The study by Paul and Dawson was the only one I could find that expressly looked into information disclosure in the developing world within the context of voluntary vaccination. However, Verweij and van der Hoven (2005) used a quantitative mail out questionnaire to explore informed consent policies in Dutch Nursing homes. They wanted to see how these different informed consent policies affected the influenza vaccination rates. They also wanted to explore whether deviating from standard informed consent procedures could be morally justified. All nursing homes responded that the freedom of choice of the residents was considered important. The authors found that tacit consent was used in 43.3% of the nursing homes with an immunization rate of 89.3%. Express consent was required in 40.8% of nursing homes with a vaccination rate of 82.3%. Only 40% of the nursing homes had a written policy concerning consent to the influenza vaccine. Institutions without a written policy had a substantially higher vaccination rate as written policies often included a requirement of express consent.(8)

Express consent implies that the vaccination is given only if the resident, or their proxy, has consented. Tacit consent implies that the vaccination procedure will be administered unless the resident, or their proxy, refuses. This is similar to the opt in or opt out procedures in HIV testing. However, tacit consent assumes that vaccination is in the best interest of the residents either as an individual or a group. Nursing home staff are busy and a policy of tacit consent also simplifies their work as it takes less time and leads to higher vaccination rates. The high number of nursing homes using a tacit consent procedure implies that the influenza vaccination is important to them.(8)

Nursing homes using an express consent policy had procedures for obtaining informed consent. The information process was crucial to these procedures. Four procedures for information disclosure were identified; personal oral information, personally addressed written information, written group information such as a posting on a bulletin board, and oral group information. In centres with express consent personal oral information was given to competent residents and personally addressed written information was sent to incompetent residents proxies. Following this a normal four-step informed consent procedure was used. Information was disclosed to the residents or their proxies. The resident or proxy should understand the information. Next they will voluntarily decide whether or not to have the vaccination. Finally, this decision is communicated as consent to the person who requested it. If the express consent is received the health worker has ample opportunities to make sure that the four steps are followed and the resident/proxy understands what they are consenting to. Tacit consent procedures leave huge gaps in this four-step process. The health worker cannot be sure that the information has been received by the resident/proxy, they cannot check that they have understood the information presented, but most importantly the authors argue that the health worker has no basis to believe that a decision has been made or if there has been a decision whether it was voluntary as no consent is communicated to the health worker.(8)

The authors conclude by recommending that as a minimum requirement there should be a high quality information and communication process as consent is only as good as the information given and the quality of the communication process by which it was given. They find that vaccination policies that favour efficient non-express consent procedures are lacking a coherent moral justification. Verweij and van der Hoven recommend implementing institutional immunization campaigns that include express consent and stimulate education and discussion between residents, proxies and nursing home staff.(8)

Another study that explores policies of consent in adult voluntary vaccination programs is, UK armed forces response to an informed consent policy for anthrax vaccination: A paradoxical effect? by Murphy et al (2006). In this article they discuss what happened, in 2003, when the UK Ministry of Defense changed their policy for the anthrax vaccine to a voluntary policy based on informed consent. The change in policy was supported by a vaccine information program that included a video and written information which was distributed and viewed prior to consenting to the vaccine. The personel were then given a cooling of period before being asked to sign the informed consent form and be vaccinated. This informed consent procedure was only applied to the anthrax vaccine and none of the other voluntary vaccines, a policy which made some personel suspicious of the safety of the vaccine.(30) The article is based on responses to qualitative questions placed in a quantitative questionnaire. The authors found that the new policy of informed consent for the anthrax vaccine had damaged trust in the vaccine and lead to confusion amongst personel. They found that people felt like they did not have enough information to make the decision, and the policy differences between the anthrax vaccine and the other vaccines were confusing. Personel were concerned that the material given to them did not contain enough information or address their specific concerns about the vaccine. There was also suspicion surrounding the change in policy and the fact that many health workers were not taking the vaccine now that it was voluntary. Another influencing factor was that the acceptance or refusal of the anthrax vaccine had to be recorded in the person's health records.(30)

Murphy et al., conclude that although the purpose of the informed consent policy was designed to increase knowledges and decrease worries the opposite was found to be true. They highlight that trust was the main barrier to the informed consent policy along with the trust in the anthrax vaccine vaccination program in general. The mistrust of the military personnel was the main influencing factor associated with all findings. This article raises an interesting question. The military implemented the informed consent policy out of an ethical obligation to their personnel. However, *"does an informed consent policy that actually increases anxiety fail to achieve its goal?"*(30) This study raises simlar issues as the studies by McMurray et al.(27) and Sporton and Francis.(9) The information given to participants must be relevant to their individual situations and come from a source they trust. In the case of the anthrax vaccine the major trigger for mistrust was the fact that it was only the one vaccine which had an informed consent policy. Perhaps the results would have been different if they had moved to an informed consent policy for all of their voluntary vacccines.

The article by Murphy et al, found that a policy of informed consent implemented on a previously mandatory vaccine raised suspicion and mistrust among those who were asked to take it. They found that this could have a negative effect on vaccination rates. Manfredi et al. (2009) used mathematical games to determine when the choice to vaccinate would be optimal in a community when the vaccination was voluntary. They focused on the role of rational exemption in vaccination rates. The authors define rational exemption as, "*the parent's decision not to immunize their children after a seeminlgy rational comparison between the perceived utility of vaccination with its in-utility."*(2) The authors believe that this perception of vaccination is short sited as it only takes the present situation into account and does not address the risk of future diseas epidemics if the population stops vaccinating. The main problem found is the extent to which families are informed about the diseases and the vaccine. This has an enormous influence on how they evaluate the risk of vaccination versus the benefits.(2)

Manfredi et al's mathematical games found that if families were fully informed disease elimination was a problem unless those families who were provaccination did not associate any cost to vaccine side effects. They argue that the case of non-fully informed families produces a better coverage outcome. They conclude by saying that to achieve good vaccination coverage you need populations which associate a very small cost to vaccination side effects and a lack of knowledge amongst parents about critical herd immunity. Parents should believe that 100% coverage is necessary to eliminate the disease.(2) These findings raise ethical concerns similar to the arguments against non-disclosure raised above. It is important that those participating in voluntary vaccination understand both the vaccines and the disease they prevent in order to make an informed decision whether or not to vaccinate their children.

In conclusion, information in vaccination is important but so is the way in which it is delivered by the health worker. Trust is essential in this relationship in order for the information given to be accepted and succesful open communication between the two parties. Too much information can be as destructive to the information process as two little. Too much information about rare and severe side effects, may influence parents not to vaccinate. This is the method used by the anti vaccination campaigns to persuade parents not to immunize. As vaccine preventable diseases become less visible in the community it may become even more important to inform parents about the importance of vaccination and the diseases which it prevents. Appropriate information about the purpose of immunization and the diseases that vaccinations aim to prevent may enhance acceptance but no conclusive indications have been found.(29)

2.6 Communication in vaccination

The communication process is at the centre of information exchange in vaccination. Krantz, Sachs and Nilstun (2004) discuss the important ethical implication that communication has in vaccination. They state, *"The manner in which information is given, interpreted, and understood by the parties concerned must also be in focus in any discussion on ethical issues concerning immunization programs. Communication difficulties between professionals and lay people can, in themselves, create ethical problems."*(31) This can be seen in research that shows that rude behaviour of health workers at vaccination sites is one of the main reasons that parents do not bring their children for vaccinations. Streefland states that it is crucial to monitor the behaviour of the vaccinators towards their clients, particularly during the mop up vaccination stage.(3) This rude behaviour limits the communication between vaccinators and guardians. It also shows a lack of respect between the two groups, which is essential in good communication.

In the section on informed decision making it was discussed that informed consent or informed decision making is rooted in two-way communication. I will not go in depth into communication theory in this thesis, however it is important to understand one-way information and two-way communication. In one-way information, information travels only in one direction. This is the case for mass media and paternalistic encounters in health care. Information is delivered or disclosed to a target audience with no option for that audience to respond. Two-way communication involves a conversation. The health worker presents information to the participant/patient and then the participant/patient is given the chance to ask questions and respond to the information presented. Two-way communication is more effective in increasing understanding on the side of the recipient and for clarifying where the participants understanding may be lacking. It is the gold standard, which is recommended in the EPI book.(32) Both forms of communication exist in vaccination and will be discussed further below.

2.6.1 Mass media and one-way information

Mass media can play a positive or negative role in the promotion of vaccination in a community. Reluga, Bauch and Galvani, included the role of the media in their mathematical games on vaccination. They found that, "*Mass media might play an important role in shifting the public's perception of vaccination and potentially triggering epidemic instability."*(16) We live in a media centred world where most of our daily information comes from various outlets such as radio, television and newspapers. Some people are critical of the news presented by the media but many do not question the information they receive. Often it is difficult to present complicated scientific material to the general public. One famous example of this in vaccination was the famed case of the link between the MMR vaccine and autism published in the article, Autism, inflammatory bowel disease and the MMR vaccine, by A. Wakefield (1998). This link has since been disproven but the public frenzy and fear over the announcement has harmed measles control in many countries. Many parents chose not to immunize their children supposedly because of this one study based on 12 children.(33) The Lancet retracted this article twelve years after it was published but the damage has been done.(34) This study has now been reported as fraudulent. The British Medical Journal published in January 2011 that information on the participants had been falsified.(35)

This is just one of the many examples where mass media has had a negative effect on vaccination programs. It is impossible to determine how many parents chose not to vaccinate their children for MMR due to the media attention this story garnered. Furthermore, how many children contracted these illnesses, suffered life long side effects or died?

The mass media play a positive role in promoting vaccination knowledge and awareness in the community. This is often in the form of health promotion campaigns, which, are supported by the government and various NGOs. In the case of the mass media I think that this communication is definitely one sided. When the target population is presented with this information about vaccination they cannot respond with questions or comments. There is no one with whom to have a conversation to clarify the information they are just expected to absorb it.

Mass media are the main source of one-way information about vaccination. One-way information can also occur during the vaccination encounter or group education when information is presented to guardians without giving them the chance to ask questions or interact with the person presenting the information.

2.6.2 The importance of two-way communication in the vaccination room

> "*To ensure more timely and engaging information transfer simply providing more leaflets, television campaigns, and didactic verbal statements, in which medical evidence on the effectiveness and safety of the vaccines is meant to flow from the producers to consumers, is to fail to recognise the need to contextualise information with 'situation specific knowledge, often personal to individuals.' Parents need to be seen as partners in learning enterprise, rather than passive receptors or empty cognitive vessels waiting to be filled. Considered thus, the challenge becomes one of managing information exchange so as to collaboratively transform, rather than coercively supplant, existing parent knowledge."* (27)

This quote by McMurray et al., demonstrates the importance of two-way communication in order to contextualize and individualise the information given to guardians about vaccination. One-way information provided by media outlets and government programs are not enough to answer the questions guardians have. When it comes to two-way communication in the vaccination room it is very dependent on the motivation of the health worker involved. What the health worker considers important is soon reflected in the information given to parents. It is important to motivate health staff to discuss issues surrounding vaccination with the guardians. The information given by the health worker should be related to the risks and benefits of the intervention and also be linked to the local context and individual child. Peltola (1997) conducted a study in Sweden where everyone working with vaccination was invited to twenty-five seminars held around the country at the launch of a new vaccine. At the seminars the background information concerning the new vaccine was presented, problems about knowledge discussed and the upcoming launch was described. Seven booklets with different questions about the vaccine were made available to the participants. Peltola found that this preparation was fruitful. The nurses were motivated to discuss this new information with their clients. She concludes by saying that, "*regardless of the system, good motivation of vaccinators is decisive no matter who they are. Means of compulsion are not always the best. Where there is a will there is a way*."(36) In other words, when the vaccinators are motivated, communication during the vaccination encounter improved.

The biggest barrier to two-way communication in the vaccination room seems to be limited time due to an increased patient load. Tenrreiro (2005), researching in the USA, found that patient education was likely the first area to suffer when health workers felt pressed for time. Open communication is necessary in vaccination in the USA because of the drop in vaccine preventable diseases. It is unlikely that a parent in the USA has come in contact with most of the vaccine preventable diseases. The government suggest giving a letter with the relevant information regarding the vaccination before the appointment for the guardians to review as well as assisting parents to independently obtain information.(28) This way parents can come prepared to the immunization encounter. This is facilitated in the USA by the pre-existing information booklets provided by the government as well as rules and regulations surrounding information provision. The policies in place in the USA will be discussed in the next section.

Another central topic when discussing two-way communication is respect. It is important that the two parties involved respect each other in order to have open communication. Davis et al. (2001) found in their national survey on vaccine risk/benefit communication in the USA that on average health workers spent three minutes discussing vaccine related risk/benefit information with parents. This was seen in a positive manner by the parents and increased the trust and respect of the parents for their provider. The most common question asked were concerning side effects. Common side effects were also the top answer when health workers were asked what they thought parents needed to know about vaccination (79%). This was followed by the benefits of the vaccine, when to call the doctor, the immunization schedule, contra indications and severe side effects.(37)

A study from New Zealand conducted by Plumridge, Goodyear-Smith and Ross, found that respect was a key factor in the successful two-way communication between parents and health workers in the vaccination encounter. The study’s goal was to evaluate the communication strategies used by nurses with the aim of empowering parents. They discovered that parents for the most part treated the nurses as experts and accepted the asymmetry of knowledge between them concerning vaccination. They conclude that patients wish to be informed but also trust their health professional to guide their decision-making. The authors argue that the interaction between the nurse and caregiver is one of the most crucial elements in vaccination. If the parents are dissatisfied or feel that they have been treated badly they may not complete the vaccinations. Furthermore, they may influence others not to vaccinate. Nurses find themselves in a delicate situation where they must allay parent’s fears, give a painful injection and attempt to involve parents in the process while educating and remaining professional.(38)

This section has presented the importance of two-way communication in vaccination. Communication is a two-way exchange between health workers and communities/clients. Knowledge of the perceptions and understandings of both parties is necessary for communication to be effective. Aubel, Rabei and Mukhtar, found that there were two important factors, which were identified as contributing to the quality of the interaction between the two groups. The first was the technical knowledge and skills of the health worker. The second was the health workers' attitude towards their clients. They found that in the absence of an effective communication relationship between health workers and their clients, important health messages were more likely to be ignored.(39) Health workers also need to understand the perspectives of their clients around vaccination in order to respect their perspectives and approach the situation to communicate effectively. Effective communication is one of the most difficult tasks to achieve in medicine due to the complex nature of the information that needs to be exchanged and understood by non-professionals. Krantz, Sachs and Nilstrum argue, "*information is seldom simply the neutral transmission of facts. It is interpreted and evaluated from a particular perspective in a specific context."*(31) Once the information has been exchanged it is re-contextualized by the person who has received it to fit an interpretation that is practical to their everyday lives. In order for this final personal interpretation to take place the patient must be able to ask questions and clarify misunderstandings with the health worker. This requires a mutual respect, for the health worker to listen to the patient and open two-way communication.

2.7 Existing practices in vaccination

Different countries have adopted varying practices when it comes to vaccination. In the majority of countries in the world vaccination is now legally voluntary. However, many social scientists studying vaccination still view it as socially mandatory in order to be accepted into society.(11) An example of this is Bangladesh where a completed immunization card is needed to enter school and obtain a passport. Law does not require vaccination itself but it is needed in order to live a full life as a citizen and receive an education.

Below I will discuss examples of vaccination policy from four countries; British Columbia, Canada, Norway, the USA and Bangladesh.

2.7.1 British Columbia, Canada

Informed consent in immunization has been implemented since 2008 in British Columbia, Canada. Health care workers came together and developed a standardised guide for informed consent in immunization and how to communicate this information to participants and parents. In Section 1b of the British Columbia Centre for Disease Control guide to the Immunization Program informed consent is discussed. The opening sentence states, "*Informed consent is an essential pre-condition to providing immunization. It is the professional and legal responsibility of the provider to obtain informed consent prior to immunization. The intent of this informed consent standard of practice is to achieve a more client-centred, consistent, and expedited* *approach*."(40) The handbook has a short discussion about informed consent and then specifies the seven different steps to take to obtain consent during the immunization process. These are:

Step 1: Determine authority to provide informed consent

Step 2: Assess capability to give informed consent

Step 3: Provide standard information [BC Health File(s)]

Step 4: Confirm understanding of standard information

Step 5: Provide opportunity for questions

Step 6: Confirm consent

Step 7: Document informed consent or refusal

The vaccinator is then given a checklist for each immunization interaction to fill in.(40) So far no studies have been done to see the implications of this new policy.

2.7.2 Norway

In Norway vaccination is voluntary. An eleven-page brochure published by the National Institute for Public Health is available in many languages. It explains the vaccination schedule, side effects and the diseases the vaccines prevent. However, the brochure states that the only thing the vaccinator will ask the parent during the vaccination encounter is if the child has any contraindications to vaccination.(41) Based on informal conversations I have had with health workers in Norway, there are no standardized guidelines for health workers about the information they should give to parents during the vaccination encounter. However, studies have shown that health workers are the main source of information for guardians when it comes to vaccination in Norway.(42)

2.7.3 USA

Since 1968, communications about the risks and benefits of vaccination have been legally required in the USA. This was due to the passing of the National Childhood Vaccination Injury Act. Parents are required to be given a vaccine information statement before their child receives the vaccination. However, consent is not required and is not mentioned in the policy. The policies surrounding vaccination are contained in the Red Book. This Red Book does not specify what needs to be said and by whom. A study found that two-thirds of physicians distributed the required information sheets.(37)

2.7.4 Bangladesh

In Bangladesh law does not require immunization. EPI vaccines are available and are supposed to be free. However, there are often costs associated with vaccination. Some clinics charge a small fee for the material. In other clinics bribes may be given to skip the queue etc. Bangladesh also has a private immunization program that has more vaccines than the EPI. For example, EPI gives measles whereas the private vaccination program gives MMR. This private program is unregulated and can cost different amounts depending on where the vaccinations are given. No matter where it is given it is expensive. (knowledge gained from interviews)

Vaccinators in the EPI program in Bangladesh are supposed to follow the Bangladesh EPI book.(32) This book deals with all aspects of vaccination from cold chain to communication. It was difficult to find a copy of this book. It was only available at the hospital library and only in Bangla. I never saw a copy in any of the vaccination rooms. There is government and various NGO training programs for vaccination workers in Bangladesh.

2.8 Conclusion

This chapter began with a discussion of vaccination programs. Vaccination programs exist worldwide but there are no worldwide standards when it comes to consent, information disclosure or whether vaccines should be mandatory or voluntary. There is no standardization of the vaccination process from an ethical or human rights standpoint either. Power plays an important role in vaccination programs. Health care has an inherent power structure built into the way it operates. The physician and patient will never be equals as the physician has more knowledge than the patient. The physician, or vaccinator, often holds a higher position in the social hierarchy than the patient. This also influences the way in which the two interact. In some scenarios this can lead to paternalism.

Vaccination also raises the ethical dilemma of the rights of an individual versus the rights of the greater public. Vaccination survives because the public trusts in the vaccination program. This public trust needs to be maintained for vaccination to continue to be a successful public health intervention. Part of this trust is based in the mutual respect of the parties involved. This trust and respect can be fostered by good communication between the two groups. One way of vaccinators showing respect to guardians would be asking before vaccinating the child. Vaccinators should not assume that the guardian has made the decision to immunize but should ask and help the parent in making a choice.

The vaccinator asking before giving an injection leads to the debate around informed consent in vaccination. Informed consent has been used as a method of standardizing information disclosure during the vaccination exchange. It has also been recognized in many countries as being a necessary legal procedure if vaccination is voluntary. The focus in informed consent is on information disclosure. However, this is shifting towards understanding. Informed consent is a communication between two people that alters their moral relationship. It focuses on the autonomy of the person deciding to participate. It protects this autonomy by making sure their consent is clear and not coerced. Different forms of consent were discussed in this chapter. Most vaccination programs use tacit consent. Ethicists such as Verweij and van der Hoven argue that express consent should become the ethical standard in voluntary vaccination.(8) This would make sure that participants are making an autonomous decision to immunize by having vaccinators expressly seek the consent of those being vaccinated.

Informed consent is an important tool in the discussion of the ethics of vaccination and information disclosure. However, it may not go far enough in encouraging interaction and active communication. One alternative is informed decision making. Informed decision-making places the emphasis on the process of making the decision with a two way interactive communication approach. This is also seen in shared decision-making where the decision is made in consultation and communication with a health care provider. The information that is exchanged needs to be relevant to the patients' everyday situation. If a shared approach is used the decision should be reached through discussion.

Ethically, it is important that guardians be informed about vaccination. Too much information can be as damaging as no information when making a decision to vaccinate. Limited access to independent information sources can also be an issue. In this case the guardian is forced to rely on the state and the health worker for their information. If vaccination is voluntary then the choice to vaccinate needs to be autonomous and informed. It is the responsibility of the government and the health workers to inform guardians about vaccination. Guardians also have a responsibility to inform themselves.

Information is important in the autonomous decision to immunize but equally important is the way in which it is delivered. A balance of one-way information, mass media, and interactive two-way communication is necessary. The information needs to be relevant to the needs of the guardian and communicated in a clear way. This can be seen in the discussion of existing practices concerning vaccination policy. This is especially defined in the program from

British Columbia where the vaccination encounter has been standardized. The vaccinator is given a checklist to be completed which includes giving a standard set of information, asking questions to make sure the information has been understood, leaving room for questions from the guardian and asking before vaccinating.

In conclusion, a decision to immunize should be made based on the disclosure of adequate, relevant information given and discussed with the health worker using open two-way communication. The ethical ideal of shared decision-making is not yet realistic in many settings but a focus on informed decision making can pave the way towards a system of shared decision making in vaccination programs.

Chapter 3: Bangladesh Study Background

"Side effects of vaccines are a reality that cannot be ignored. Clients need to know what the actual side effects are, which ones are necessary in order for the immunization to do its work, which ones are minor, which ones are major and how they can best be managed. An earlier Study found that fewer than half of clients in Zone 3 Dhaka City receiving an immunization were given any counselling about possible side effects and how to manage them…. Immunization programmes need to provide clients with information about what each dose is for, when it is needed, and why one should complete the entire series as soon as possible. Talking with clients takes much more time than simply giving an injection, so new methods will have to be devised and tested to effectively and efficiently communicate the information."

ICDDR, B. Barriers to immunization among women and children living in slums of zone 3 of Dhaka City, Bangladesh: A qualitative assessment. Health and Science Bulletin, 2009, Jun; 7:2 *(43)*

This chapter will discuss the purpose and objectives for the study in Dhaka City, Bangladesh. It will present a country profile of Bangladesh and give background on the current state of vaccination in the country. After continuously reading that one of the main reasons a child is not immunized is lack of information I decided to look into how information is exchanged during the vaccination encounter. As I was preparing my literature review I realised that no one had ever specifically looked into the interaction and communication between vaccinators and guardians in a developing world vaccination room. Studies have been done where these interactions were observed but the objective was to find out the barriers faced by guardians in completing the vaccination schedule. My study looked into guardians and vaccinators' perceptions of information in vaccination. Perceptions about the amount of information exchanged/received were the focus. This study did not specifically address whether guardians and vaccinators understood the information they were exchanging. The focus was on the interaction in the vaccination room and on other information seeking methods used by the participants.

3.1 Study Purpose and Objectives

3.1.1 Study Purpose

The purpose of this study was to observe what takes place in a vaccination room. The specific focus was on how information was exchanged during the vaccination encounter. Perceptions of guardians and vaccinators towards information and information seeking were discussed. This information was examined with the goal of exploring whether enough information is exchanged to allow the guardian to make an informed decision around the immunization. I explored the perspectives of the vaccinators about the right to information and which information they feel it is important to give to the guardians during the clinical encounter. Discussion with guardians centred on where they get their information about vaccination from and if they feel they are receiving enough information about vaccination.

I feel these are important questions to ask in a health system where vaccination is voluntary and there are no set standards around how much information vaccinators have to give guardians when it comes to the vaccination encounter. The guardians have a human right to information about their child's health. The vaccinators have an ethical obligation to inform guardians about the medical procedures their child is undergoing. I wanted to see if vaccinators and guardians thought this topic was important and relevant to them. If it was then I wanted to see if they felt their needs were being met in the current system.

3.1.2 Specific study objectives

-To examine and compare the communication between vaccinators and guardians in childhood vaccination in clinical Extended Program for Immunization (EPI) interactions in two different hospitals.

-To explore the information exchange and the informed decision making process in immunization.

-To identify if guardians feel they have received enough information to make an informed decision.

-To identify how guardians receive information about immunization and from what sources.

-To identify decision-making processes of Bengali guardians around vaccination

-To explore the perceptions of vaccinators about the importance of information and the informed decision-making process in vaccination.

3.2 Bangladesh: A country profile

Bangladesh is a large, low-lying country in South East Asia bordered by India and Burma. Europeans first settled in the area in the 16th century. Eventually the area that is now Bangladesh became part of the British Colony of India. In 1947, the British divided British India using religion as the determinant for the division. The result was India, mostly Hindu, and East (East Bengal until 1955) and West Pakistan, Muslim. West Pakistan is the Pakistan of today. East Pakistan was what is now known as Bangladesh. Separated by 1600 kilometres of Indian Territory, East Pakistan was administered by West Pakistan. East Pakistanis felt like they were being neglected by the stronger West Pakistan. In 1971, a war broke out in which East Pakistan separated from West Pakistan. India came to the aid of the Bengalis helping them to overthrow Pakistan. Bangladesh became an independent country in 1971. Since then there has been some political instability in the country. As late as 2007, the military helped install an emergency care taker regime, which suspended elections. This was done in an effort to reform the political system and put an end to corruption. Democratic elections were held in 2008. Sheikh Hassina Wajed was re-elected to run the country.(44)

This colonial history is important in understanding the way health workers are trained in Bangladesh. A colonial English system of education remains based on rote memory and technical skills.(45) Critical analysis and thought are now starting to be integrated into teaching methods at some nursing schools. (Personal Observation)

Bangladesh floods annually and cyclones are a threat during certain times of the year. This makes accessing rural populations difficult. Despite the difficult environmental conditions Bangladesh is estimated to be the 7th most densely populated country in the world with a population estimated at 156 118 464 in 2010. This large population is very young with the median age being 22.9 years. Life expectancy is 69 years. Ninety eight percent of the country is ethnically Bengali. Eighty nine percent of the country is Muslim. Hinduism is the second most popular religion at 9%. Forty-eight percent of the population over the age of 15 can read and write but only forty-one percent of women.(44)

Due to the large, dense population and annual flooding the risk of infectious disease is high, especially water and vector borne diseases such as dengue fever, typhoid fever, and cholera. The health status of the people is also affected by a high trend towards urbanization as well as a low GDP per capita of 1500 US dollars a year. The prevalence of child labour is high. It is estimated that 37% of the population live below the poverty line.(44)

(See geographic map of Bangladesh in Appendix 1)

3.3 Literature review of vaccination in Bangladesh

South East Asia, and Bangladesh in particular, is participating in the push for mass childhood vaccination. In 2006, Bangladesh conducted the world's largest ever measles eradication campaign. Thirty-three and a half million children between the ages of nine months and ten years were immunized over a 20-day period.(6) However, despite these efforts only 81% of children in Bangladesh have been immunized against measles according to UNICEF.(46)

The Extended Program of Immunization (EPI) was started in Bangladesh on April 7, 1979. The intensification of the program in 1986,(47) consisted of basic training for anyone involved with EPI, and conducting advocacy and planning meetings around the country. The implementation strategy was five fold. First, all children under 1 year in the country were to be immunized. Secondly, all women of childbearing age, including those who were pregnant, were to be immunized for tetanus. Third, the services would then be extended to the community level in urban and rural areas in an attempt to cover the whole population. Fourth, community level health and family planning workers were to be trained as vaccinators. Finally, was the initiation of campaigns to mobilize different groups through both private and public mass media channels.(48) The government of Bangladesh funds sixty-three percent of routine EPI vaccination. The rest is funded by outside sources. As a result of the intensification of the EPI program the number of fully immunized children in Bangladesh rose from 2% in 1986 to 62% in

1991. Since then the rate has plateaud to about 50%.(47) In a 2003, quantitative thesis conducted in a slum area of Dhaka city, Chowdhury found that 51% of children aged 12-23 months had completed their entire series of immunizations.(12) UNICEF reports a decrease in immunization coverage in Bangladesh in recent years. A ten percent drop in coverage was reported in most districts between 2004 and 2005. In 2004, 94% of districts were reporting DTP3 coverage of 80% or higher. In 2005, it dropped to only 84% of districts reporting 80% or higher coverage for DTP3.(46)

The immunization coverage statistics for Bangladesh are highly disputed. According to the WHO 80% immunization coverage is the global target for countries to attain and to ensure enough coverage to prevent the vaccine preventable diseases from thriving. The WHO statistics show 80% coverage for Bangladesh.(10) GAVI reports 80% of districts with at least 80% coverage for DTP3.(49) The Bangladesh Health Equity Watch reports complete immunization coverage of 50% in 2001.(47) Some of this variation comes from different ways of accounting for immunization coverage. Some statistics only use first visit and others count full immunization.

What is clear from these statistics is that immunization coverage in Bangladesh is far from ideal. There are huge variations across the country defined around geography and socioeconomic status. In Bangladesh there is a 40% chance that a child has completed their immunization schedule.(50) So why aren't Bengali children completely vaccinated? Quantitative and qualitative studies on barriers to vaccination in Bangladesh have shown the most common contributing factors include;

- Being female (47)(51)(52)
- Illiterate and/or uneducated mother (12)(47)(50)(51)(52)(53)
- Having more than three children in the family (12)(50)
- Lack of knowledge about vaccinations and/or the vaccination schedule (12)(43) (50)
- Dependant on the source of information (HW vs. Mass media etc) (12)(43)(52)
- Far distance to closest health facility (12)(47)(50)(52)
- Low socio-economic status (47)(52)
- Living in a rural or slum area (43)(47)
- Behaviour of health workers (scolding, yelling) (43)(50)

Mothers are the main decision maker when it comes to vaccination.(50) Most studies show that the main reason for mothers not fully immunizing their children is fear; fear of the unknown, fear of side effects and lack of information. Some don't even know that vaccines prevent illness, others understand but think that vaccines have more effects/ results than they do.(43) This knowledge can influence whether or not a mother finishes the vaccination schedule. Another main factor for not completing the vaccination schedule is that mothers are not told when to come back for the next vaccination.(12) Other reasons found for drop out cases were not knowing when the clinic was open, not knowing that the child had to complete all of the vaccines, refusal of the vaccinator to vaccinate the child because the mother did not bring her card, irregular session times, rude behaviour from the health worker, cost, wait times, and the fact that the vaccines do not prevent diarrhoea which is the main cause of child death. Socio-economic status was found to be one of the determinants of how mothers were treated by health workers. Those who were well off often-received preferential treatment or were able to skip the queue. This dissuaded poor mothers from using the services.(43)(50)

Many of the barriers and reasons for dropping out are related to the knowledge guardians have about vaccination. So where are they getting their information from? Nationally, knowledge about polio has increased since the introduction of National Immunization Days (NID) in 1995. A quantitative study done on the increased awareness found that slum women got their information from health workers who visited their homes whereas non-slum women received most of their information from the television. However, the communication strategies used by the health workers were questioned. The way the information was communicated was found to be a barrier.(54) Uddin et al. found that exposure to mass media was significantly associated with complete immunization.(53) Chowdhury found that the most common information source in the slums of Dhaka was a health worker from an NGO, followed by mass media, private and public health workers, other mothers and other relatives. The more sources a guardian receives information from the more likely they are to absorb it and put it into practice. She found that mothers with good knowledge of vaccination are two times more likely to complete the vaccination schedule than those with poor knowledge.(12)

Assuming health workers are the number one source of information, which seems to be the case,(11)(12)(50), then it is important to understand what is happening during the immunization encounter. I was only able to find a few studies that actually observed vaccinations in Bangladesh. However, many of the studies provide anecdotal evidence of what happens during the immunization interaction. Streefland et al., found from their observations of vaccination sessions and interviews with mothers that the context of the vaccination encounter, "*does not allow them sufficient time and comfort to ask questions. Health workers are hurried and rude* *behaviour sometimes puts the mothers off."*(11) Mothers complained about how the vaccinations were given including lack of information, late arrival of health workers, rude behaviour and technical incompetence of the vaccinators. Mothers came to expect a low quality of care and put up with it because it was their only option.(29) The lack of training of health workers has also been seen as a problem in a number of studies.(11)(43) (12)(50)(53) This fact was acknowledged by a field worker in Chowdhury's 2003 study who said, *"I am not knowledgeable about the vaccination disease. What are we going to tell mothers? I don't know which diseases DPT and Measles are given for. I know polio is given to prevent paralysis."*(12)

Rude or rushed behaviour was by far the most mentioned reason in interviews and observations for dissatisfaction with vaccination services. This affects the trust of the mothers in their local health system. It also limits the amount of information mothers receive from the health workers. Studies have shown that mothers are eager to learn about the vaccine preventable diseases and more about vaccination itself. Many commented that they were not told about the diseases that the vaccination was given for due to lack of time. However, they insisted that they should be told.(11)(12) This could be done in group sessions or one on one during the vaccination encounter. Those mothers who did receive information about side effects viewed them as normal. Some even thought that if their child suffered from a vaccine side effect it meant the vaccine was working. In these cases most information about side effects was given at the first vaccination.(50) Perry et al., conclude their study by saying, "*Care should be taken not to attribute the low immunization coverage to laziness and ignorance of the mothers when the main contributing factor is poor quality of service."* They found that 80% of mothers requested more counselling and better explanations about side effects when asked how immunization services could be improved.(43)

EPI in Bangladesh is run in a top down manner, often with little to no community involvement. Health workers are in charge of organizing sessions and informing the mothers. Health workers also often have a lot of political influence, which can negatively affect the vaccination sessions. Khan found that when the community was involved in organizing the EPI sessions and monitoring a higher success rate was recorded.(50)

There are a number of barriers to achieving better immunization coverage and services in Bangladesh that have been discussed in the above chapter. The majority of the studies concerning barriers to and knowledge about vaccination in Bangladesh have been quantitative. Structural barriers, such as infrastructure and the urban, rural, slum divide must be addressed by the government and effect more than just immunization services. Gender and class also play a large role in who gets vaccinated and how they are treated. The focus of this thesis is on what goes on inside the vaccination room. I have demonstrated above that one of the main barriers to higher vaccination coverage is the low quality of care provided in the vaccination room. I believe that many of these issues could be addressed through the improvement and standardisation of the information that is exchanged between vaccinators and guardians. An informed consent procedure could be the structure in which to standardise this information. Within this new framework health workers would have to be trained in communication as well.

Chapter 4: Methodology and Research Design

"Methodology is a theory of how research does or should proceed…It is in methodology that the theory and method come together in order to create a guide to, and through analysis and representation."

Hesse-Biber SJN, Leavy PL. The Practice of Qualitative Research. Second Edition. Sage Publications, Inc; 2010.(55)

In the world of biomedical research methodology is divided into two, sometimes overlapping, sub categories. The researcher can choose either a quantitative or a qualitative approach to the research question they have formulated. However, there are an increasing number of projects that choose to work from a mixed methodologies approach. It is common practice to let your research question guide the choice of methodology.

Qualitative research is concerned with the processes behind a phenomena or event. *"Most quantitative data techniques are data condensers. They condense data in order to see the big picture and to make statistical generalisations and inferences. Qualitative methods, by contrast, are best understood as data enhancers. When data are enhanced, it is possible to see key aspects of cases more clearly."* (p.11, 55) Qualitative methodology aims to explore beyond cause and effect and delve into the ideas and perceptions behind what is taking place. Qualitative methodology is based on interpretive or phenomenological perspectives. It is focused on knowledge building and observational and/ or interactional ways of knowing. It attempts to explore the events, meanings and emotions behind human interactions and actions. Qualitative methods are also particularly suited to investigate how people reflect on and interpret particular situations and events of social interaction, what they value and what they don't. It is not generalizable, but an exploration of a certain specific setting or phenomena.(55)

I chose to use a qualitative methodology and research design for my project. It has allowed me to explore the perceptions and thoughts of the vaccinators working with immunization as well as the guardians bringing their children to be immunized. A qualitative methodology allowed me to adjust and change my project to fit a field setting that I had never visited before. This flexibility allowed me to add a second research site after arriving in the field as well as adjust the interview format I used with the guardians. This chapter will discuss the methodology and research design of the project. I will talk about how the project was implemented, which methods were used to collect data, how I recruited the participants, and how and why the project changed during its implementation.

4.1 Theoretical Framework

A theoretical framework helps the researcher to structure and plan their study. It orients the way you as a researcher view the world and perceive what is going on around you. It helps you frame problems encountered in the field and the steps you will take in approaching your fieldwork. David Silverman states in the opening of his chapter on theory in Doing qualitative research, "*How we think about our research is always shaped by our assumptions about the nature of social phenomena and the proper ways to investigate such phenomena."*(56)

This study can be placed, epistemologically, in the hermeneutic tradition of philosophy. This tradition is often referred to as the interpretive perspective.(56) The interpretive epistemology is rooted in the interpretation of interactions and the social meaning that people assign to them. Social meaning is believed to be created during these interactions. This means that the different social actors in an interaction may interpret the event differently producing different meanings and analysis. Research of this kind involves building relationships between the researcher and the research participants who become collaborators in the research process. This creates a reciprocative relationship between the two groups. The reality the researcher wishes to study is created during the research through the interactions observed and participated in. The value of this research is believed to be in how it adds to our substantive knowledge on a particular subject and not to what extent it is generalizable.(55)

Epistemological beliefs are enacted through a theoretical frame. A theory provides an account of a social reality that goes beyond what has been empirically investigated. One of the main goals of qualitative research is to create, refine and build theory. Theory is an integral part of any qualitative study. Due to the fact that the researcher is trying to create theory, or add dimensions to existing theory, an inductive approach to research is often used. This helps the theory develop out of the data.(55)(56) In this study I used a semi inductive approach to go into the field. I had some idea of what I would encounter after doing my literature review. However, upon entering the field I kept my mind as open as possible. This semi-inductive approach allowed me to adapt to different hurdles that presented themselves during the research process.

During this study I referenced three theoretical perspectives. The first is a human rights perspective. I have used the human rights perspective to highlight the right to information and the right to safe and affordable health care. This theoretical perspective was crucial in framing the argument that guardians should be receiving information about vaccination.

The second theoretical framework was based in ethics. I applied the perspective of informed decision making to highlight the need for interaction within immunization. In order for the guardians to receive information surrounding vaccination it needs to be communicated to them in a clear manner. Theory on informed consent and in particular the move from informed consent towards informed decision making framed the aspect of communication within this study.

The third theoretical perspective I have used in this study was discovered late in the analysis. Granovetter's theory of the strength of weak ties (57) helped to frame how parents seek and receive information during their decision making process. It helped me to clarify analysis around the decision making of guardians about immunization.

4.2 Study time line

I arrived in Bangladesh in mid August 2009. I received ethical clearance from Norway about 10 days after my arrival. After receiving the Norwegian clearance I applied for ethical clearance from ICDDR, B. This was a very lengthy process and I did not receive ethical clearance until the end of October. I had initially thought that data collection would take from August to early December 2009. However this time frame was shortened to about five weeks due to the delay in ethical clearance but also the numerous holidays that took place during the research period. (Eid ul-Fitur, Durga Puja, Eid al-Adha and Diwali)

4.3 Study Sites

I chose to use two study sites in this study; The International Centre for Diarrhoeal Disease Research Bangladesh (ICDDR, B) and Paedicare Hospital. Originally, I was only planning on using the vaccination room at ICDDR, B. However, after arriving in Bangladesh the ethical clearance from ICDDR, B took almost three months due to the numerous public holidays. I began to fear that I would not be able to complete my research on time. It was at this point that I approached Paedicare Hospital to see if they were open to the possibility of taking part in the project. This addition of a second research site will be discussed in more detail later in this chapter.

The first research site was the International Centre for Diarrheal Disease Research, Bangladesh (ICDDR, B). It is an NGO hospital dealing with cholera and Diarrhoeal disease. It provides all treatment for free and is very busy as a consequence. ICDDR, B is located in the Mohakhali district. The second research site was a small private paediatrics hospital located in Uttara district. Both study sites were located within Dhaka City limits.

(See Appendix 1 for a map of Dhaka City with the location of the two research sites)

4.3.1 International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR, B)

ICDDR, B Hospital’s immunization cell was preselected as my research site due to the agreement between the University where I was working and the hospital. ICDDR, B is a research hospital and was very accepting of adding a new researcher.

Founded in 1978, ICDDR, B is a research-based organization that provides free health care to the people of Bangladesh. They focus on Diarrhoeal disease but also treat other health problems such as HIV. Best known internationally for the development of oral rehydration solution (ORS), ICDDR, B plays a vital role in the health of the people of Bangladesh. They also support and run public health outreach programs.(58)

Research, for this thesis, was done at their biggest hospital in Mohakhali sector of Dhaka City. The Hospital was first established in 1962 and has continued to grow and treat over 110,000 people every year. While continuing to treat a large number of patients the hospital also has a continuing focus on research. Most recently, they have been investigating zinc therapy to treat diarrhoea. The hospital provides all treatments free of charge.(58)

The hospital is composed of three units: Special Care Unit, Longer Stay Unit and Short Stay Unit. My research was completed in the immunization room, which was located in the corner of the children's short stay unit. The Short Stay Unit is comprised of triage, the outpatient department, short stay children's ward, BRAC Bank short stay ward, Emergency ward, critical care cell, immunization cell, surveillance cell, and the breast feeding cell for the promotion of exclusive breast feeding. The average time of admittance is 12-24 hours.(58) The ward was crowded with beds covered in plastic with a circular plastic tube descending into a bucket to collect the diarrhoea from the children. On the first few visits the ward was overwhelming, the smells and noises were disconcerting as it is an open ward with no walls.

The Immunization room is a small crowded room in the corner beside the nurse's station. Health Assistants give the immunizations and Health Workers prepare the room in the morning, fill in the vaccination cards, and give a vaccination talk at 8:30 every morning in both the long and short stay units. The health workers also identify mothers and children who have missed a vaccination and bring them to the immunization room. The room can get very crowded especially in the mornings after the immunisation talks. The immunisation cell is responsible for all of the EPI vaccinations for both children and women. Besides serving those children and women admitted to the hospital they also serve the local community. Time is short for each client interaction. On the days I was observing in the vaccination room the majority of the vaccines given were tetanus toxoid for women. All vaccinations are given free of charge.

ICDDR, B also provides private vaccines at their Travellers clinic. The clinic is located in the hospital but serves mainly the expatriate community. The clinic is set up with a waiting room and two consultation rooms. There is a fee for vaccination service at this clinic so foreign nationals as well as rich Bengali families use it. Here the doctors can be Bengali or foreign.

4.3.2 Paedicare Hospital

Paedicare hospital was selected through serendipity. I was looking for a second research site due to the delays in ethical clearance at ICDDR, B as well as the limited number of childhood routine vaccinations at the ICDDR, B immunization cell. I found Paedicare Hospital during a rickshaw ride to the local market. They had erected a banner on the main street through the sector to advertise their immunisation services. Research Assistant 2 and I went in and spoke with the hospital director, Dr. Shariar. He agreed that they were willing to have me do research in their hospital in return for giving some workshops on communication and detecting child abuse after the research was finished. The ethical issues surrounding adding a second research site will be discussed further in chapter five.

Paedicare hospital is a new hospital in Sector 9 Uttara. It was opened by a group of doctors who felt that the closest neonatal and paediatric care were too far away. In traffic it could take up to two hours to reach the closest neonatal hospital. It is a small family centred hospital with a general family practice and about 10 beds upstairs for patients with low birth weight, respiratory distress and other neonatal conditions. They offer EPI vaccination services on Wednesdays from 10-1. The vaccines come from City Corporation, a western NGO that provides vaccines and training to small private clinics. The nurses attended an extensive one-week training course given by them. City Corporation delivers the vaccines every Wednesday morning.

The vaccination services are run on a first come first serve basis. The client enters through the front of the hospital passing a pharmacy while being greeted by a male receptionist. They continue up the hallway to the general waiting room. Once they enter the waiting room they present their immunisation card to the secretary and pay a fee of 50 Taka (~4.6NOK). After paying they sit and wait in a tidy waiting room. On the wall are posters concerning vaccination. Glaxo Smith Kline vaccines are used in the clinic so their name brands are displayed on the vaccination posters. There are also EPI posters displaying the national EPI Logo.

When it is their turn the family is called into the vaccination room, which consists of a desk with two chairs on both sides and a bed at the far end on which the immunizations are given. There are two nurses in the room who are trained in vaccination. The hospital also provides private vaccine services. These are done by appointment any day with the general practitioners.

4.4 Study Population

There were two main study populations in this research project. One group was the guardians, which refers to the person bringing the child for immunization. This was usually the mother but often her spouse, mother, mother in law, sister or house staff accompanied her.

The second study group were the vaccinators. This population included those people involved with giving the vaccinations. Within this study population there were two groups. The first group includes the Health Assistants at ICDDR, B and the nurses at Paedicare Hospital. They are the ones who physically injected the vaccines. The second group includes the Health Workers at ICDDR, B. They kept the vaccination room going and filled in vaccination cards.

4.5 Methods used in the data collection

This study looked into the perceptions of guardians and vaccinators concerning immunization and the exchange of information regarding immunization. I used four methods to gather information; observations, in-depth and semi-structured interviews, material analysis, and the ‘Health Workers for Change Workshops’. The wide variety of methods were employed in an attempt to prevent vaccinators from feeling judged. My hope was that by including them in different ways this would encourage them to feel like their views were important and that they were really involved in the research process. It also allowed me to explore a broader picture of the immunization process and consent in this process. Finally, this variety of methods allowed strong triangulation of the data.

Three research assistants (RA) were employed during data collection. RA1 was employed for work at ICDDR, B during observations, interviews and workshops. RA2 was employed for observations and interviews at Paedicare Hospital as well as facilitating the ‘Health Workers for Change Workshops’. RA3 was used once as a fill in when RA2 could not attend a workshop.

4.5.1 Observation

Over two hundred immunization encounters were observed during fieldwork. Observations were conducted at both study sites. Each site had a specific room where immunizations were done so this is where observations took place. The observations were mostly non-participant. I sat and watched what went on. I had permission from both hospitals to observe so each individual was not asked. However, if they had questions about who I was I would answer them through my translator. At both clinics I sat on a chair as out of the way as possible. However, I was still very visible as the rooms were small. In order to attempt to blend in as much as possible I dressed in local clothing and did not wear any makeup.

I kept a field notebook where I recorded the details of each immunization encounter as well as the time that each group entered and left the immunization room. During the first visit to each hospital, observation was done for approximately three hours to gain insight into how the clinic functioned. After this, observations were interspersed with the interviews. Each observation session lasted approximately two to two and a half hours. I wanted to be able to observe the vaccination and then interview the guardians about their experience. Observations were conducted to compare what happened in the vaccination room to the way it was described by the participants. After each observation session I would return to my home and flesh out the field notes from that day. I would also right small memos with any insights into questions I had or patterns that emerged.

ICDDR, B also has a private clinic, which administers vaccinations. One morning of observation was done to compare with the EPI clinic as the nurse in charge was also participating in the Health Workers for Change workshops. However, I was unable to make this a fully active 3rd site. The number of immunizations happening at the clinic were too little to make observing there feasible.

4.5.2 Interviews

4.5.2.1 Guardians: Semi structured interviews

Eleven guardians were interviewed at ICDDR, B. The majority of these interviews were with mothers alone. One involved a couple where the father remained quiet. The final interview involved both the mother and mother in law.

For part of the time I was at ICDDR, B I had access to an office just beside the vaccination room. The majority of the interviews occurred in this office. After observing an immunization my research assistant would ask the guardian if they were willing to be interviewed. If they consented we would accompany them to the office where they would read the informed consent form. If they were illiterate the form would be read to them and time for questions was allowed. Illiterate participants granted their consent with a thumbprint. The office was a safe and secure private environment.

At ICDDR, B I was also observing the morning vaccination (tikka) talks. Tikka is the Bangla word for vaccination. On the days when I did not have access to the office I would interview Guardians, in this case all mothers, on the ward at their child’s bedside. I would select mothers who had participated in the tikka talk in the morning. My research assistant would approach the mother and ask permission and then signal to me if the mother agreed. These interviews focused on the content of the tikka talk and on vaccination experiences in general. They had to be done at the child's bedside as the mothers were required to attend to their sick children at all times. Children were immunized upon discharge at ICDDR, B.

I was unable to conduct any interviews with guardians from the private clinic at ICDDR, B. We approached two different guardians who refused after they had read the informed consent form and had asked a few questions.

Equally, eleven guardians were interviewed at Paedicare hospital. All of the participants were literate and able to read and sign the informed consent form on their own. In opposition to ICDDR, B many of the interviews were done with more than one guardian. Pairings included couples, couples plus a mother in law, mother with mother in law and mother with house help. Everyone present in the room participated in the interview.

Similarly to ICDDR, B, my research assistant would ask the guardians if they were willing to participate in an interview after the immunization had been completed. If they agreed she would signal me and we would accompany them to the small emergency room which we used as our interview room at Paedicare. The room had a desk, three-four chairs, a hospital bed and a sliding door. We were only once interrupted by an emergency.

A semi structured interview approach was used with the guardians for two main reasons. I attempted to conduct two test in depth interviews with guardians at the beginning of the study. However, in both interviews fussing children interrupted us. Parents also had short answers to my questions. Culturally, women are not asked to elaborate on their opinions very often. When I asked questions that addressed what they would like to see changed with the vaccination encounter many said they were happy with the way it was. I am unsure if this was because they were truly happy with the experiences they were having or if it was something that they had not reflected on before.

There were about 12 core questions we asked during interviews with guardians. If the child remained calm and the parent was interested in the interview we would continue with probing and further questions. As I felt it was important to interview the guardians after the immunization we decided to do more interviews then we had planned using the semi structured approach to compensate. (See Appendix Two)

The present thesis focused on the amount of information parents were receiving and from which sources. I explored whether they felt they were receiving enough information. I did not explore their understanding of the information they were receiving. This would have made the scope of the project too broad. Understanding is very difficult to measure. I was also afraid that if I started asking parents knowledge questions that they would feel like they were being judged or tested in some way. Further study on how parents understand the information they are given would be interesting.

4.5.2.2 Vaccinators: In depth interviews

Vaccinators at both hospitals were interviewed at a time convenient for them. At Paedicare hospital we interviewed the two vaccinators together after the vaccination session had finished for the day. I decided to interview the two nurses at Paedicare together as they always worked as a team and had very distinct roles within the vaccination room. It seemed far more natural to interview them together then to break them into two interviews.

Vaccinators at ICDDR, B were interviewed in the afternoon after the morning rush had passed. The vaccination room was very busy in the morning around discharge time and very quiet in the afternoon. The first interview was done in the vaccination room. The rest of the interviews were done in the office where the guardian interviews occurred. It was important to me that I did not take the vaccinators away from their work so in one case an interview was interrupted while a vaccination was given and then continued afterwards.

In depth interviews were conducted with the vaccinators. We had the time and they were more relaxed than parents with children. A thematic interview guide was used to interview the vaccinators. This allowed for an open flow of conversation and probing. The vaccinators at ICDDR, B, I felt, were comfortable being interviewed by me as we had been working together already with the HWFC workshops and many of the themes addressed similar issues. (See Appendix Three)

4.5.3 Material Analysis

Three types of material analysis were conducted during this study to attempt to see how information was provided to the public about vaccination.

The first material analysis I did was to sit and observe five vaccination talks at ICDDR, B hospital. Locally they are known as tikka talks. The material analysis was done on the transcripts of these talks as they followed a pre-defined script. Analysis was also used on the posters used during the talks. Observation added to the analysis by being able to witness how the presenter interacted with the people who were watching.

Tikka talks are part of the health education of ICDDR, B. Every morning at 8:30 health workers spread out through the adult and children wards and give a 15 min talk on vaccination. Later in the day there are also talks on nutrition and how to make Oral Rehydration Solution (ORS). I sat in on four talks on the children’s ward and one on the adult ward. To participate in the talk you had to be sitting on a chair. If you were not seated the health workers would often tell the participant to go away. The talk was very rehearsed with little to no room for questioning. The health worker presented a series of posters. The first is about the tetanus toxoid vaccine for women.

Image 4.1 ICDDR, B teaching poster for the tetanus toxoid vaccine

The second on the different diseases prevented by EPI vaccination.

Image 4.2 ICDDR, B teaching poster for childhood EPI immunizations

However, this second poster was out of date, as two more vaccines have now been added to the EPI program, Hepatitis B and HiB. The vaccination schedule is written on the bottom of both posters.

The second form of material analysis was to look at the cards and information given by the health workers to the guardians. The only time I ever saw the vaccinators give the guardians anything but their vaccination card back was at the private clinic where during one session they handed out a small card about feeding supplements.

The final form of material analysis was to follow the mass media (as best as I could not being fluent in Bangla). I received both major city newspapers in English and paid attention to the television as well. I also was on the lookout for billboards and murals. There was one faded mural about vaccination painted just outside the hospital. I did not have access to radio. The Bengali symbol for EPI is very recognizable. The six arrows represent the six diseases in EPI. This also needs to be updated to reflect the new editions.

Image 4.3 The Bangladesh EPI logo

The reason for doing a material analysis was to see how much information about vaccination I could find without being able to read Bangla. I felt this was important, as only approximately 41% of women in Bangladesh are literate.(44) Studies have shown that women are the main decision maker in the family when it comes to the vaccination of their children.(50)

4.5.4 Health Workers for Change (HWFC)

The HWFC method was developed in South Africa to improve quality of care in clinics. The goal of the workshops is to enable health workers to see their work from their client's perspective. This is done through discussions, role-play and the use of music and poetry. Another key theme is the role and status of women in society and how this affects their health seeking behaviour. Finally, the method uses group discussion as a process to aid health workers in identifying problems. The process also enables health workers to come up with their own solutions to these problems.(59) The six workshops have been pre-designed. As a facilitator and organizer of the workshops I followed the workshop manual while implementing the workshops.(60) The workshops are made culturally relevant through the choice of local music and poetry as well as the input of the participants and local facilitator.(62)

The methodology uses six workshops to address issues of communication, perception of clients and quality of care. The provider client relationship is very important in vaccination where the guardian has to come back to the clinic numerous times to complete the full vaccination schedule. Research in Bangladesh has shown that negative health worker attitudes are one of the reasons Bengali mothers do not return for follow up immunizations.(11)(12)(50)

The first workshop addresses the reasons why the vaccinators became health workers, and how these reasons influence their relationship with the guardians and children. In this workshop each participant is asked to draw a river that represents their life and how they came to be a health worker.

The second workshop explores how health workers think their clients view them and how these views may influence the interactions at the clinic. The goal of this second workshop is to develop a questionnaire based on quality of care at the clinic. I modified the second half of this workshop to address issues of immunization instead of health care in general. The main topics were what information they felt was important to give mothers. How would they like the interaction of their own children's immunization to happen? And how they think they interact with mothers at the clinic?

The third workshop looks at the health workers perceptions of women's status in society. The main objective of this workshop is to gain an understanding of the control women have in Bengali society for bringing their children for immunization, their day to day lives, and the decisions they make about their lives, homes and families. Two local poems were used to start discussion. The women were asked how they related to these poems. The participants especially related to the poem called 'when I am 18' which describes what happens to a Bengali girl when she turns eighteen. For the participants this brought up issues of the limited independence they felt women had when it came to marriage, child bearing and seeking health care.

The fourth workshop deals with the unmet needs that women have related to their health care and to begin to identify possible solutions. I used this workshop to focus on the unmet needs in the vaccination clinics and how they think the provider client interaction around information could be improved as well as general unmet needs in the clinic. In this workshop we read a story about a Bengali woman who wanted to immunize her children but could not complete the series because the clinic was too far away and her husband would not let her go by herself.

The fifth workshop discusses how to overcome obstacles at work and the situations at work that affect their interactions with female clients and their children. The aim of the workshop is to discover what areas of work give the health workers job satisfaction and to define factors that are within and out of their control to change.

The sixth and final workshop addresses solutions to the problems that have been raised during the five previous workshops. It concluded the workshop series by planning things that can be done at the clinic to improve quality of care and information exchange.

This method was crucial for allowing me to understand the perceptions and attitudes of the health workers towards their clients and vaccination. It also enabled me to work with them during the fieldwork instead of just observing and interviewing. Finally, I hope that it instilled a sense of participation and ownership of the results in the health workers at ICDDR, B that will encourage them to follow through with the changes they recommended.

(For more information see Health workers for change; A manual to improve quality of care (60))

The head of the short stay unit, also overseeing the immunization cell, invited the health workers to participate in the HWFC workshops. All of the health assistants working with vaccination were invited as well as three of the health workers. At the first workshop all of those selected were given the informed consent form to read. Questions were discussed and they were offered the opportunity to decline participating in the workshops. Their supervisor was not present at any of the workshops and full confidentiality was ensured to the participants for what was said during the workshops and if they chose to withdraw. One workshop was held a week over a period of six weeks. Each workshop lasted for approximately 1 hour. Snacks and drinks were provided during the workshops. We celebrated the last workshop by eating a hot lunch together. The workshops were held in the same office as the interviews, offering a private, air-conditioned, and closed off setting from the ward.

The HWFC workshops were not offered at Paedicare as there were only three staff working with vaccination and a minimum of five participants are needed to run the workshops.

4.6 Sampling

The sample of guardians was recruited using convenience sampling.(55) Guardians were selected from the clinic after they or their child had received their immunizations. There may be some sample bias as we chose to select children who were not as vocal or crying after having received their shots.

Mothers were not asked for demographic data for a number of reasons. I felt that this kind of data was not relevant to the study question. If I had asked about their education level they could have felt like an outsider was judging them. Similarly the number of children they had or their ages was asked only indirectly by the question,” Is this your first child?” There have been enough quantitative studies done on the link between demographic factors as linked to vaccination status that I did not feel that it was necessary to re investigate these questions.

Total sampling was used for the vaccinators.(55) I interviewed everyone giving the vaccinations in both hospitals. Three Health Workers were interviewed at ICDDR, B of the five I saw working in the immunization room. They rotated through different wards and jobs. Two of the three health workers interviewed were participating in the HWFC workshops. The third was not involved in the workshops but was frequently working in the immunization room during the research period.

4.7 Research Assistants (RA)

In total four research assistants were employed during the project. RA1 was employed from the beginning of the project to the last week. She was employed at the recommendation of the hospital. She had a background in environmental science and media communications. She was put through two weeks of training on the project and interview methods. We did a number of mock interviews and role-plays as well as discussing various scenarios that might arise. RA1 was responsible for translating and transcribing all of the interviews done at ICDDR, B. She was the assistant during the HWFC workshops.

RA2 was hired when I decided to add a second research site. RA1 lived a fair distance from Paedicare Hospital and would not have been able to commute. RA2 was a recent business graduate and was keen and interested to do the work. She received approximately one week of training in interview techniques and we discussed the proposal. She was very helpful at setting up meetings and the research at Paedicare Hospital would not have been possible without her. RA2 was responsible for all of the translating, transcribing, and meetings with Paedicare hospital. RA2 was trained as the facilitator for the HWFC workshops and did the transcription of the workshops.

RA3 was a female Nepalese nursing student whom I was sharing an apartment with. She stepped in to help for one of the HWFC workshops when one of the research assistants couldn’t make it due to a family issue. She was also available at home to discuss the project with and gave great insights into what it was like to work in a Bengali hospital.

RA4 was not actively involved in the research process. He is a male Bengali third year nursing student. He was hired to review the transcripts and redo some of the problematic translations before I left the field.

RA1 and RA2 both signed contracts ensuring confidentiality of the research material gathered. They were paid a weekly salary commensurate with other first time employees in Bangladesh. Transportation and meals were paid if they were travelling or sharing meals with me. Neither had any experience with medical studies. RA1 had a small child and had been through the immunization process with her daughter. We used her experience during training as a test interview. Culturally it was very important that the RAs were women. It would have been culturally inappropriate for women in Bangladesh to be talking to a strange man. It was necessary to have a translator/RA, as I do not speak Bengali fluently. They were also very important in teaching me how to navigate the city and bargain with rickshaw drivers etc.

I will discuss the use of research assistants more in the section of this chapter entitled strengths and weaknesses.

4.8 Reflexivity

I decided on my study topic for a number of reasons. Firstly, I come from a family that is very involved in public health. My father was a public health officer, and my mother a public health nurse for the Interior Health Authority of British Columbia. I grew up in the Kootenays, an area where alternative culture is popular and many families choose not to immunize their children. There is a very active anti immunization movement. It always fascinated me that people would choose not to protect their children from life threatening vaccine preventable diseases. I often wondered how they made the decision not to immunize and if it was informed. I found it very interesting that after an outbreak of meningitis in my community the vaccination rate rose quickly to a high level and then remained there.(61) The most recent debate has come about over a recent outbreak of whooping cough. Over thirty percent of young children remain under or unimmunized in the region and this presents a threat to public health.(62)

Secondly, during the first year of this thesis I lost a friend to meningitis. This made me start to think more about vaccination and the choices people make. I knew I was vaccinated against meningitis but I didn’t really know what the disease was or how the vaccine worked.

Finally, I have always been interested in a human rights perspective to health. After having studied medical anthropology in my undergraduate degree I was interested in the structural barriers to health. Particularly, I found Paul Farmer’s theory of structural violence fascinating. It made sense to me that infrastructure and a government could be perpetuating violence against a population by restricting their access to safe and affordable health care, education, food, safe drinking water and housing. Structural violence is occurring in Bangladesh. This was especially visible when it came to infrastructure. The roads were bad. There was limited access to safe drinking water due to arsenic in the ground water. I heard stories from participants and people I was working with of health clinics that had been built but never staffed in the rural areas. Many Bangladeshis I talked to also mentioned corruption and nepotism as being major stumbling blocks to attaining basic needs and rights.

I was also interested in how people make decisions concerning their health care. After hearing about immunization in different countries from my classmates I realized that there was a lack of communication about vaccination in most of the stories I was hearing. This went as far as one class mate saying that she had witnessed children being immunized in her home country without their parents' knowledge.

These experiences and stories made me wonder if parents in the developing world are getting information about their children's vaccinations? If they were able to make an informed choice about the vaccinations? And what the human rights and ethical perspectives of not informing parents were? Where I grew up there is a policy of informed consent in vaccination with fairly strict standards concerning information exchange. I wanted to see if this was happening in other countries as well.

I decided to travel to Bangladesh for my thesis fieldwork based on the advice of a family friend who had started a nursing school at a local Dhaka university. In exchange for room and board I taught introduction to nursing research five hours a week. They also helped me in setting up contacts at ICDDR, B.

I definitely affected my study setting, as I was very visibly different from the people attending the hospitals. I tried to take this into consideration when dressing to go to the research site (and to teach) I wore local clothing that I had tailored to be not too tight. I wore very conservative clothing i.e. nothing without sleeves and nothing that did not cover my whole leg. I did not cover my head because I am not Muslim and even in Bangladesh many women do not cover. When working at the public hospital I wore very plain clothes. Nothing fancy as the women I was interviewing were often very poor and just had on plain cotton saris or Salwaar Kamiz. A Salwaar Kamiz is the traditional outfit worn in Bangladesh. It is made up of loose baggy pants and a long tunic. A scarf to cover the chest area always accompanies it. When researching at the private hospital I would wear a slightly nicer Salwar. My outfits became an entry point into discussion with health staff at both hospitals. My hair also fascinated people. Many children, while I was interviewing their parents, would touch my skin and hair just to see how it felt. My translator even told me that while walking through the children's ward to reach my office I would get comments like, “She must come from a good Muslim family.” I was also told that Heather was a good Muslim name. My RAs told me that this people's way of acknowledging the effort I was making to fit in and be friendly.

Besides the way I looked I feel that I stood out at the public hospital because I always tried to be cheerful and pleasant, smiling at the mothers on the ward and asking some how they were. I had to walk through the ward to reach the office I was using. I hope that this made them feel comfortable. This was different from the other hospital staff that hardly ever acknowledged the mothers. By attempting to be cheerful and open to questions I had the impression that it made the environment more relaxed and it opened the floor to be approached. These were not the mothers I was interviewing but mothers staying at the hospital to tend to their sick children.

I tried my best to fit in culturally but never did master the never use my left hand mantra. Because I was different people were more tolerant of this. I learned enough Bangla to be able to introduce myself and ask how people were doing as well as follow conversation.

I analyzed the data with a focus on information. As a result I had to leave out a lot of information around other subjects such as the feelings of health workers and guardians about topics unrelated to vaccination. The human rights and ethics frame of reference also had me focus on the ways in which things were said and if parents felt that they had received enough information. I did not look into whether they understood this information. One of the hardest parts of the study for me was when guardians said they were completely satisfied with the service they were receiving. From my perspective the service they were receiving, in many cases, was of a low standard. My fist day observing at ICDDR, B was a bit of a shock. Mothers were being yelled at on the ward to bring their children to be measured. Another mother was being led to the vaccination room by a health worker who was gripping her arm. I understand that clients were happy with the service because of the end result of their child being saved. However, some expressed that the process of being in the hospital had been upsetting. My pre-understanding of what a hospital should look like definitely effected how I viewed the hospitals I was working in. However, I believe that a health worker should never yell at a patient or drag them physically around the hospital. During interviews at ICDDR, B many participants expressed discontent with the service they were receiving from the hospital in general. However, they were more satisfied with their experience in the vaccination room. Unfortunately, there was not space to include findings about general hospital satisfaction in this thesis. After I left ICDDR, B was planning on conducting a quantitative survey of patient satisfaction. It will be interesting to see what they find.

4.9 Data Analysis

Qualitative analysis is an "art of interpretation" according to Norman K. Denzin. "*This may also be described as moving from the field to the text to the reader. The practice of this art allows the field-worker-as-bricoleur…to translate what has been learned into a body of textual work that communicates these understandings to the reader.*" (p.313, 63)

Transcription was done by RA1 and RA2 during the fieldwork. At the end of the field work all of the raw audio data from ICDDR, B was given to RA4 to re transcribe. I had concerns that it was not done word for word and was just a summary of the conversation. This turned out to be the case after I received the re translated data from RA4. In the final analysis I used the transcripts done by RA4 and referred to the original audio if there was a discrepancy. Audio transcripts and written transcripts were kept on three USB sticks. There were no names attached to any of the interviews or mentioned in any of the interviews on the USB sticks. Final transcripts were kept on my personal computer, password protected.

In this project, data analysis was approached from an abductive perspective. I entered the field with a semi inductive approach. I was partially informed by the ethical and human rights perspectives. However, during fieldwork I began to notice a number of patterns in the data. This led me to do the data analysis form an abductive approach. This approach looks into the data from a partly deductive and partly inductive approach. In an abductive approach to qualitative data analysis the researcher first attempts to detect patterns in the data. This is done with both predefined themes and allowing the data to reveal new themes. Next, the aim is to generate concepts and themes from the detected patterns and or phenomenon. After generating the concepts the research attempts to uncover data that supports the concepts. I did this using exploratory factor analysis. This analysis identifies sets of themes or variables that are highly correlated with each other. Once these variables are identified the researcher looks for common themes amongst them. These common themes develop into a concept. The next phase of the abductive approach is to engage in analogical abduction. This is intended to develop and refine theories. The final phase is to appraise the theory you have developed by returning to the data and concepts.(64)

My data analysis began during the fieldwork as I read through my notes from observations and the initial interview transcripts. As the interviews progressed patterns were recognized and focused on during observations and interviews. Memos were written during the fieldwork in the form of a field journal and discussed with RA2. Thoughts and ideas were also discussed with the students in my nursing research class to get their feedback on the cultural perspectives of the interactions I was witnessing. I also discussed the project with the two other faculty members I was living with. They had both been visiting Bangladesh for six years. Interviews and field notes were organized in chronological order by date, time and place. During my time in the field the focus was on recognising the patterns in the vaccination interactions. This is the first phase of analysis. It was completed in the field.(55)

Phase two and three are the data exploration phase and the data reduction phase.(64) These two phases are intertwined and the researcher travels between them. In the exploration phase the textual data is read, the audiovisual is listened to and the visual materials reviewed. Then you take time to think through all the material. The focus of this phase is on description. Highlighting and memoing may occur. Coding begins and the researcher starts to make links in the data.(55) I began be reading through all of my material a couple of times. Next I sat down and jotted out any ideas I had while reading through all of the data. I put these to the side to reference after analysing each method individually. After doing this I begin an individual data analysis of each method. I began with my observations. Firstly, I re wrote out all of my observation into a combined notebook. Previously, the observations for each hospital had been kept in their own notebook. While rewriting the observations I recorded the time of each interaction, when, if and what information was exchanged and which immunization was given in a table. This allowed me to identify patterns in the vaccination encounter. Some of the themes that emerged from observations were the decrease in time spent with each client at each consecutive vaccination, how the way the space is set up effected interaction, displays of power between vaccinator and guardian, if questions are asked or not, when information was given, the role of the family, the effect of apparent job satisfaction/motivation on the vaccination interaction and talking to the baby to put the parents at ease.

Secondly, I read through all of the interviews from guardians. I pulled quotes that I thought demonstrated the opinions of each guardian. For the questions that I had asked the majority of participants I made a table with the answers. This made their responses easier to compare. After reading through the interviews and data tables I wrote all of the main themes from the interviews down. These themes included who made the decision to immunize, family involvement, the status of women, information sources, preferred information sources, the amount of information (enough or not enough), clinic environment, behaviour of vaccinators, seeking a good clinic, previous experiences with vaccination, and thoughts about vaccination in general.

Thirdly, I used the same process as with the guardian interviews to read through the interviews with vaccinators and the HWFC workshops. Common themes amongst the interviews and workshops were identified and noted. Common themes were job satisfaction, previous job experience, the status of women, clinic environment, vaccination education, the importance of information, which information they thought was important, communication differences between different clients and in the role plays, respect, trust, the role of the family, information sources and knowledge versus action.

Finally, I looked through the data on the tikka talks. I compared the five talks I recorded to see if there were any major differences. I also started to analyse the posters and how they were used in the presentations. I again identified the main themes within the tikka talks and noted them. The themes I identified in the tikka talks were group versus individual education, talk structure, teaching method (question and answer), invitation and commencement, side effects and disease presentation, the myth of measles, being a good mother, women's status, the ability to question, use of teaching aids, impact of the disease on the child's life and family finance, and missed opportunities for information exchange.

After noting all the themes from each of the methods I wrote separate documents for each method. In each document I used the identified theme as the title and referred back to the raw material to pull quotes that were relevant to that theme. All of the quotes relevant to the theme from that method were placed under the heading in the method document. After completing this I re read each of the documents and noted any links or connections between themes in each document and between documents.

Next I took the main themes from each method and wrote them out on big sheets of paper. I cross-referenced to see which themes appeared in all or a majority of the methods. These themes became the central codes for analysis. Four central codes or concepts were identified. These were environment, job satisfaction, decision-making and information and trust/respect/power. I then re worked the theme documents into code/concept documents. In these documents all of the findings around each of the four identified themes were consolidated from the method document. At this point all data unrelated to the four central codes/concepts were set aside. Further analysis was done on consolidating the data in the code documents, using analogical abduction, before writing began.

During data analysis I had some thoughts on theory that emerged. As I was reviewing my code/concept documents and reflecting on what I had seen during observation I began to apply ethical theories from informed consent, and informed decision making to the data. This led me to think further on how these two concepts can be bridged in vaccination. These thoughts are presented in chapter twelve.

4.10 Discussion of methodology

4.10.1 Validity

Validity is conceptualized differently in the qualitative paradigm than in the quantitative paradigm. Validity is a concept that qualitative researchers address as they make a case or argument for the knowledge they have produced being valid. To simplify, validity is the argument that the knowledge produced reflects some aspect of the social world.(55) This study covers an event that happens all over the world every day. The majority of people in the world have experienced at least one vaccination in their life. It approaches this event during a specific period of time, in two hospitals, in one city in the world. The methods used have triangulated the data. The event of immunization is presented from three perspectives; the guardians, the vaccinator and the researcher. This helps to increase the validity of the study. During analysis and interpretation the focus was on letting the voices of the participants speak representing their reality through their story.

The findings from this study are drawn from a small sample of participants. The findings are not generalizable and that was not the goal of the method. However, the findings may be relevant to other immunization programs in the world as the vaccination encounter happens in similar ways no matter where you are based on the WHO EPI guidelines.

Qualitative research is subjective. There is one person exploring the thoughts, feelings and perceptions of a separate group of people. What the researcher chooses to focus on may not have been what the participants would have focused on. The results of the analysis may be different when done by an outsider than if they had been done by the participants in the research. Qualitative research is also explorative and allows different social actors to come together and exchange ideas. During my interactions with the participants of the study different opinions and ideas were exchanged. I learned a lot about how the participants perceived the city they lived in and their everyday work and lives. I was also questioned a lot about what life was like in Norway and what I did in school. A favourite topic of questioning by the health workers was when I was getting married. I think that they thought I was too old to be single.

In this thesis I did the analysis mostly on my own. I was not familiar with Bengali culture before entering the field and I do not speak the Bengali language fluently. This makes how I experienced Dhaka City very different from how my participants experienced it. This will also affect how I interpreted the data. However, I have focused on letting the subjective voices of the participants come through in the findings. During the fieldwork I was constantly reflecting on how my subjective perceptions were different from those of my participants and how I was affecting the field.

I believe that the multiple methods used in the study helped to strengthen the internal validity of this thesis. The majority of the themes used in the final analysis came up in all of the research methods. The findings from the observations, interviews and workshops intersected. Main messages such as ‘information is important’ were found in the preliminary analysis of all of the methods. Which information was important differed between methods. The fact that the majority of the findings were represented in findings from all of the methods, I think, shows that they are central to what was actually happening.

4.10.2 Changes during planning and implementation

In qualitative research the process is as important as the analysis. Qualitative research allows the researcher to change the study to adapt to the study environment. Two major factors influenced the changes that took place in the study between the design in the protocol and the final result. The first was the small number of vaccinators at the immunization room at ICDDR, B. Before leaving for the field I was under the impression that the immunization room at ICDDR, B was bigger than it was. This along with the extended amount of time it took to get ethical clearance led me to find a second research site. Paedicare hospital was selected for its location and for the fact that as it was a private clinic it was very different from the immunization program at ICDDR, B.

The second major change in the study was the shortening of the active research period from three months to five weeks due to the delay in ethical clearance and the national holidays celebrated during the research period. Instead of doing one interview per day at the research site we ended up doing three or four. Another unanticipated cultural influence was the shyness of many of the guardians participating in the interviews. It was often difficult to encourage guardians to expand their answers beyond a few sentences. This made the interviews short and the depth I wanted to discuss the subjects in was not reached. In order to compensate for this I adopted a semi structured interview approach with the guardians. This allowed for a broader comparison between the interviews. I also doubled the number of interviews I had expected to do with guardians hoping that the increased number would allow for a deeper understanding.

The final change was the modification of the HWFC workshops from two hours down to one. It was impossible to take health workers away from the ward for longer than an hour. They are very busy. As a compromise the hospital agreed to run the workshops and I agreed to cut them to one hour. This affected the depth of the conversation we could reach during the workshops. However, I believe that even though the workshop time was shortened they were still very relevant. A lot of insight into the vaccinators' perspective was gained from these discussions and the health workers enjoyed coming to the workshops.

Throughout the process of making changes to the study design I attempted to stick with a semi inductive approach to the research. As the research continued it became more deductive. That is why analysis was done using an abductive approach. The changes that took place happened in a very organic way and seemed like a natural evolution of the project in the field. It was impossible to stick exactly to the protocol without ever having visited the field site or visiting the country before. The learning process of making these changes was very important and contributed to my education as an independent researcher.

4.10.3 Strengths and weaknesses

The strengths of this study are the multiple methods used for data collection as well as the choice of two contrasting study sites. The two hospitals represent the two ends of the care spectrum in Dhaka City. I was also trying to find a local community clinic to visit but ran out of time. Paedicare hospital has a very caring environment and is a very small hospital with approximately ten beds. ICDDR, B is one of the biggest hospitals in the country that is very efficient in curing diarrhoeal disease. They are all about getting people in and out as fast as possible. The environment is very sterile and there is not much of a sense of community among the patients.

Another strength is the involvement of the Health Workers at ICDDR, B in the workshops. They seemed to enjoy these workshops and it was an opportunity for the three different levels of employees involved to learn about each other and work together. Some of the workshop participants suggested that it had made the teamwork environment in the immunization room better.

An unexpected strength of this study came from the fact that I was teaching an introduction to Nursing Research 4th year class at The International University of Business Agriculture and Technology (IUBAT) in Dhaka. Teaching how to do research at the same time as doing my own project made me reflect on what I was doing in the field. I also think that it made the teaching more interesting for the students as we were able to discuss real scenarios in the classroom and I was able to get their feedback on cultural and research scenarios. This turned out to be invaluable. I was also able to “use” some of my students to train my research assistants. They were great actors and participated with enthusiasm in both interview and workshop scenarios.

The main weakness of this study was the use of translators. I worked with two research assistants during the study, one for each hospital. Both were present at the HWFC workshops. RA1 who was employed for ICDDR, B went through a rigorous two weeks training in interviewing and research. She did well in training however, once the research began, she did not do so well. I was continuously trying to talk to her about not interrupting the research participants or answering her phone during interviews. She would chat with the health workers during observation time and in my opinion disturb the environment in the vaccination room. After this I brought her to the hospital only for interviews and did observations and material analysis on my own. After having her transcripts re translated I found out that she would sometimes give me the answer she thought I wanted to hear and not the answer given by the participant. She would also reprimand participants if she thought they were talking too much. All these issues affected my ability to probe during interviews. She would often give her opinion during the workshops. Even after repeated corrections she continued to act in the same way. I ended up letting her go in the last week of the research.

RA2 was hired when I realised the RA1 would not be able to handle the workload of a second research site. She was trained for one week in interview techniques. RA2 assisted me at Paedicare Hospital. She was a great translator and able to adapt to different interview scenarios. Her translations were lacking in detail at times but she was able to help me probe with the participants.

Another change to the methodology was the compressed time line, which I ended up working with. Initially I had thought I would have three months for data collection but between the delay in ethical clearance and the major holidays this was shortened to five weeks. This meant that my team and I were doing 3-4 interviews a day and did not have a lot of time to sit down and discuss the interviews in-between. It also meant that I could not sit with my RAs as they did their transcriptions. This was because I was working at two hospitals on opposite days and alternating between RAs. So while RA1 was transcribing I was out doing interviews with RA2 and vice versa. I think that this time limitation had an effect on my research. There was a constant feeling of being rushed. I had a short discussion with my RA after each interview to talk about cultural points I did not understand and to see how they felt the interview went. If the interview had been poor we discussed how we could make the next one better. If the interview was good we talked about why we thought it had been good and how we could continue this in the next interview. The main analytical weakness was not being able to sit down with my RAs and transcribe the interviews together. I think I lost out on some of the cultural richness and understanding by not doing this during the research. When I returned to Oslo I did go through some of the interviews I couldn’t quite understand with two Bengali friends who elaborated on the cultural meaning behind the statements I found confusing. This was very helpful. However, the study would have been stronger if I could have done this in the field.

A further limitation of the study is that I was sampling participants from within vaccination clinics. This means that this study only covers people who actively came to immunize their children.

4.11 Dissemination of findings

After this thesis is completed a copy will be submitted to the University of Oslo Library where it will be available to the general public. An electronic copy will also be sent to the Libraries at ICDDR, B, IUBAT and Paedicare Hospital.

Is the choice to vaccinate informed? A qualitative study on information exchange in the vaccination encounter in Dhaka, Bangladesh

Chapter 5: Ethical Considerations

"Ethics aims to achieve two fundamental objectives: to tell us how we ought to act in a given situation, and to provide us with strong reasons for doing so."

Schüklenk U. Module one: introduction to research ethics. Dev World Bioeth. 2005 Mar;5(1):1-13. (65)

It is important as a researcher to apply to the appropriate research ethics committees before commencing research. The job of these committees is to question your research protocol and make sure that it is in the best interest of the people whom you would like to research, that you will do no harm. This project was conducted in accordance with the Declaration of Helsinki,(66) the International Ethical Guidelines for Biomedical Research Involving Human Subjects from the Council for International Organizations of Medical Sciences (CIOMS),(67) and the Universal Declaration of Human Rights.(68)

5.1 Ethics approval and permission

5.1.1 Ethics Approval

Ethical approval for the study was first given from the Norwegian research ethics committee (REK) in August 2009. Permission for the study was granted after a few minor adjustments were made to the protocol to account for more details in the sampling method.

After, receiving permission from REK, I started the process of applying for ethical approval at ICDDR, B. This was a long process. The first time I applied at ICDDR, B the proposal was turned down due to problems with the informed consent form and a lack of a structured questionnaire to be used during interviews. My research assistant and I reviewed the informed consent form and made the necessary changes for it to be accepted. The ethics committee was not used to dealing with qualitative projects. I had a telephone interview with the person in charge of reviewing my proposal to explain that in qualitative research with an in depth interview design I would be using a thematic guide to interview participants and not a structured questionnaire. I submitted some possible sample questions to be used in interviews. The proposal was passed by the ICDDR, B ethical committee at the end of October 2009.

5.1.2 Other permission: Paedicare Hospital

Paedicare hospital does not have an Ethics committee. I had a meeting with the hospital director after he had read my protocol. He agreed to allow me to do research in his hospital in return for offering some classes to his staff on communication and child abuse. I held two classes on communication with the nurses in the hospital and my colleague Deirdre Evans, a trained social worker from Vancouver, Canada, held the session on child abuse. All parties involved signed a written agreement.

5.2 Informed Consent

Informed consent forms were presented to participants before the interview. The informed consent form, which had been approved by the ICDDR, B ethics committee was used at both hospitals. There were separate informed consent forms for vaccinators and guardians. The informed consent form consisted of a study information sheet followed by the actual consent sheet. Participants were given the informed consent form to review before the commencement of the interview. If the participant could not read the research assistant would read the form out loud to them. If the participant had any questions they were discussed before the form was signed. Those participants who could not sign their name signed with a thumbprint. The participant was given a copy of the informed consent form to take home. This contained my local contact information if they had any further questions about the study or wished to withdraw at any time. All participants were told that they could withdraw from the study at any time, or choose not to participate in the study, with no negative ramifications for their personal treatment at the hospital.

5.3 Confidentiality

Participant confidentiality was maintained in the study by giving each participant a code with the hospital name and their interview number i.e. ICDDR, BM1, or MU1. This was the case for both the guardians and the vaccinators. Because no follow up was needed in the study these codes were never attached to the informed consent forms. If we had needed to track someone down then we could refer to the date of the interview to find him or her. All of the interviews with guardians at Paedicare Hospital were done in a private room. Most of the interviews at ICDDR, B were also done in a private office, however, a few were carried out on the ward. My RAs and I did not see this as a problem as the subject we were discussing was not sensitive in the Bengali context. When we did the interviews on the ward it became a bit more of a group interview, as mothers at surrounding beds would chip in with their own experiences. I think being able to interview these mothers together gave them a feeling of power. The power differential between myself as a western, educated women and they was reduced in this scenario.

The interviews with the vaccinators were coded in the same manner as the interviews with the guardians as mentioned above. However, as I interviewed all staff working with immunization in both hospitals it is possible that they could be identified. So I would say that the vaccinators are quasi anonymous. There were three vaccinators at ICDDR, B. They were interviewed separately in a private room. The assistants at ICDDR, B were also interviewed privately in a separate room at their convenience. The two vaccinators at Paedicare Hospital were interviewed together as they worked in tandem during immunization and this felt natural to do.

The concept of confidentiality is also different in Bengali culture. Many people may come together to the immunization room. The idea of personal privacy is also quite different in Bangladesh. People felt very free to talk openly about their thoughts and feelings as well as criticizing or praising others they worked with. This cultural difference made it hard for me to explain to my research assistants that they were the only ones to see the data and that they were not to discuss it with their family members. Culturally, it is not normal for a wife to keep secrets from her husband in Bangladesh and in the end I think the data gathered was probably discussed with family members at home. I know that family members helped with the translation of some transcripts. I did not feel that that overly infringed on the participants' privacy as no name was ever given on tape and the recording was labelled with the participant code. There was no way the family member would have known who they were listening to.

5.4 Ethical dilemmas faced in the field

I think any researcher working in the developing world will face ethical dilemmas during their fieldwork. Many of these will stem from the clash of cultures between practices in the researchers home country and the field site. For me the most apparent ethical dilemma in my research was the issue addresses by the research question itself. This was the lack of information given to patients in general not just during immunization. As mentioned in the description of the study site in chapter three, I had to walk across the children's ward to get to both the immunization room and my office. As I was obviously a foreigner, wearing traditional clothing did nothing to disguise this fact; hospital patients thought I was a doctor. I quickly learned how to say, "Ami Doctor Na" (I am not a doctor) but this did not stop the questions from coming. The mothers sitting beside their children's hospital beds were desperate for information about how long they would be at the hospital, why their child's condition was not improving etc. Many felt like the doctors ignored them. I forced myself to smile and acknowledge these patients on the walk to my office in the morning and this would always open a floodgate of questions. I did my best not to get involved. Only once did I get involved with a mother right outside my office that had been there for a number of days. On the third or fourth day when I smiled and said hello she burst into tears. I finally sorted out, through my translator that she had already been in the hospital for six days and her child wasn't improving. The doctors were not answering her questions and she wanted to take her child home. I went and got one of the health assistants I was working with who calmed her down and was able to answer some of her questions. I think word must have got around because at the next rounds I saw the doctor talking to this mother.

This was one of many ethical dilemmas faced during fieldwork. Others included local children where I was living begging for food, health workers yelling at mothers at the hospital and a general hierarchy in the hospital where there was a sense of superiority between the different levels of health workers.

5.5 Beneficence and usefulness of the study

From an ethical perspective the study should contribute to the greater good of the population it studied and be useful to them. I was very aware of this entering the field. This is why I chose to use the Health Workers for Change Workshops. These workshops allowed me to work alongside local health workers to understand their perspectives on what I was like to be a health worker in Dhaka, how they viewed the gender roles in their society, what information they thought was important to communicate to the patients and how, and what challenges they faced in their day to day work. Over the six workshops I could see subtle changes in the health workers I was working with. The gained better understandings of whom each person was and formed a closer teamwork bond. There were even some small, noticeable changes in how they interacted with patients.

I also chose to teach at a local university during my fieldwork as a volunteer visiting faculty member. I taught introduction to nursing research and was able to introduce fourteen soon to be local nurses to research and what it could do. In class we discussed the issues I was being confronted with in the field and the students gave critical insights into what it was like to be a nurse in Bangladesh. Each of these students completed a research project on a local health issue that I helped supervise. I believe that the trickledown effect of working with nursing students, although not directly involved with my research project, was the biggest positive legacy I left behind.

Finally, the results of this study will be presented back to the hospitals where the fieldwork was done. Hopefully steps will be taken to implement some of the suggested recommendations.

Is the choice to vaccinate informed? A qualitative study on information exchange in the vaccination encounter in Dhaka, Bangladesh

Chapter 6: Introduction to Study Findings

Image 6.1 The sign marking the door to the immunization room at ICDDR, B.

The following section of the thesis will present the results from my fieldwork conducted in Dhaka, Bangladesh from August-December 2009. The findings section includes four chapters, one for each of the main findings in the study. These findings are; the effect of environment on vaccination interaction and communication, vaccinator job satisfaction and its consequences on communication, interaction and information in the vaccination clinic, information exchange and the informed decision making process of Bengali guardians, and the role of power, trust and respect in the vaccination encounter and informed decision making. I have decided to present the findings and discussion on each topic in its own chapter. I feel this allows me to focus on each finding in more depth. Each finding is based on information collected during fieldwork. As mentioned in the methodology chapter I used a number of methods to collect my data.

I performed 22 semi-structured interviews with guardians after observing their or their child's vaccination. I interviewed eleven guardians from each research site, Paedicare and ICDDR, B. Each interview is given a code that identifies the participant and the research site. Guardian interviews are identified with a G. Each hospital is recognized by the first letter of its name, I or P. Finally, a number is assigned. This represents the placement of the interview in order of time. For example the 5th guardian interviewed at Paedicare Hospital is GP5.

I did eight in-depth interviews with vaccinators over the two research sites. At Paedicare Hospital the vaccinators were trained nurses who worked in the vaccination clinic one day a week. They worked together as a team. They are coded as VP1 and VP2, vaccinator Paedicare one and two. I did six interviews at ICDDR, B. Three were with the health assistants who performed the vaccinations. These women were trained as field health workers. They are coded as VI1-3. I also did three interviews with health workers who work in the vaccination room at ICDDR, B. The health workers are trained to fill in the vaccination cards, give vaccination group education, and prepare the vaccination room for the day. They are coded as VI4-6.

I observed and recorded five tikka talks during my fieldwork at ICDDR, B. Tikka is the Bengali word for vaccination. These talks are coded as Tikka Talk #1-5 with the date on which they were recorded. Each talk was given by a different health worker in a different location on the ward.

I observed and recorded 73 vaccination encounters at Paedicare Hospital and approximately 120 vaccination encounters at ICDDR, B. These were observed over fifteen observation sessions. In total these approximately 193 recorded vaccination observations allowed me to understand what was happening during the vaccination encounter and match this to what I was being told during interviews. Many more were observed but not recorded during visits to the clinic on non-observation days.

Finally, I conducted six Health Workers for Change (HWFC) Workshops. Findings from these workshops are presented both as individual quotes and group statements. If a finding from the workshop is presented as an individual quote it is coded as Vaccinator, ICDDR, B, HWFC Workshop #1-6. Each quote is labelled as vaccinator to protect the anonymity of the person who said it.

This study produced four main findings. Each will be presented and discussed in its own chapter. Chapter seven will address the effect of environment on vaccination communication and interaction.

Chapter eight will explore health worker job satisfaction and its consequences on communication and interaction in the vaccination clinic.

Chapter nine looks at information exchange and the informed decision making process of Bengali Guardians.

Chapter ten deals with power, trust and respect in the vaccination room and how this effects the vaccination interaction.

Finally, a short summary of the findings and discussion will be presented.

Is the choice to vaccinate informed? A qualitative study on information exchange in the vaccination encounter in Dhaka, Bangladesh

Chapter 7: The effect of environment on vaccination communication and interaction

"The environment of the immunization room is small. We can't give the mother a seat, and there is no place to inject the child. We can't work properly. Because of the small space we can't easily provide the service to our clients."

Health Worker at ICDDR, B
Dhaka, Bangladesh
During Health Workers for Change Workshop #5

From the first day of observation the role the clinic environment plays in vaccination communication and interaction was apparent. As the field study progressed the topic of environment came up repeatedly in observations, interviews with both guardians and vaccinators, and during the Health Workers for Change Workshops. In this chapter I will explore the role the clinic environment has on communication and interaction during vaccination. This finding will be described from three perspectives; observations, the perspective of the vaccinators and the perspective of the guardians. Finally, a discussion about the impact of environment on communication will be presented.

7.1 Environment, interaction and communication from the perspective of observation:

7.1.1 Paedicare Hospital

I spent the first week of the field study observing the daily routines of the two clinics I would be conducting my research in. The contrast between the two clinics became evident from the first day of observation. Paedicare Hospital is a private clinic in Uttara Sector of Dhaka City. Uttara is a mixed neighbourhood with all levels of society represented from the very rich to the very poor. The clinic was situated two blocks from the major local hospital, Bangladesh Medical. Bangladesh Medical did not provide EPI immunizations and refers families to Paedicare. The clientele at Paedicare Hospital were middle to upper class. There was a charge of 50 Taka (~ 4 NOK) for vaccination.

Paedicare Hospital had a clearly defined system to their immunization process. Guardians and children would enter through the front door of the clinic where they would be greeted by a receptionist and instructed to continue on to the waiting room. When they entered the waiting room they would approach the registration desk, introduce themselves, pay and then take a seat. The waiting room had good natural light and was well ventilated. Guardians and children had access to toilet facilities and safe drinking water. There were a number of posters about vaccination up on the walls. From the waiting room parents would be called into the vaccination room. Upon entering the vaccination room they would take a seat across the desk from the two vaccinators. The vaccinators would ask some questions about the child and its previous vaccinations. The vaccination card would be handed over and the information about that day’s vaccination would be given. Then the guardian would be asked to place their child on the bed at the far end of the room. They were then instructed to return to the area behind the desk while the nurses gave the vaccinations. One of the nurses would then hand the child back to the parents along with the vaccination card and repeat when they were to come back for the next vaccination. This process was calm, quiet and controlled. The nurses appeared cheerful and parents relaxed.

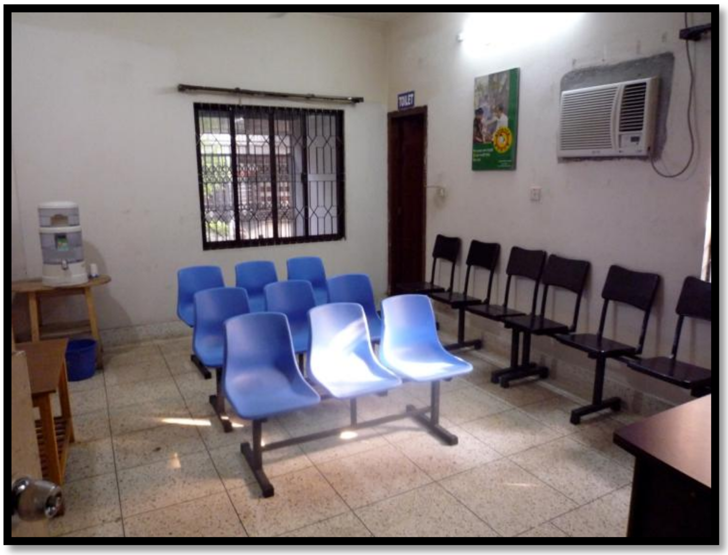


Image 7.1 The waiting room at Paedicare Hospital

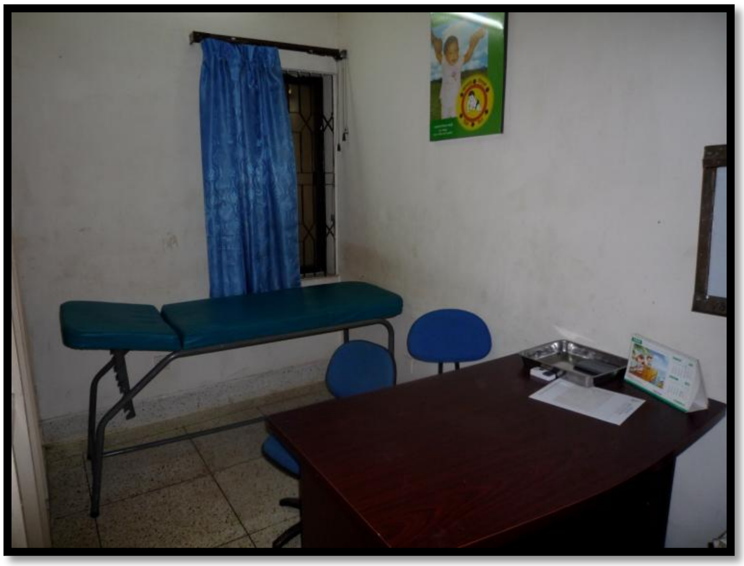


Image 7.2 The vaccination room at Paedicare Hospital

7.1.2 ICDDR, B

The EPI room at the International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR, B) had a very different system in place. The immunization room is situated in the back corner of the children's short stay unit. It is currently in a doctor's room that has been temporarily turned into the vaccination room during hospital renovations. The clinic can be difficult to find. It is cramped and has little to no natural light or ventilation. The room is cramped with two large freezers and many boxes containing immunization equipment. The room is noisy and crowded and the smell from the ward drifts in. The door is constantly opening and closing. During busy periods the door is left open. The door opens into the clinic making entry awkward when the room is full. When a guardian enters the room she checks in with the Health Worker sitting by the door. The Health Worker checks her card and fills it in or makes a new card if the woman does not have one. The Health worker tells her when to come back for the next vaccination. The woman then waits her turn as she watches all of the women and children ahead of her being vaccinated. There is a small stool for the person receiving the vaccination to sit on, everyone else is standing. Mothers hold their children on their laps during the child's vaccination. There is no bed and no privacy.

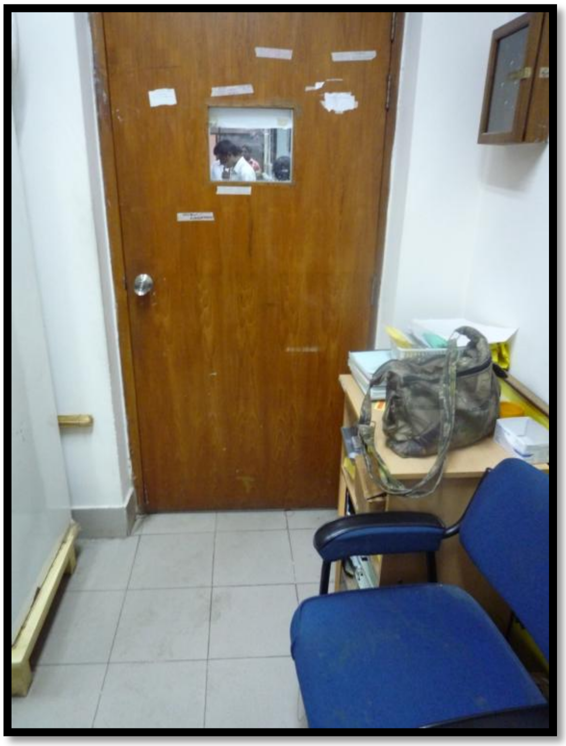


Image 7.3 The entry into the vaccination room at ICDDR, B. The door opens in.

Image 7.4 The organisation of storage in the vaccination room at ICDDR, B

Image 7.5 The vaccination room at ICDDR, B. The area where the vaccinator is standing is where the client sits on the green stool to be vaccinated at ICDDR, B

7.1.3 Comparisons from observations between Paedicare and ICDDR, B

The stark contrast in the way the two clinics are set up facilitated the observation of how the space effects the communication and interaction between the vaccinators and the people receiving the vaccines. At Paedicare where the space was clean, calm, and light, guardians and vaccinators were visibly relaxed. The clinic administered on average 30 vaccinations a day with an average visit time of five and a half minutes. Each client had the full attention of the vaccinator. The more medicalized atmosphere promoted question asking by parents. The nurses and guardians would often discuss the vaccines and side effects as well as future vaccinations during the visit. The parents were focused on what the vaccinators were saying, as there was little to no distraction, besides the child. The vaccinators at Paedicare did not often seem rushed and took longer on average with clients. This could be due to the fact that they could not see how many clients were waiting in the waiting room.

In contrast, at ICDDR, B the atmosphere was quite different. On average this clinic gave 50-60 vaccinations a day with an average time of approximately one and a half minutes. The space was crowded and cramped with little to no privacy during the busy hours of the day. I observed up to twenty people in the room at a time. They had to squeeze past each other to reach the vaccinator. Instead of having an equal vaccinator to guardian ratio as seen at Paedicare the vaccinators became outnumbered in their own space. They were obviously feeling rushed as they could see how many people were waiting and just wanted get them through as quickly as possible. When crowded the room was also very noisy which made communication difficult. I observed that on busy days attempts to communicate were given up in order to vaccinate all of the patients who were waiting. The noise and crowds also made it difficult for the vaccinators to communicate with each other. A few brave women would ask questions during their vaccinations but most looked scared and rushed, kept their eyes down, received their vaccinations and left.

7.2 Environment, interaction and communication from the perspective of the Vaccinator

It quickly became evident during the interviews with the Health Workers that they felt their work environment effected how they communicated with their patients. During the 5th Health Workers for Change Workshop (HWFC) the vaccinators at ICDDR, B were asked what they thought was the biggest factor preventing them from doing their work well. One of the vaccinators exemplified the feelings of the other participants of the workshop when she said,

> *"The environment of the immunization room is small. We can't give a seat to the mother, and there is no place to inject the child. We can't work properly. Because of the small space we can't easily provide the service to our clients."* Vaccinator, ICDDR, B, HWFC Workshop #5

The topic also came up during interviews with vaccinators at ICDDR, B. The vaccinators identified their small immunization room and working environment as a factor that prevented them from doing their work the way they wanted to. This vaccinator reiterated the point made in the workshop about the environment of the vaccination room during her interview,

> *"The room is not good, but we are good workers for the mother and child, but the room is not good."* VI1

Many of the vaccinators felt like the small space affected the experience of the mothers coming for vaccination in a negative way. Previously they shared a room with the family planning program. This provided chairs and a waiting space. During her interview one of the vaccinators explained what she thought the advantage of a larger space with chairs was,

> *"The mother was sitting to take the vaccine…Those who come for the vaccine they need to relax when they take the vaccine."* VI5

This health worker thought that the current environment was not conducive to the mother being relaxed as she received her shot. This made the mothers more nervous during vaccination that could make them tense their arm.

Another vaccinator talked about how she felt rushed due to the size of the room and the number of patients who she could see waiting:

> *"Everyday I am where, where, where, where…Okay the mother will come and see the surrounding space and I will talk to her for enough time. But this is not too good a place for a mother to sit and for me to talk enough…The mothers come and go, come and go…because of the small space. Another mother is sitting outside waiting for this mother to finish, quickly go… quickly go. It is not fair."* VI2

The vaccinators at ICDDR, B shared with me that the room they were in was temporary as the room they used to work in was under renovation. They missed the freedom and space that the old vaccination room provided. I began to ask them what they would like their new vaccination room to look like, what they would change?

All of the vaccinators at ICDDR, B wanted a larger room. An important factor of the new room would be somewhere for those who were waiting to sit. Many felt that the people who were standing and waiting to receive their vaccinations became bored and did not feel well standing for so long.

Another issue that was raised was the location of the vaccination room. The Health Workers thought that the current location was difficult for people to find. A number of participants thought that the ideal location for the vaccination room would be beside the pharmacy. This was because many people who were discharged from the hospital were directed to the pharmacy before leaving. The pharmacy would also be easy to find if you were a visitor to the hospital. One of the vaccinator's talks about her wish for the location of the clinic,

> *"After being discharged they are vaccinated. So, many mothers and children take medicine at the pharmacy (after being discharged, before they go home). So our room*

> *should be near the pharmacy. We would catch more children, people…Here it is very small and…what…like a corner or like a prison."* VI1

Cleanliness was another issue that was raised by the vaccinators at ICDDR, B. They felt that the room was very difficult to keep clean. When I asked one of the vaccinators what she would change about her working environment she responded without hesitation,

> *"First, I would improve my room, my working place, because my working place is very, very narrow and nasty. Our first need is cleanliness. We also need good lighting and um… air, fresh air. This room we have now is very nasty. All of us are constantly cleaning. It is the first thing we do in the morning, start cleaning. I would like it to be neat and clean."* VI2

All participants did not agree on whether there should be a waiting room in the new space. Arguments for a waiting room concerned the privacy of the person receiving the vaccination. They felt that this privacy would also increase the ability to communicate. Those who did not want a waiting room felt that if the vaccinations happened where those waiting could not see that the people waiting to be vaccinated would get nervous. A second argument was that if the vaccinations were separated from a waiting area the Health Assistants would not be able to keep an eye on the Health Workers. If the Health Worker went outside for Namaz (prayer) or a meal then there would be no one to greet the people coming into the clinic.

One of the vaccinators at ICDDR, B also mentioned the lack of teaching tools in the temporary vaccination room. Previously the posters that the Health Workers use in their vaccination talks to explain the diseases prevented by vaccination and the vaccination schedule were also displayed in the vaccination room. She felt that having these pictures displayed helped to create interaction and communication. She was confident that when the construction was complete the pictures would be put back up.

Finally, during the workshops another environmental factor was discussed. It had also come up during one of the vaccinator interviews. This final factor is the pride, which the workers wanted to take in their workspace, but instead they felt ashamed of their working environment. They felt that ICDDR, B was an institution that was recognised around the world and that their vaccination room did not live up to this world-class reputation.

> *"We are surprised that ICDDR, B is an international centre but the immunization room is not good. This is an important program and a worldwide program, but ICDDR, B is not providing a healthy environment for it. They (the hospital administration) are feeling good about our behaviour but we think that we are neglected here. Clients are not satisfied with our environment. Sometimes our relatives, neighbours come here to take their vaccines and see the environment of the immunization room. When this happens we*

> *feel very shy. This makes us feel neglected."* Vaccinators, ICDDR, B HWFC, Workshop #5

Although the vaccinators at ICDDR, B think that the clinic environment is important and have interesting ideas on the position and layout of the new clinic they were not asked for their input into the new vaccination room.

This sense of shame in their work environment also impacted on job satisfaction. I will discuss this topic further in chapter eight.

In their interviews the nurses at Paedicare did not mention space or the clinic environment as a factor, which effected their communication and interactions with their patients. I observed that when they felt busy or pressed the length of the communication interactions would decrease.

7.3 Environment, interaction and communication from the perspective of the Guardian

Guardians also mentioned clinic environment when talking about present and past experiences. It was quite clear that the clinic environment became one of the deciding factors of whether or not to return for the next vaccination or to seek out a different clinic to see if it was better. Many parents mentioned that they continued to change clinics until they found one that they were happy with. Cleanliness and feeling rushed were the two main factors they used when judging a clinic.

The parents interviewed at Paedicare hospital were in general very happy with the environment, as expressed by one of the mothers,

> *"The first clinic I visited had a bad environment. The way they injected, cleaning etc., the environment was not healthy. I tried somewhere else for the third vaccine because I was not happy but it was closed so I ended up at Paedicare. Compared with the other places this place is very good…clean."* GP5

A number of parents mentioned the fact that previous clinics had been crowded and felt rushed as a reason for not returning. Many had to wait for a long time, up to a couple of hours, for their vaccinations but were then rushed through. Many parents wanted to ask questions but felt that because of the rushing they were unable to. In her interview one of the guardians expresses her frustration with the scenario she had experienced at a previous clinic. She explains,

> *"I said nothing. I wanted to know more but, it was too busy so I felt that it was better to go home and come back to ask later."* GI1

Another mother had a similar experience at a clinic that caused her to fall behind in her vaccination schedule. However, she found her treatment at ICDDR, B to be much better and had enjoyed her experience.

> *"I tried to ask questions but the nurse* (at the other clinic) *ignored me. I tried to ask when to come back but the nurse didn't say so I missed some vaccinations. I like ICDDR, B because it is helping my child for free. I like the environment for vaccination. I enjoyed the system and the vaccine did not hurt"* GI6

Although many of the parents had been dissatisfied with their experiences in vaccination and raised this during their interviews, others had been satisfied and did not raise the issue during their interviews.

7.4 Discussion:

The effect of environment on communication and interaction is a somewhat expected finding. Environment was not mentioned in the literature I read leading up to the study. This is perhaps because it is so self-evident. However, from the first day in the field it was clear that the environment of the clinic had an impact on the communication and interaction between vaccinators and guardians.

In her article, Employing immersive virtual environments for innovative experiments in health care communication, Persky discusses the difficulty of researching the effect of environment on communication in a natural setting. From a quantitative perspective it is too difficult to control the multiple factors that influence interactions and communication in a natural clinic setting. Attempting to control these variables in a natural setting can reduce the quality of care given to patients and may prove unethical. She suggests using virtual environments for research and training in communication. This would enable the researcher to isolate different variables such as patient appearance. However, this method is very resource intensive and there is a trade off between control and realism.(69) In the context of Bangladesh I think that this type of research would miss the everyday encounters and subtle fluctuations that make the difference in communication and interaction. You would not be able to recreate the smell or atmosphere of a clinic. The focus on quantitative research by Persky also limits the scope of its applicability to ethnographic research.

After I started observing the role that environment played in clinical interaction I started asking about it in the interviews as well. As seen in the findings portion of this chapter, participants voiced their opinion that their clinic environment did effect their interactions with clients. The anthropology of space shows how we use and occupy space and how these spaces effect our interactions within them.(70) I had previously researched this in how we occupy space in a city landscape. I think this had an impact on my choice to focus on the environment and use of space after observing it on the first day. My time in Bangladesh was a clear example of the differences in how space is organized and how this effects the interactions that take place within them. The contrast between the two clinics along with the culture shock I felt upon arriving in Bangladesh clearly highlighted the difference of the use of space in the two clinics. Even the atmosphere created in the two clinics was different. This can be seen, at least partially, from the photos presented in the first part of this chapter.

When you enter Paedicare clinic there is a sense of caring, compassion and organisation that is calming and welcoming. In order to access the immunization room at ICDDR, B you have to walk through part of the hospital where there are a number of small children who are very sick and often crying, mothers who look lost and exhausted and the smell of cholera, which can be very overpowering. It is stressful, noisy and anything but calm. The immunisation room itself seems quiet after walking through the ward. The sounds and smells become muffled and you are buffered from the hectic hospital outside. However, during busy times this sense of calm is often breached when the door is kept open to accommodate all of the women who are waiting to be vaccinated.

Pettigrew found that environment did play a role in communication in her study entitled, Waiting for chiropody: Contextual results from an ethnographic study of the information behaviour among attendees at community clinics. She discovered that the environment created in these temporary foot care clinics has a significant impact on the way in which clients and nurses exchanged information. When discussing environmental factors in her study she describes details like the type of building and room in which the clinic was located, the layout of the clinic and even the weather on clinic days. The clinics were made to feel comfortable and social with sofas to sit on and coffee and tea being served. She also found that when hospital curtains were used to increase privacy this increased the amount of information exchange between the health worker and the patient.(71)

Pettigrew concludes that environmental factors can affect the flow of information in several ways. Weather became an icebreaker topic of conversation. The social atmosphere made it easier for people to enter into discussions and participate in informal exchanges of information. Environment, in the context of this study, facilitated the interactions between participants and thus increased the amount of information that was exchanged.(71)

A similar result can be seen if we compare the two clinics in Dhaka. The private clinic created a comfortable atmosphere. Relaxed parents felt more confident to ask questions and this increased the amount of information that was exchanged between the vaccinators and guardians. In contrast, at ICDDR, B the rushed and crowded nature of the clinic along with the noise this created produced an atmosphere that induced both vaccinator and guardian to move through the space quickly. This was not conducive to asking questions or the exchange of information.

The findings presented in this chapter make it clear that the environment of the vaccination clinic has an impact on communication during the vaccination encounter. Becker et al. also found that the modern health care environment "*makes good communication among patients, families, and care givers harder and hared to achieve.*"(72) I think that environment is something that needs to be taken into account when looking at communication. Environment can often be a simple fix such as tidying or cleaning but can have a big impact on the encounter-taking place in the space.

In conclusion, a poor, crowded, busy environment seems to make vaccinators and clients feel rushed. Vaccinators just want to get people through as quickly as possible to clear the space. Clients can feel the stress of the vaccinator and often opt not to ask questions as they can see the vaccinator is rushed. This point becomes particularly important in a hierarchical setting like Bangladesh. Poor, illiterate clients may feel intimidated by the vaccinator who holds a higher position than them in the hierarchy. If the vaccinator does not engage the client and invite questions than it is unlikely the client will do so on his or her own. This adversely affects the client's right to information. Without this information received from vaccinators the guardian's ability to make an informed decision is impacted. Environment also effects satisfaction with the vaccination experience as demonstrated by the guardians who said it was one of the influencing factors determining whether they would return to the clinic. Finally, the environment of the vaccination room had a negative impact on the job satisfaction of those working there. Job satisfaction and its impact on communication in the vaccination encounter will be discussed in the next chapter.

Chapter 8: Vaccinator job satisfaction and its consequences on communication, interaction and information in the vaccination clinic

"This is my sorrow because I have been working here (ICDDR, B) for a long time. I have been here for fourteen, fourteen years. But still I am in the same position, no promotion or increase in reward, gift, token or salary…"

Vaccinator at ICDDR, B
Dhaka, Bangladesh
During Interview

During fieldwork job satisfaction came up as a topic of discussion. It was discussed in positive and negative terms and was demonstrated through the actions of the health workers as well as the pride they had in their position and work. Over the course of the study it became apparent that the workers job satisfaction had an impact on the way they communicated and interacted with patients. Workers who had a higher degree of positive job satisfaction were more likely to be motivated to interact with their patients. They tended to be more cheerful and communicative. Job satisfaction has a large impact on the interaction the patient has with the vaccinator. It also impacts how much information is exchanged during the vaccination encounter and how each participant experiences this encounter. A satisfied vaccinator is a key factor to successful communication in vaccination.

This chapter will focus on the experiences of the health workers, as parents did not directly mention this as an issue.

8.1 Job Satisfaction

The job satisfaction of a vaccinator has an impact on how they interact with their clients. It effects a vaccinator's motivation, body language, and behaviour during the vaccination encounter. I observed, during the study, that those vaccinators who appeared to be happy in their work interacted more with the guardians and children that came for vaccination. They smiled more frequently and asked more questions. Often, with the older babies, they would make faces or talk to the baby while giving the vaccination. Those vaccinators who appeared to have lower job satisfaction, noted through complaining or lack of motivation to be in the office, interacted much less with their patients. They were more focused on the negatives such as the overwhelming amount of paperwork they had to do.

8.1.2 Positive aspects of job satisfaction

All of the Health Workers interviewed were very proud of the work they did. They felt like they were helping the Bengali people and making a positive difference for the health of children. They showed a great deal of pride when discussing the role they played in protecting children and mothers from disease. One of the vaccinators illustrated this point during a workshop by emphasizing how...

> *"We are the vaccinators, health workers, and health assistants. Besides government programs, we are the only resource people. So we are performing a moral duty, a human duty. We are upholding their rights. This is maternal and child health on a global level. We are the only people. We have our own dignity. We are valuable to society (even if we are not recognized) but we think we are very valuable. And we are taking care of a*

> *special part of our society. Not only special babies but also for our babies. So if you respect them (clients) they will respect us."* Vaccinator, ICDDR, B HWFC Workshop #6

For many of the participants they became Health Workers in order to help those in need. It was also viewed as a profession suitable for women and girls to enter. They thought that there work *"Felt Good."* The vaccinators at Paedicare were especially satisfied with the work they were doing. Here both of the Paedicare vaccinators comment on why they chose to become nurses and why they enjoy working as a nurse.

> "*I like it. It is a helpful, safe, important profession for the girls. For that I choose this job."* VP1

> "*The service that I provide I like it. I want to build up a friendly relation with the people."* VP2

All of the vaccinators who participated in this study really enjoyed working with vaccination.

Each vaccinator enjoyed their job for a different reason. These reasons were often linked to time spent interacting with clients. Some enjoyed the aspect of teaching and interacting with parents,

"*Sister I feel great interest by giving class to the mother, we say something to mothers and we teach something to them. It feels good."* VI5

This feeling of being helpful and teaching mothers about helping their children was what made this vaccinator enjoy her job.

Vaccinators also enjoyed working on a team. Teamwork made work easier for everyone involved by breaking up the number of monotonous recording tasks that had to be done. Working on a team also facilitated communication during the vaccination interaction as one vaccinator could be preparing the vaccination while the other was speaking with the guardian. The importance of teamwork was mentioned at Paedicare and ICDDR, B.

The importance of teamwork in communication was especially visible at ICDDR, B. On days when there were two vaccinators working with a health worker in the vaccination room at ICDDR, B the atmosphere was much more relaxed. On days when there was only one vaccinator and one health worker in the vaccination room the vaccination process became much more rushed. Below one of the vaccinators at ICDDR, B explains how teamwork facilitates the vaccination process and makes her job more enjoyable and how difficult it is when she has to work alone.

> *"If everyone works together then it feels good. When teamwork is used it is easier to keep track of who in the room has received their vaccinations, who is still waiting and who is trying to leave without having been vaccinated. We work together. If I had to work alone than I could not keep track of all of the mothers and all could be deprived of their vaccinations."* VI5

Teamwork was also mentioned during the Health Workers for Change Workshops. One of the vaccinators felt that if there was a lack of teamwork it was an obstacle to giving good vaccination service.

> *"One person cannot provide the vaccine. There needs (to be) counselling, pre-counselling, post- counselling... (We) also have to give the mother education. So in this sector, if they made a team for counselling, that would be better. If a counselling team existed here, then I could do my work properly. Also, (I) have to keep the record of the vaccine. I do my work, but if there is no output that will be a bad thing for me. Suppose I provide 2 vaccines to a mother, but how can I know that she takes all other vaccines or not?"* Vaccinator, ICDDR, B during HWFC Workshop #6

The participants really felt that when they had to work alone the aspect of teamwork was missing. As described above vaccinators felt that teamwork really affected the way they could interact with their patients. When teamwork was not present it decreased their ability to interact, communicate with, and educate the mothers and children they were vaccinating.

The nurses at Paedicare expressed during their interview that they were happy with their jobs. I tried to probe around areas where they could have been dissatisfied such as paperwork but they were adamant that they really enjoyed their work and were happy in their positions. They felt respected and in control of their environment. They worked well as a team and felt that they could take time and communicate with their patients. Part of their satisfaction with their work derived from being in control of the vaccination room. One of the vaccinators at Paedicare liked that, " *I have an assistant and I do all the work in the vaccination room."* (VP1) The two vaccinators at Paedicare described how they enjoyed the opportunities that they had for further learning and advancement in their profession.

> *"Whatever we learn that's enough but there is no timeline or limit to gaining something more. We are going to get our next training in January and we (will) learn something new. There is a possibility that whatever we know is not enough for this job. In this clinic (there is) one paediatrics consultant and one paediatrics professor (who) are available. But if we get the chance to learn more, than definitely we will take the opportunity."* VP1, VP2

The above section has discussed what vaccinators enjoy about their work. These positive influences on job satisfaction mostly have something to do with interacting with patients and co-workers.

8.1.2 Negative aspects of job satisfaction

In contrast to Paedicare, the overall job satisfaction at ICDDR, B was lower. The reason that the nurses at Paedicare were satisfied with their work including, the ability to learn and advance, were some of the reasons the vaccinators at ICDDR, B were so unsatisfied. At ICDDR, B the vaccinators discussed two main factors that contributed to overall low job satisfaction. The first was a growing sense of frustration at not having the opportunity to be promoted in job or pay scale. The second was a feeling of boredom with their work. This was due to the restructuring of hospital programs a few years previously. In brief, as I understood it from the vaccinators I interviewed, a few years ago the hospital had been divided into the units it is in now (Long stay, short stay etc). When this division occurred the health assistants were reorganized into permanent program positions. The health assistants I was working with had been assigned to work in vaccination. Previously, they had rotated between the various programs including nutrition and breast-feeding. When asked, the health assistants expressed that they preferred the rotation schedule and had found it more interesting and challenging. In the following quote one of the health assistants expresses her views on the new system as compared with what she used to do. The health assistants were not asked which department or program they would like to work with when the split happened.

> "*Do I like the new system? It is monotonous. If it were a kind of new work then it would be nice. Before we had rotations. We used to work with everyone, side by side during rotations. The experience was nice and the practice was good. Work was enjoyable. Now we do not have any work with them. Now the working area is limited. Now (we are) only involved in the vaccination program and are stuck in one room. Before we used to talk with the mothers and supervise the others. Now we are with vaccination and nothing else. What is the reason? Now we have a work overload. We need to record all the vaccinations in the notebook. We need to make the government tally list. We need to enter all the vaccinations in the computer. We do the same work three times."* VI3

This quote demonstrates the lack of interaction the vaccinator now has with previous colleagues. She finds the work she does monotonous. She especially misses the interactions with mothers and children outside of the vaccination room. This was also one of the key times where she felt she was able to discuss information with guardians and answer their questions. She and the other vaccinators mentioned that they felt "trapped" in the vaccination room. One of the most important factors that contributed to this boredom was the overwhelming amount of paperwork that the vaccinators had to do. On days when two vaccinators were working they said that the paper work was manageable. However, if they were on their own they found it to be too much. Vaccinations had to be recorded three or four times to satisfy the different registers that had to be reported too. The vaccinators felt that the paperwork was taking away from time with clients.

The key reason for low job satisfaction amongst the vaccinators at ICDDR, B was their inability to advance in their positions. When the vaccinators agreed to participate in the study part of the agreement was that I would take the findings from the workshops and interviews and present them at a meeting with the director of the hospital to see what could be done. One of the vaccinators made it very clear in her interviews what she thought I should tell him.

> *"You write there that we need a big room and that it should be near the pharmacy. Say this and tell them about us that we are mentally very upset that we are still in the same position, on the same level. Now we are level 3, no grade change, Matlab (a sister ICDDR, B hospital) changed to level 5 (for the) same work."* VI1

Another vaccinator expressed a similar point of view when comparing her previous government position with the position she holds at ICDDR, B.

> *"Both jobs were the same. Both were working with poor people. But now the job is less and the position is less. The government salary was low but now it is reaching the same level. Now I am upset because if I was still there I would be a trainer and in a high position in the registrar's office. This is my sorrow because I have been working here (ICDDR, B) for a long time. I have been here for fourteen, fourteen years. But still I am in the same position, no promotion or increase in reward, gift, token or salary…"* VI2

During the fifth Health Workers for Change Workshop entitled, Overcoming obstacles at work (60) the participants were asked to list the top five obstacles they faced in doing their work well. For the Health Assistants two of their top five obstacles had to do with job satisfaction concerning promotion and benefits. They expressed that they felt undervalued in their work because they had not had an increase in pay grade or been given extra benefits. All of the participants' felt that their work was not valued by the hospital management and that this was reflected in their pay grade and benefits.

When participants were asked to list factors that facilitated doing their work well they listed good behaviour, appreciation of their work, salary, promotions and the trust and respect of clients. Three out of five of the facilitating factors listed have to do with practices that have been mentioned above. Salary, promotion and appreciation of their work have no direct link to behaviour or interaction in the vaccination room. Yet these were listed as the biggest facilitators and vice versa (obstacles) to doing their vaccination work well. These issues affected their motivation. When a vaccinator is not motivated to do their work well one of the first things that suffers is her interaction with clients. They stop interacting and without interaction little to no information is exchanged during the vaccination encounter.

8.2 Discussion:

The finding that job satisfaction affects a health workers interaction is not new. Negative job satisfaction has been shown to have a negative impact on communication in health care.(11)(12)(36)(72) It has also been found that the amount of time a health worker has to communicate with patients and their relatives can influence over all job satisfaction.(72)(73) This is a cyclical argument. Increased job satisfaction can increase the communication between vaccinator and guardian. In return, the increased communication between the vaccinator and guardian can increase the vaccinators' job satisfaction. It was made clear by the vaccinators at ICDDR, B that job satisfaction effected their interactions with clients. They felt underappreciated and forgotten within the hospital. They said this made them not want to do their job well. In contrast, at Paedicare where the vaccination nurses were recognized and well respected by the other staff they felt happy and proud to do their job.

One of the contributing factors to negative job satisfaction mentioned by the vaccinators at ICDDR, B, which effected their communication with clients, was the monotony of the work they were doing. This was one of the main differences between ICDDR, B and Paedicare. At Paedicare, the nurses only worked one day a week with vaccination. The other days they were included in the normal rotation of nursing duties at the hospital. In contrast, at ICDDR, B the vaccinators were now only working with vaccination.

Both sets of vaccinators said that they found the paper work they had to do with vaccination overwhelming. Each vaccine had to be recorded four times or more. Paedicare was still working with hand written records. ICDDR, B had introduced a computer, which the vaccinators had to enter all of the vaccinations into on top of the multiple paper records that had to be kept. At Paedicare there were always two nurses working with vaccination. They found the paperwork stressful but not overwhelming. As mentioned in the findings above on days that there were two vaccinators working at ICDDR, B the paper work was not much of an issue. However, on days when vaccinators were working alone it was clear that the amount of paperwork that had to be done was very overwhelming and stressful. Often preoccupying time that could have been spent with clients.

Becker et al., make a similar argument in their study, Four minutes for a patient, twenty seconds for a relative- an observational study at a university hospital.(72) They also found that an increased load of administrative work was associated with feeling pressed for time and low job satisfaction. In this quantitative study, done in a German hospital, Becker and his colleagues explored the effect of communication on job satisfaction. They used a quantitative observation checklist and timed the interactions and different activities doctors participated in throughout their shift. Physicians were also asked to asses their job satisfaction on a six point likert scale concerning time for communication with patients and their relatives.(72)

This study found that during an average shift a doctor communicated for 4 minutes and 17 seconds per day per patient and 20 seconds per day with patient’s relatives. They found that during self-assessment physicians thought that they had spent twice as long with patients and seven times longer communicating with relatives then they actually had. They also thought that documentation and paper work took three times longer than it actually did. Physicians felt like they had to shorten their communication times with patients due to the number of tasks they had to do during their shift.(72)

After experiencing the clinics in Bangladesh I think Becker et al’s findings from Germany are very relevant. Vaccinators felt overwhelmed by the amount of administrative work they had to do. They were continuously multi tasking during their shifts. This feeling of constant time constraint made them feel like they had to limit the amount of time they spent interacting with patients. However, most of the vaccinators thought they were spending more time interacting and communicating with patients then they actually were. Patients have a right to information and talking with a vaccinator is the easiest way to receive this information. The fact that paperwork is taking time away from patients needs to be considered. Is this ethical or could someone else be trained to perform the administrative tasks in the vaccination room freeing the vaccinators to spend more time interacting with their patients?

Perhaps even more relevant is the finding from Becker’s study that showed physicians who spent more time communicating with patients had a higher job satisfaction.(72) The low job satisfaction when linked to decreased communication can be understood from the perspective of the doctor and the patient. Doctors know that patients are happier when the doctor communicates with them. So if communication between patients, relatives and doctors is reduced patient satisfaction is also reduced.

The same outcome can be applied to the findings from my fieldwork in Bangladesh. Those vaccinators who could spend more time with their patients were happier and had a closer relationship with their patients. Patient satisfaction was also increased. Besides patient satisfaction this is an important ethical finding. If administrative tasks are taking too much time away from communication and interaction with patients then patients may not be receiving the information they need to make an informed decision.

One of the biggest factors that links job satisfaction and communication with clients is motivation. If a vaccinator is motivated and excited to interact with her clients she will be more likely to interact and share information with them. Peltola et al., also found that communication in the vaccination room was very dependant on the motivation of the vaccinator. The information that the vaccinator considers important will become the information they choose to pass on to the guardian. She found that it was very important to motivate vaccinators to engage in discussions with guardians about vaccination. She found that by giving vaccinators information related to the risks and benefits of the vaccination that were linked to the local context they became more informed themselves. In turn, this motivated them to discuss the vaccines with the parents.(36)

Other studies in Bangladesh have found that part of the lack of communication between vaccinators and guardians was due to a lack of information on the part of the vaccinator.(12)(50) However, in this study all of the vaccinators were very knowledgeable about the vaccines. The key de-motivating factor in communication with guardians at ICDDR, B was low job satisfaction.

In order for parents to make an informed decision concerning vaccination they need to interact with vaccinators. Guardians need to be treated as partners in the vaccination process. This was happening to a certain extent at Paedicare hospital where job satisfaction appeared to be high. However, at ICDDR, B where job satisfaction was perceived as low this key partnership was missing. This lack of communication at ICDDR, B is especially crucial due to the fact that they are providing mop-up vaccinations for children who have fallen behind or dropped out of the immunization program. It is important for the parents of these children to be informed and understand the importance of completing the vaccinations for their children. A key opportunity for education, understanding and facilitating informed decision-making is being missed.

In conclusion, the vaccinators at both clinics are motivated by their wish to help people and protect children from the vaccine preventable diseases. All of the vaccinators wanted to be able to communicate with their clients. However, the main obstacles to communication are limited time and the amount of paperwork that is required. These pressures, along with other factors mentioned above, have lead to a decrease in job satisfaction in the vaccinators at ICDDR, B. These same pressures influence interaction with patients. A rushed vaccinator who feels the stress of multiple administrative tasks and who does not feel appreciated in her work will not be motivated to take the time to interact with her clients to make sure they are informed about the vaccinations they are receiving. This lack of communication goes on to negatively effect the informed decision making process of guardians who miss out on two-way communication and the opportunity to clarify questions they may have.

Chapter 9: Information exchange and the informed decision making process of Bengali guardians

"It is important to give vaccines to our children. If they get sick then what will happen? We have to understand first. It is a major problem. When children get sick, then they think why didn't I take the prevention. If people know all of the information about vaccination then there is no problem. People need to understand the importance of vaccination. So make them understand about vaccination."

GP5
Dhaka, Bangladesh
During Interview

The main focus of this study is to see how information is exchanged during an immunization encounter by looking at the communication and interaction in the vaccination room. I thought that it was equally important to interview guardians to see if this topic was important to them. I wanted to find out if they felt they were getting enough information to make an informed decision about vaccination. I also wanted to look into how they made the decision to immunize their children. In this chapter I will explore the guardians perspective on immunization with a focus on how they made the decision to immunize and where they got their information. The thoughts of the vaccinators around the importance of information in vaccination will also be included. This allows the exploration of the two viewpoints to see if they mesh.

In the first part of this chapter I will discuss how parents made the decision to immunize. Then I will go on to discuss where they received their information. This discussion will be broken into information received outside of the clinic, information received in the clinic and experiential vaccination knowledge. The information wants of guardians along with the best information sources will be discussed.

9.1 The decision to immunize

Twenty-two guardians were interviewed in the course of the fieldwork. Some interviews involved more than one guardian but are only counted as one answer in analysis. Eleven guardians were interviewed at each hospital. Sixteen guardians were able to discuss who made the decision to immunize the child. In eight cases the mother and father had decided together. In five cases it was the mother alone who made the decision to immunize. Two revealed that it was the extended family that had made the decision. One parent said that her doctor had made the decision and she followed his instructions. There was only one instance where the mother had decided to immunize the child but the husband was not supportive. IM6 said that her husband did not agree with the immunization because he thought it would cause pain to the child. However, she felt that if he had more information he would have agreed. This is a good example of the important role education and information around vaccination has to play in the decision to immunize. It will be discussed in more detail later in this chapter.

I was interested in the role the extended family played in the decision to immunize. It was clear from the answers given by parents that in most cases the extended family was not the primary decision maker when it came to immunization. However, in Bangladesh there is a strict hierarchy within the family unit. If the mother in law, for example, did not support the immunization of the child this would make the parents decision to immunize problematic. Thirteen parents responded that the extended family had been supportive of the decision to immunize. One participant felt like this did not matter, as she was the one making the decision. Although her family was supportive she did not feel that their opinion should count in the decision. The other participants felt like this family support was important.

I discussed the role of the family in the immunisation decision with the vaccinators during the Health Workers for Change (HWFC) Workshops. When giving a vaccination the vaccinators thought that it was important to ask the mother if she had at least the father's permission to vaccinate the child. If there was a disagreement among the family members about vaccination they said that they would encourage the mother to bring the dissenting family members to the clinic so that they could explain to everyone at the same time in order to convince them to vaccinate. They thought that the role of the family, especially the husband, was very important in the vaccination process. It was most often the mother in law or husband who posed the biggest barrier to immunizing the child. Some of the vaccinators described this as their number one barrier to doing their job well, as exemplified by one of the vaccinators during workshop #5.

> "*We ask the mother to take the vaccination for the child but the mother doesn't agree to take it. The mother says that if her husband or mother in law were agreed then she would take the vaccine for the child. So we have to motivate the husband and mother in law."*
> Vaccinator, ICDDR, B, HWFC Workshop #5

The vaccinators thought that this was very frustrating as they had to explain themselves multiple times and this took up a lot of their time.

All of the families interviewed felt like immunization was very important for their children. Below, a parent interviewed at Paedicare hospital gives their opinion on the importance of vaccination.

> *"It is important to give vaccines to our children. If they get sick then what will happen? We have to understand first. It is a major problem. When children get sick, then they think why didn't I take the prevention. If people know all of the information about vaccination then there is no problem. People need to understand the importance of vaccination. So make them understand about vaccination."* GP5

This is not surprising as I was interviewing parents at vaccination clinics. The result could be different in other settings. The majority of the guardians interviewed also felt that the information they had received was essential to making their decision to immunize. Most had the understanding that the vaccinations were something that would protect their children from illness as demonstrated by the thoughts of a guardian interviewed at ICDDR, B.

> *"Everybody told me that if I did not vaccinate my baby then he would get sick."* GI8

The majority of the participants felt like they had received enough information to make the decision to immunize. However, many felt that more information would have been better. This guardian interviewed at Paedicare explains how she feels information is crucial in making a decision around vaccination.

> *"Yes from an early age I know about it, that it is an important thing. The information about it is very important because if I don't know how can I take the step?"* GP3

This guardian discusses the challenges that he feels people who lack information about vaccination face.

> *"Yes everyone must have an idea and have to follow the process. We see that in the village some people are scared when the child faces some side effects from vaccination and they don't want to come again. So it is important."* GP4

These quotes demonstrate the importance of information in the eyes of the guardians in making the decision to immunize. They also show the understanding from the guardians' perspective that those who do not have the "knowledge" or "information" may not make the decision to immunize out of fear or lack of understanding. In the next section the different sources of vaccination information will be discussed.

9.2 Information sources in the Bengali context: Perspectives of guardians and vaccinators

The quotes at the end of the last section demonstrate how important parents feel information is in making the decision to immunize as well as following through on completing the vaccination series. Without information they felt a parent could not make a decision to immunize. But where do parents get their information? Sources of information varied for different socio economic groups. Those guardians who could read had access to more information than those who could not. The most informed group of parents were those who could read, had access to TV and radio and most importantly access to the Internet. Guardians listed a number of sources where they had obtained information concerning vaccination. These included:

-TV

-Internet

-Extended Family and Neighbors

- Family members working in Health Care

-Electronic Media

-Advertisements

-Books

-Newspapers

-Radio

-Miking (loud speaker playing from a Rickshaw)

-NGOs Such as Bangladesh Rural Advancement Committee (BRAC)

-Home visits by village Health Worker

-Doctor

- Nurse

-Health Worker

-Local vaccination Center

-From Childhood

This list can be divided into three categories. The first is outside information sources. This is information that is received outside of the clinic environment. The second category is inside information sources. Inside information sources are those sources received while at the clinic. The final category is experiential vaccination knowledge demonstrated in the list above by “from childhood”.

9.2.1 Outside information sources

Outside information sources were important for guardians. They include mass media, family and friends, miking, NGOs, electronic media, books and village health workers who go door to door in communities. A few parents found that these outside sources were the easiest source from which to learn about vaccination. This guardian discusses how she feels outside sources are the best source of vaccination information.

> *“It is easiest to get information from news papers because I don’t want to have to depend on anyone.”* GI11

Another parent thought it was the responsibility of the government to inform the population about vaccination using outside information sources. According to this informant, this would have to be done differently for rural and urban populations.

> *"I think the government should take steps through media and television to give some advertisements. If the government provides the advertisements then people can access it easily. Other ways are good but the government should provide advertisements. We have to apply a different strategy in the villages. In the city, people are watching TV, but in the village people don't. The government should take help from the NGOs (in the villages) because (it) doesn't cover the whole country. Villagers are not aware. There are also some areas, which still do not have access to electricity. So, without the help of the government, NGOs cannot work properly."* GP5

The issue of the urban rural divide came up a number of times with both guardians and vaccinators. This argument does make sense. The differences between rural and urban Bangladesh concerning education and infrastructure are still important. The same education strategy used in the highly educated areas of a city will not be appropriate for a rural community with low levels of literacy.

Another concern raised by both guardians and vaccinators was the fact that mass media tended to focus on the National Immunization Days (NID) for polio. There would be a big surge around information about the oral polio vaccine coming up to a NID. However, little attention was paid to the other vaccines that were not included in the NID. One of the vaccinators interviewed at Paedicare talks about the advertising of NIDs below.

> *"In the media they don't tell about the hospitals (clinics). They only tell about the national vaccination day. These vaccines are provided at and with the help of Primary schools, colleges etc."* VP1

Vaccinators, in general, felt like the most important outside sources of information were the mass media, especially, TV, newspapers and radio. However, both guardians and vaccinators felt like the best place to receive information was at the vaccination clinic. Guardians thought that this was the easiest way to receive information. Vaccinators thought that this was the best place to receive, what they considered, good quality information. This is information that they felt was correct and trustworthy.

9.2.2 Inside information sources

Inside information sources are crucial to successful communication in vaccination. They include doctors, nurses, health assistants, health workers, and group education. Inside sources may also include teaching aids used in clinics such as posters and cards. Outside sources of information are important but lack the inter-activeness of communication with health workers, nurses or doctors. Outside sources such as mass media are one-way information tools. They do not allow participants to discuss problems or ask questions. This is one of the reasons that in clinic communication and interaction becomes so important. Both guardians and vaccinators felt that the easiest way to learn about vaccination was during vaccination encounters. Here two guardians who were interviewed at Paedicare tell which source of information was the easiest for them to access.

> *"I found it easiest to talk directly with the doctor."* GP1
>
> *"The health worker is the easiest source of information."* GP2

One of the advantages of two-way communication with vaccinators is the ability for guardians to ask questions about the immunizations their children are receiving. It also allows vaccinators to clarify that guardians understand what the vaccinations are, side effects, and when they need to come back for the next vaccination. Guardians felt that it was important to have the option to ask questions if you needed to. Some parent's felt like they wanted to ask questions and some felt that they knew enough before going into the vaccination room. The following quotes show the range of information wanted by parents. This first guardian received some information but talks about how she would have liked to know more.

> *"They (the vaccinators) gave me information about tikka (vaccinations) and the remaining vaccines that were not taken including private tikka and a leaflet. They told me information on side effects after vaccination, fever and no breast-feeding for 30 minutes. I would have liked to know more about side effects."* GI3

This second guardian talked about how her questions had been ignored by the vaccinator and the repercussions this had on her child's subsequent vaccinations.

> *"I tried to ask questions but the nurse ignored me. I tried to ask when to come back but the nurse didn't say so I missed some vaccinations."* GI6

Finally, this guardian felt she had enough information and did not need to know more.

> *"I did not want to ask questions."* GI5

The three quotes above show the range of information wanted by guardians. Outside sources can help fill in the gaps of lack of communication in the vaccination room but they cannot be a replacement for two-way communication and interaction in the vaccination room.

Information received during vaccination interactions seemed to increase guardian's satisfaction with the vaccination encounter. In many cases it was what kept them returning to the clinic. It increased trust in the vaccinators. Guardians who had received information felt more relaxed if their child suffered from a side effect. This guardian interviewed at Paedicare talks about the information she was given and how it became helpful after the vaccination.

> *"I was fully informed at the first vaccination visit about all of the side effects. My child suffered from fever but I had been told how to treat it."* GP1

Another guardian interviewed at Paedicare expresses the impact receiving vaccination information had for her.

> *"Yes, I received more than enough (information). It made me feel more comfortable with the vaccine."* GP2

Other parents felt that when they were given information it increased their satisfaction with the visit. This guardian liked the way they were treated when the vaccinator communicated with them.

> *"The nurses told me I must complete the full schedule. I liked the way I was talked to."* GI7

One guardian felt that she had had her question answered but not in the depth that she wanted. She felt that the interaction was rushed and she did not get the information she needed.

> *"I asked a question during the tikka talk about when to come for vaccination and she answered. During the vaccination the nurse wrote when to come back (on my card) but was very busy and so had no time to explain. So she said it quickly."* GI6

This mother left feeling rushed out of the clinic without having her questions answered to her satisfaction.

During my observations I focused on when and how information was exchanged during the vaccination encounter. I observed that the amount of information given to parents decreased with the number of vaccinations the child receives. At Paedicare, the most information and detail is given at the first vaccination. At subsequent vaccination appointments the vaccinators checked to see if the child had experienced any side effects from the previous vaccination. They then reiterated what to do in the case of fever, not to breast feed for thirty minutes after oral vaccines, the diseases prevented by that days vaccinations and when to come back for the next appointment. At ICDDR, B the vaccinators consistently gave more information for the BCG vaccination than the others. This is the first vaccination in the series. It is important that the mother takes care of the vaccination site and this is why the information is given. At subsequent vaccinations little to no information was given besides when to come back for the next vaccination.

I never saw information about side effects being given to adults who received the tetanus toxoid vaccination at either clinic. They were only told when to come back for the next vaccination in the series. If a woman showed up too early or too late for her next vaccination she was lectured on the importance of the spacing of the vaccinations.

From observations, telling parents when to come back for the next vaccination is the most commonly given piece of information at both clinics. Almost all guardians were told when to come back for the next vaccination. This is in contrast to the information wants of parents who in general wanted more information on side effects. This is also in contrast to the views of vaccinators who think that the most important piece of information is the need to complete all of the vaccinations. However, in quantitative studies telling a parent when to come back for the next vaccination rates as one of the most important pieces of information to give.(12)

When to communicate information to guardians is almost as important as communicating the information itself. At Paedicare parents were far more attentive when the information was communicated before the vaccination. During interactions when information was given during or after the child's vaccination the child who was usually crying or fussing distracted parents. Information at ICDDR, B was communicated during or after the vaccination, very quickly, in the majority of situations. Parents were often distracted due to their fussing children. They were more worried about their child's well being then the information being given to them by the vaccinator.

9.2.2.1 Tikka (vaccination) talks at ICDDR, B

The biggest source of inside information for guardians at ICDDR, B was the morning vaccination talks. Known as tikka talks at the hospital, these happened every morning at 8:30 on both the children's short stay and adult short stay units. The talk lasts for approximately ten minutes. After each tikka talk the Health Worker giving the talk would round up those who were behind on their vaccinations and take them over to the immunization room. This was one of the reasons the room became so crowded first thing in the morning. The tikka talks contain information about each of the diseases the vaccinations protect against. This includes the six traditional EPI vaccines, BCG, DPT, OPV, measles and vitamin A. Hepatitis B and HiB, which were added to EPI in early 2010 with the new pentavalent vaccine, were mentioned depending on the preference of the health worker giving the talk. In the following transcript a Health Worker at ICDDR, B describes how she gives her morning tikka talk.

> **Translator**: *What do you usually say in the tikka class to the mothers?*
>
> **VI6**: *First I give Salaam. After the Salaam I show the posters. I ask, 'how many pictures are there?' Mothers see that there are 6. I ask, 'Is everything good? Are they all nice healthy babies?' Mothers see that the children in the pictures are sick and say so.*

> **Translator**: *So the posters have pictures of diseased babies?*
>
> **VI6**: *Yes… bad diseases, it is not a simple disease. They are very major diseases. If this disease occurs then the patient does not survive. I ask them if they want their child to end up like this? No mother wants this! So I ask, 'What can we do?' If they can answer they answer… and if they cannot then we give the answer. 'You can be aware beforehand and take the necessary steps so that these diseases do not occur.'*
>
> *Your child needs to take the tikka and finish the tikka within these days. These diseases are there! I say the name of the diseases, their symptoms and what to do to protect your baby and yourself. After saying these symptoms the mothers become a little flexible. They say 'Allah such a terrible disease.' Then the mothers ask if it is good to give the vaccines or bad. I explain more about the schedule and disease symptoms. Then the mothers say, 'Sister, it is good to give vaccines.' Then I ask 'Do you want to protect the baby?' They say 'Yes'.*

The health worker felt her class was very important to educate mothers about vaccination. Here she talks about why she thinks her class is important.

> "*It is important that they know that the diseases will attack. If their child gets these diseases there is no treatment for it. If the baby gets sick then it will die. So if the mothers get this class then they have more knowledge."* VI6

As communication was difficult inside the vaccination room at ICDDR, B these morning tikka talks were often the only information that mothers received about vaccination. During observation of these tikka talks and material analysis of the transcripts, some interesting themes emerged. During the talks the Health Worker would present both the children's vaccinations and the tetanus vaccinations for women. It seemed to be up to the health worker whether she wanted to present the tetanus poster first or the childhood EPI poster. (see chapter four for pictures of the posters)

The talks were based on a question and answer format. The health worker would use the poster as a teaching tool to point at while asking questions. This is visible in the quote above where she asks how many pictures there are and if the children look well. The success of this question answer interaction depended on how engaged the health worker was with her audience. Some health workers were very engaged and would take answers from the mothers and discuss these with them. Other health workers would answer their own questions and move on without waiting for an answer from the audience.

All of the presenters talked in detail about the symptoms of the diseases pictured on the poster. They wanted the parents to understand what the child would experience if they were to fall ill.

> *"This baby has diphtheria. This baby cannot eat. The mother sees that there are sores in the mouth, so the baby cannot eat. There is a lot of saliva secreting from the mouth. It comes like a river. The mother thinks that it is because of the sores in the mouth, but it is not. When she goes to the doctor it is seen that there is a white curtain in the throat. So if there is a white curtain in throat then can the baby eat? No, it cannot eat anything. The breathing pathway is blocked and the baby dies. It is diphtheria."* Tikka Talk #1, 08.11.2009

For tetanus they would also explain to the audience how a person could contract the disease.

> *"This is tetanus. Where does it occur? Why does it occur? How does it occur? Tell me the answer. Does anyone know? No one knows. Okay if one leg is cut, or if burnt, or if you prick yourself with a needle during sewing this is how you can catch it. If a fever comes then it can be the shivering of tetanus. If the injection is given after the body has been cut, or burnt, or pricked, or spiked than tetanus will not occur. So is giving the injection good or bad?"* Tikka Talk #3 16.11.2009

The person presenting the talk would do the same for polio. Lula is the Bangla word for polio.

> *"Ok see here. This is polio. What happens? Any part of the body can become paralyzed, become Lula, become thin. The baby becomes fractured for life. Where does the polio germ live? It lives in water. See that polio occurs whoever the mother of the baby is, whether the baby is male or female. If the baby gets polio then is there any value of life? (Mothers: No) If male then he won't be able to live or do work. If female then she will not be able to marry. What is done for the polio? Tell. The government gives tikka for polio. The government gives two drops of polio tikka. Need to feed polio to the baby on schedule."* Tikka Talk #3 16.11.2009

For Tuberculosis the health worker presenting the talk discussed the treatment available and the fact that both pulmonary and extra pulmonary tuberculosis exist. The focus when talking about measles was not on the disease itself but on the side effects and knock on effects to the child such as malnutrition.

As can be read from the quotes above the focus of the tikka talks was based on the description of symptoms of the vaccine preventable diseases and the impact that the diseases would have on the children. The focus was placed on the fact that the child would die if they contracted the disease or that the child's quality of life would be so affected that it might not be worth living. They were clearly trying to connect with the mothers' emotions, especially fear, in order to convince them to vaccinate their children.

There were some missed opportunities during the tikka talks. The side effects of the vaccines were not discussed. After talking with guardians this is the information they most often felt they were lacking. Health workers, for the most part, also missed the opportunity to engage mothers in meaningful discussions about vaccination. They stick to their script and rarely allow for questions or discuss mothers concerns. During the talks mothers held their children, which was distracting for them and other participants as this guardian describes.

> *"I love to hear my children's voice so (I) was not attentive to the talk."* GI6

I am not sure what can be done to decrease this distraction from learning, as mothers must stay with their sick children. On the adult short stay ward older children would listen in on the tikka talk and learn for themselves.

9.2.3 Experiential vaccination knowledge

A number of parents mentioned that they had an experiential knowledge of vaccination. In this thesis I am qualifying experiential knowledge as knowledge someone has learned through experience and socialisation. In the following quote a guardian interviewed at Paedicare talks about how she learned about vaccination.

> *"Yes from an early age I have known about it (vaccination), that it is an important thing. The information about it is very important because if I don't know how can I take the step?"* GI3

As the quote above shows this mother has known about vaccination from an early age. This demonstrates the socialisation of vaccination into the general population. This generation of parents is one of the first generations that would have experienced the EPI vaccinations themselves as children. As more and more parents internalise vaccination knowledge the general knowledge level and acceptance of vaccination will probably increase. This experiential knowledge seems to normalize the vaccination process for those involved as described by this guardian interviewed at Paedicare.

> *"Everyone knows about that (vaccination). From my very childhood I know about this from my parents."* GI7

This woman is very satisfied with her vaccination knowledge. It makes her feel comfortable and knowledgeable in her choice.

9.3 Teaching materials used in the clinics

Using material analysis I reviewed the teaching tools used as inside sources of information at ICDDR, B. Paedicare did not actively use any teaching tools in their clinic. They had some posters hanging in the waiting room that talked about the vaccination schedule. However, they did use the same vaccination cards as ICDDR, B. There are a few problems with these teaching tools. The vaccination cards are often difficult for illiterate mothers to understand. There is only writing and no pictures on the vaccination card. If a mother is not told when to come back for the next vaccination by the health worker and if she cannot read her card then she will not know when she must return to the clinic. She will have to actively search out someone who can read in order to know. The same problem applies for which vaccines were received. If she is not told and cannot read she will not know which vaccines her child has received. With illiterate mothers I often saw the health workers at ICDDR, B perform oral autopsies to find out how many vaccinations the child had received. They would ask questions like, "how many times has he received a shot in the arm? Leg?" "How many times have drops been put in his mouth?" This is further compounded by the fact that I observed many mothers did not know the date of birth of their child. They would relate the child's birth to events that had happened around them such as a storm, election or religious holiday.

The posters used in vaccination education at ICDDR, B were also out of date. In early 2010, the pentavalent vaccine was introduced to Bangladesh. This vaccine combines DPT, Hepatitis B and HiB into a single injection. However, the teaching posters had not been updated to include Hepatitis B and HiB. Some mothers did not know that their children were receiving protection against these diseases as well.

Another difficulty raised by vaccinators was the fact that they often had to convince multiple family members before they could proceed with a child's vaccination. This could sometimes take multiple visits to the clinic, which would put the child behind in their vaccination schedule. If outside sources of information worked better they felt that they would not have to spend so much time at the clinic re explaining and convincing family members that they should vaccinate their children.

9.4 Information wants

Nine out of the twenty-two guardians interviewed wanted to know more about vaccination. The majority of these guardians wanted to know more about side effects. Other guardians were either satisfied with the amount they new about vaccination or did not comment. New vaccines were also a common topic as demonstrated by this quote from an interview with a guardian at Paedicare.

> *"We have to be more aware. There is one vaccine that is provided in India and Bangladesh is just starting to provide it. It has to be taken within 6 months but many people don't know this."* GI8

Many parents wanted to know more about vaccination in general. They want to know how it works, what it does and why people still get sick even after having been vaccinated. A guardian interviewed at Paedicare expresses a need for more information about what would happen if you they didn't take the vaccines.

> *"The information that I get is enough but if I get more that is also good. If I didn't take the vaccine then what will happen? If I take the vaccines what will happen? If I don't come on time what will happen?"* GP11

Another guardian interviewed at ICDDR, B wanted to know more about contraindications to vaccination.

> *"Why do people who get vaccinated still die? I feel anxiety about being sick and having the vaccine at the same time."* GI1

Some guardians, such as the guardian quoted below, just wanted to know if vaccination was good for their children.

> *"I want to know whether vaccination is good or bad."* GI5

Another issue raised by a small number of parents was the belief that the private vaccines were better than the public ones. In Bangladesh, parents have the choice of following the EPI schedule for vaccination where vaccines are provided free by the government or to opt for private vaccinations that cost more money. These private tikkas, as they are referred to in Bangladesh, include protection against more diseases. For example instead of just receiving measles, EPI, the child receives measles, mumps and rubella. Children following the private tikkas are also offered a number of vaccinations that those following EPI are not. I was only able to interview one guardian who was following the private vaccination schedule. In the following quote she describes why she chose to giver he child the private tikkas.

> *"I don't think that the EPI vaccines can be as good as the private ones because they are free."*GI11

I do not know if this was a common reason for guardians choosing the private vaccines over the EPI program. In one sense she is correct. The private vaccines give coverage for more diseases than those given under EPI. They are also often given in private clinics where doctors administer the vaccinations. These private tikkas are very expensive and the average person cannot afford to follow the private vaccination program.

9.5 Discussion

In countries where vaccination is voluntary, like Bangladesh, it is important that parents make an informed decision to vaccinate. They need to be provided with the information necessary to make the decision to vaccinate. In this chapter the information needs as well as where guardians get their information from were presented. In my thesis the definition for informed decision-making as an ethical concept has been taken from Charles et al.(26) They describe the informed decision-making model as deriving from the informational asymmetry present between the patient and physician. Physicians hold technical knowledge whereas patients hold personal preferences. The informed decision-making model aims to increase patient's knowledge of their medical options so that the patients can make a treatment decision for themselves. This model is based on information sharing and communication between the patient and physician. Control is clearly placed in the hands of the patient. The physician's role is limited to exchanging information and communicating technical knowledge to the patient to facilitate their decision-making.(26)

The informed decision making model stresses the importance of communication and information exchange between the health care provider and the patient. This sharing of knowledge and technical expertise allows the patients to make an informed decision about whether or not to immunize. In relatively low risk health procedure like vaccination I think that this focus on the patient making the decision by themselves is appropriate. This may not be the case for more complicated health care decisions such as elective surgery or cancer treatment. In more complicated procedures a process of shared decision-making would be more appropriate. What is important in the presented model of informed decision-making is communication. The above findings demonstrate the important role of communication in information exchange and the informed decision making process of parents. Information is communicated to parents from a number of sources. Outside sources include mass media, family, neighbors and acquaintances. Inside sources include material given at the clinic and the health workers themselves. It was also demonstrated that some parents have experiential vaccination knowledge from when they were children. All of these sources of information are important in the parents' decision-making process. The more sources they receive information from the more likely they are to retain it.(12)

One of the ways of studying how information source effects the parents' decision to vaccinate is by using social network theory. During the literature review for this chapter I came across an interesting article describing a theory developed by a library and information science researcher. In his article The strength of weak ties: A network theory revisited (1983), Granovetter (57) describes how different people in social networks influence decision-making. Granovetter distinguishes between people to whom we have weak ties, acquaintances and distant friends, and those with whom we have strong ties, close family and friends. Each person's social network is composed of both strong and weak ties. Granovetter proposes that weak ties are more valuable in the transmission of new information within personal networks. These weak ties act as bridges between different groups of people bringing new information into different groups. Strong ties act as information validators. They offer their opinions on the information brought into the social network by the weak ties.(57)

It made sense to apply this theory to the informed decision making of parents to vaccinate their children. If we treat mass media and health workers as weak ties and family members and close friends as strong ties in the context of this study it fits with Granovetter's theory. Parents related that the majority of the information they had received came from media or health workers. These weak ties provided the information that the majority of parents used to make their decision. Family and close friends, the strong ties, provided their opinion and understanding of the information and vaccination in the decision making process either confirming or objecting to the information received from the weak ties.

This strength of weak ties theory can also help to explain the different views of the importance of the family held by guardians and vaccinators. Only some of the guardians interviewed felt that family played an important role in the decision to immunize. In most cases guardians stated it was the mother or the mother and father together who made the decision. However, the health workers felt that the family played an important role in the decision to immunize. They expressed that the father or mother in law often blocked the immunization of the child. The Health workers felt that one of the main barriers to immunization was having to explain to so many people before they could immunize. These strong ties in the family were influencing the decision to vaccinate. The weak ties, in this case the health workers, were giving the information but being met with resistance by strong ties. Health workers suggested that adding a second group education class for fathers on vaccination during visiting hours would facilitate solving the dilemma.

As discussed above it is important that information is available to guardians to facilitate their decision-making. However, it is equally important that guardians can relate to the information they receive. Two studies done in the UK by McMurray et al (27) and Sporton and Francis (9) as well as a study from the USA by Tenrreiro (28) explored how parents made the decision to immunize. The studies all found that although parents thought their decision to immunize was informed often it was not. The authors argue that the biggest barriers to a knowledgeable decision to vaccinate were a rushed general practitioner, and a lack of information that was relatable to the parents' everyday understanding. Experiential knowledge also played an important role in the decision to immunize or not.(9)(27)(28) Similar factors were visible in the clinics in Bangladesh. Time pressure was an issue mentioned by both the vaccinators and guardians. The information parents were being given in Bangladesh did not match the information they thought was most important to receive. Parents wanted to know more about side effects. Davis et al. also found that questions about side effects were the most commonly asked questions in the American vaccination encounter.(37)

In the findings, it is interesting to note that only one parent mentions a health professional being involved in her decision to immunize. In the western context there is an expectation of shared decision making between health workers and guardians around health related issues. Saba et al., discuss this in their article entitled, Shared decision making and the experience of partnership in primary care.(74) They believe that shared decision-making is being promoted as an ideal and ethical model of patient physician interaction. The basis is that patients and physicians come to a decision only after openly communicating and exchanging information and personal beliefs. It is only after this has happened that an ‘explicit’ decision can be made.

This ideal of shared decision-making is indeed an ideal and ethical model of decision making between physicians and patients. However, in Bangladesh I did not observe any shared decision-making between guardians and vaccinators. Vaccinators assumed that the decision to immunize had been made once the guardian and child entered the clinic. They did not bother to confirm this decision with the parents or check to make sure that the parents understood what vaccination was. An opportunity to ask question was given at Paedicare and some parents took this opportunity to clarify questions with the vaccinators. The opportunity to ask questions was rarely given at ICDDR, B. I think that this has a lot to do with the social power imbalance between the vaccinators and guardians. This will be discussed further in chapter ten. As seen in the quotes in the findings section many parents wanted to receive more information from the vaccinators but the concept of making a shared decision with the vaccinator to vaccinate the child was not considered. In all but one case the parents felt that it was their decision and theirs alone whether or not to vaccinate their child. It would be interesting to explore the concept of shared decision making with Bengali parents to see what they think of it.

The information provided by the health workers is very important. Most guardians identified them as their easiest source of information. However, it is clear that in many situations this communication is not happening, or if it does happen it is very short. The average interaction time at Paedicare was five minutes and thirty seconds. The average time at ICCDR, B was approximately one and a half minutes. Both vaccinators and guardians raised the importance of information pertaining to vaccination. Guardians felt that having information about vaccination decreased the fear they had for their child and made it easier to make the decision. In her study, Pettigrew explored information exchange and information seeking in chiropody in Seattle. She also looked into how and when information was exchanged between the patients and health care workers. She defined information as a process, or communicative construct, that is produced in social context. It is a dynamic process that involves two or more people. In her study she found that not all of the nurses identified themselves as information sources yet all were exchanging information with patients.(71) In my study all of the vaccinators I interviewed did identify themselves as sources of information for guardians. They understood themselves within this role and felt it was an important part of being a vaccinator. However, in contrast to the US study not all of them exchanged information with the guardians that would match the definition used by Pettigrew. Many provided information to parents but this was rarely if ever a dynamic process involving both parties.

Rao et al., conducted a review of studies looking at communication interventions aimed at conversations between patients and physicians. (75) Communication plays an important role in patient centered care and they wanted to explore whether providing communication training to physicians improved communication between physicians and patients. They argue that a focus on patient centered care can improve the patient’s experience of health care, and enhance medical decision-making. This centers on effective communication between physicians and patients. They state that this improved communication is associated with improved patient health status, recall, treatment adherence and satisfaction.(75)

In their review they discovered that most studies focused on only the physician side of the communication interaction and training the physician in more effective communication methods. Only a few studies focused on training the patient in how to communicate with their healthcare provider.(75) In my research I tried to focus on both sides of the communication exchange, the vaccinator and the guardian. As Rao found it is important to understand the communication interaction from both sides involved. Vaccinators in Bangladesh receive various degrees of training around communication. Those at Paedicare received more communication training than those at ICDDR, B. The review by Rao has shown that providing more communication training to health care providers has a positive impact on the clinical interaction. This was visible in the different communication strategies employed at Paedicare and ICDDR, B when interacting with patients. However, as far as I know patients in Bangladesh have not had any training in regards to their rights, for example the rights to ask questions, and how to interact with health workers. This could be very interesting. The hierarchical structure of Bengali clinics and society make it difficult for patients to ask questions. It would be fascinating to explore if this would change if they were taught how to interact with health workers and be more assertive.

Besides the lack of training of patients, Rao et al. identified two gaps in communication research that should be investigated further. The first was that very few studies assessed the information verifying procedures of health workers. Verifying information is important for patient safety, trust and patient satisfaction.(75) I often saw the vaccinators giving information to parents but it was rare that they asked the parent to repeat the information back to confirm that they understood it. This simple effort could improve communication in the vaccination room and improve the decision making process of Bengali guardians.

The second gap identified in the review was the lack of focus on the content of the information exchanged. What was actually said to whom? Rao et al argue that this is difficult to do and a multi method approach would need to be implemented.(75) Observing what information was exchanged during the vaccination encounter was one of the main objectives of this study. I succeeded to a point. Language was a barrier to fully understanding exactly what was said. I observed mostly one-way information where vaccinators would ‘provide’ guardians with information and not allow time for questioning or comments.

The above discussion has focused on inside information sources and exchange. However, the encounters are lacking the interaction and discussion that a meaningful immunization interaction should contain. Even a small amount of communication and information exchange greatly increased the satisfaction of guardians about the immunization encounter. In the context of this masters study outside information was found to be very important in supplementing the guardian’s knowledge gained from the vaccinators. Both vaccinators and guardians, acknowledged this point.

The clinical context as well as the background of the guardians is very important in understanding how guardians seek information and from which sources. The major defining factor for information seeking in this study was perceived socioeconomic status. I say perceived, as I did not measure this explicitly. However, many participants mentioned their work during the interviews. In Bangladesh, the clothing you wear can also indicate status. Those wearing expensive fabrics or clothing with intricate embroidery or decorations were often more well off. Those guardians with a higher socio economic status were more likely to be higher educated and literate. They were more independent in their information seeking because they had access to literature sources, the Internet and often a family member working in the health sector. They were able to make an independently informed decision around vaccination. Those participants with a lower socioeconomic status were less likely to have a high level of formal education. Some were illiterate and very few had access to the Internet. They were much more dependant on the health workers and mass media for their information concerning vaccination.

Perceived socio economic status can also influence how vaccinators interact with guardians. This was especially visible at ICDDR, B where two mothers from outside the hospital came for vaccinations. They were treated differently from the patients in the hospital. Vaccinators took more time with them and discussed with them for longer. Other studies have also found that health works interact differently with women whom they perceive to be educated or well off. In Health providers' opinions on provider-client relations: Results of a multi-country study to test Health Workers for Change, the authors found that the perceived education of the women affected how the health worker interacted with them. They found that if the health worker believed the client was formally educated they would provide her with all of the necessary information about her problem. However, if the health worker perceived the client to have little or no education they found they reacted in one of two ways. The health worker might be frustrated by this and not give the woman any information or he/she might make a special effort to be welcoming and assist the woman in 'liberating' herself.(76) During the Health Workers for Change workshops at ICDDR, B the health workers mentioned that they found it frustrating to constantly be explaining things to the illiterate mothers. Sometimes they would just give up.

The present thesis focused on the amount of information parents were receiving and from which sources. I explored whether they felt they were receiving enough information. I did not explore their understanding of the information they were receiving. This would have made the scope of the project too broad. Understanding is very difficult to measure. I was also afraid that if I started asking parents knowledge questions that they would feel like they were being judged or tested in some way. Further study on how parents understand the information they are given would be interesting.

When focusing on information seeking and information exchange it is very important to discuss context. This was also mentioned in chapters seven and eight of this thesis. You cannot remove the vaccination encounter from its context and the context has a big effect on communication. In chapter seven, I presented how the environment of the vaccination room can affect the vaccination encounter. In chapter eight, context was discussed in terms of the Health worker. In this chapter context will focus on the clinic activities concerning information exchange.

One of the main findings around information exchange during vaccination is the importance of when to exchange information during the vaccination encounter. Parents were most attentive when information was given before the vaccination took place. If information was given during or after the vaccination their child, who was uncomfortable and fussing, distracted them. This is especially important if there is only one parent present. In cases where there were two guardians present and information was given during or after the vaccination at least one guardian remained attentive to what the vaccinators was saying.

At Paedicare, when information was exchanged was recorded during sixty of the vaccination interactions. In 38 cases information was given before the vaccination. In three cases it was given during the vaccination. In twelve cases information was given after the vaccination. No information was given in 13 cases. I was unsure of when information was given in 11 cases. These recorded information-giving times do not equal sixty as in some cases information was given at multiple points.

At ICDDR, B, I observed approximately 120 vaccinations. It was very difficult to keep track of exact interactions in this clinic as it was very crowded and at times I had a limited view of what was going on. It did not having a waiting room and injection room like Paedicare. I observed information being exchanged in six cases at ICDDR, B. No information was exchanged between the vaccinator and guardian in 60 cases. I was unsure if information was exchanged in 8 cases.

Brown et al., conducted a study entitled An evaluation of the impact of training Honduran health care providers in interpersonal communication. They found that very few studies have looked at that quality of the interpersonal communication between health workers and their clients. Their literature review found that health counseling and provider-client communication are consistently weak across countries, regions and health services. This is the case even when providers know what message to communicate.(73) This was the case observed in my research. Vaccinators knew exactly what information to communicate to parents but in many cases did not do it. Brown et al. investigated the impact of a brief in service communication training program on interpersonal communication skills of health workers in an ambulatory care setting. The participants participated in three half-day communication sessions focused on methods rather than messages.(73)

Brown et al. found that trained providers communicated more and used an increased amount of positive talk. They also used more emotional talk with patients. They were more likely to ask patients if they understood the instructions they had been given. However, trained providers were not more likely to give information about medical choices. The patients of trained providers spoke more, used more positive talk and gave more medical information. Patient satisfaction also increased. Health providers remained positive about the training seven weeks later. They felt that the communication training had improved their relationships with their patients, helped their listening skills, emphasized the human aspect of their work, and to help them deal better with clients. Brown et al also found that training the physicians would not be enough. In order for interpersonal communication to be even more successful patients would also need to receive training. This training would need to raise awareness among patients about their right to participate in the decision regarding their health and to ask questions.(73)

At ICDDR, B there were a few missed opportunities for information exchange and education on the short stay ward. I observed that there was a TV in each corner of the Children's short stay ward. These could be used to display educational programming for the parents and children staying on the ward. Many of the mothers appeared very bored while sitting beside their children. Educational programming, even without sound, on the televisions could be a welcome distraction as well as an important teaching tool. The health Assistants at ICDDR, B also suggested that during their quieter times in the afternoon they be allowed to talk to mothers out on the ward and answer their questions. They are all trained as field health workers and could answer questions on a variety of questions from breast-feeding, to birth control.

Another missing link in fostering communication was missing at both, Paedicare and ICDDR, B. Pettigrew discusses the importance of creating an environment that facilitates multiple directions of communication. She observed that during foot clinics information was being exchanged not only between the nurses and clients but from client to client, client to nurse, receptionist to client and client to receptionist. She concludes that the social atmosphere created during the clinics by having a seating area with coffee, tea and biscuits increased the information exchanged.(71) I observed that this type of information exchange was lacking in my study. At Paedicare, guardians sat and waited in a waiting room before the vaccination. This waiting room was completely silent except for the noises the children made. Parents did not converse with each other. This was a little different at ICDDR, B where there were a few instances where lively discussions broke out amongst those waiting. On the odd occasion a vaccinator would throw in their opinion. At ICDDR, B these discussions became the most lively when on a topic other than vaccination. Most of the time the women were discussing birth control or menstrual regulation. Neither of the clinics provided a comfortable social atmosphere, which would foster this multi directional communication.

In conclusion, communication and information exchange can play an important role in the decision making process of guardians about vaccination. Parents seek information from a variety of information sources. Those parents who are literate and have higher socioeconomic status have access to more independent sources of information such as the Internet. Those parents who have lower levels of education and fewer economic resources are more dependent on the information received from health workers and family and friends. Family members often play an important role in the decision making process. This study focused on the amount of information parents were receiving and from where. I found that the majority of parents felt like they had enough information to make a decision about vaccination but would like to learn more. It was observed that theories of shared decision making and patient centered care are not applicable to the current situation in Bangladesh. Making a decision with your health care provider is a foreign concept in most public vaccinations in Bangladesh. Either the parent decides or is told what to do by their doctor and agrees. Two way information exchange, and or multidirectional information exchange is weak in both clinics. A broader focus needs to be placed on the content of information and how it is exchanged. A major indicator of the success of two-way communication in the vaccination room will be in the number of guardians asking questions during the vaccination encounter.

This limited focus on two-way communication has important repercussions on the ethical ideal of informed decision-making. If the guardian is not able to participate in conversations and question asking with informed health professionals then their ability to fill gaps in their vaccination knowledge is limited to the information they receive from the one-way information sources. Two-way communication is an aim of the tikka talks given at ICDDR, B. The question answer format with interactive learning is meant to involve guardians in the learning procedure. However, these talks are often rushed and fall far short of this ideal. Information exchange and informed decision making are interaction based. With the current focus on one-way information in vaccination these ethical ideals are not being fulfilled. As a result many guardians are not having their information needs addressed.

Is the choice to vaccinate informed? A qualitative study on information exchange in the vaccination encounter in Dhaka, Bangladesh

Chapter 10: The role of power, trust and respect in the vaccination interaction and informed decision making

"In this situation I feel sorrow for the mothers…those who come and take the vaccine. The people think that they have to take the vaccine that's why they take it. Mother thinks this is her responsibility that it is compulsory. Like a prisoner they have to do it (vaccination). That's why they come."

VI5
Dhaka, Bangladesh
During Interview

Power, trust and respect are key words when it comes to vaccination, informed consent and communication. In vaccination, the person giving the vaccine has power over you. You have entered their domain, the vaccination room. In Bangladesh, the vaccinators often also have a higher social hierarchical position than those they are vaccinating. Bangladesh has a fairly rigid hierarchical structure in the general population as well as in the hospitals. Most people are very aware of their 'rank' within society or their workplace. For example, the social hierarchy on a hospital ward goes from the head doctor, to the doctors, then the nurses, followed by the health assistants, then the health workers, then the cleaners, followed by the patients and finally the patients relative who sits at their bedside. There are social norms around communication that govern communication between these groups. These include addressing someone above you with the polite form of a verb and someone below you with the common form. (Personal observations)

In Bangladesh, respect is expected for those who hold a social position above you. A guardian coming for vaccination shows respect for the vaccinator even if they are mistreated or talked down to. Trust is also implicit in the vaccination encounter. The guardian is trusting that the vaccinator knows how to administer the vaccination correctly, is giving the correct vaccination and is using sterile equipment.

Power and respect are most visible during interactions. Some displays are subtle whereas others are overt. I observed both in the vaccination rooms where I was sitting. In this chapter I will present findings around both positive and negative uses of power in the vaccination interaction. I will also discuss the importance of trust in vaccination and the role obedience plays in the relationship between trust and power. Trust, respect and the use of power can all have an impact on communication and decision making in the vaccination process.

There are multiple power relationships at play in vaccination in Bangladesh. In the previous chapter I addressed who parents felt had made the decision to vaccinate their child. I mentioned that the power structure within the family played a role in this decision. In many cases, the mother –in-law and/or husband hold the power when it comes to medical decision-making. Once a guardian enters the vaccination room there are multiple power relationships present. These include the guardian's relationship to the vaccinator and other staff working in the clinic as well as the relationships amongst the staff. There is a relationship between the clinic and the hospital or health centre in which it functions. Finally, there is the relationship that each of these groups has with the government. The overarching social and gender norms play into these power relationships as well. It was mentioned many times during the research process that women held a lower position than men in Bengali society. The Bengali women I was working with felt like they were subordinate to their male counterparts; husbands, directors, colleagues, brothers, fathers etc. This is demonstrated in the following quote from one of the vaccinators when she gave a summary of the workshop on women's status in society.

> "*Everywhere in the society women status is the same. Sometimes we are our father's maid, sometimes we are our husband's maid and sometimes we are our children's maid and also the maid of our daughter-in-law.*" Vaccinator, ICDDR, B, HWFC Workshop #3

All of the other vaccinators agreed when asked if they agreed with this vaccinator's summary of a woman's status in society. Negotiating power struggles is part of the everyday life of Bengali women. All of the vaccinators I interviewed were women. The majority of guardians I observed and interviewed were also women.

10.1 Demonstrations of power in the vaccination process

10.1.1 Positive demonstrations of power

I observed that sometimes vaccinators used their power in a positive way to build trust with the guardians and put them at ease. However, this did not occur as frequently at ICDDR, B as it did at Paedicare. The most common way of doing this was by addressing the child in the room and talking to them. Often the vaccinators would apologize to the child for the vaccination. This was especially true with the older children (9 months) receiving their measles vaccine. When the vaccinators started to communicate with the babies the mothers would visibly relax even if they were the one receiving the injection and not the child.

Vaccinators also demonstrated a positive use of power in the cases where they greeted guardians entering the immunization room through eye contact and verbal acknowledgement. By greeting and welcoming guardians they invite the guardians into their space. Positive use of power was also demonstrated in the instances where the health workers gave information to the guardians and guardians were able to ask questions about the information they were given.

Health workers at ICDDR, B demonstrated positive power when they invited the mothers on the ward to join in their vaccination talk each morning. The actions of inviting, greeting and informing demonstrate respect for the guardians from the vaccinators. This demonstration of respect can increase the trust the guardian has in the vaccination clinic and increase their satisfaction with the visit.

There were many other demonstrations of power during my time in the field. Most of these stemmed from the social hierarchy in general society but also within the hospital. The first power relationship I will present is between the state and its citizens. Secondly, I will present findings on the power relationships between vaccinators and guardians in the clinic. Finally, I will present findings on how this power is attempting to be balanced in the process of group education at ICDDR, B.

10.1.2 State demonstrations of power

In Bangladesh, the state has a large amount of control over the vaccination of children. It is a public health measure provided by the government, or NGOs working with the government. As discussed in the previous chapter, the majority of information given to guardians comes from outside sources such as the mass media. Most of these sources are influenced or controlled by the government. The state exerts its control over the population in another way as well. All of the vaccinators I interviewed said that vaccination was not mandatory in Bangladesh. Parents have the right to choose whether or not they vaccinate their children. However, to be successful in Bangladesh it is socially required to be vaccinated. Each vaccinator I interviewed informed me that a child could not go to public school without a completed vaccination card. A person must also hold a completed vaccination card to obtain a passport. In this manner the state is using its power over the right to education to have children immunized. One of the vaccinators I interviewed raised the subject in her interview. She felt like guardians felt that they had to be obedient to the state.

> *“In this situation I feel sorrow for the mothers…those who come and take the vaccine. The people think that they have to take the vaccine that’s why they take it. Mother thinks this is her responsibility that it is compulsory. Like a prisoner they have to do it (vaccination). That’s why they come.”* VI5

In this vaccinators opinion she feels that the mothers do not know that they have a choice when it comes to immunization. They follow what they are told to do by the government or its representatives, such as the health worker. In this scenario I feel that the state has a moral and ethical duty to the guardians to ensure they understand the process of vaccination and the benefits it has to offer as well as the side effects. The vaccinators play a pivotal role in this duty, as they are one of the primary sources of information.

10.1.3 Demonstrations of power in the vaccination encounter

The use of power by health workers in the vaccination room became apparent after the second Health Workers for Change Workshop. This was especially true of ICDDR, B where the workshops took place, but to a lesser extent also applied to Paedicare as well. During this workshop the participants acted out role-plays. The objective of the workshop is for the vaccinators to begin to see themselves from their client’s perspective. I asked them to act out a typical encounter, from their perspective, in the vaccination room. Each health worker acted out a different role; father, mother, vaccinator and assistant. The baby was played by a water bottle wrapped in a sweater. Those not acting watched. The participants acted out two role-plays. After each role-play they discussed whether they felt the role-play was an accurate representation of what was happening in the vaccination room. The exercise provided insight into the knowledge they had over what should happen during a vaccination encounter, and how they felt they were interacting with the guardian. The role-plays were in sharp juxtaposition to what I had been observing in the vaccination room.

During the first role-play the vaccination encounter lasted approximately ten minutes. The second lasted about six minutes. In both role-plays the "Vaccinators" gave all the information required, checked back for understanding with the guardian and asked permission to give the vaccine. Finally, they thanked the guardian for coming. They were engaged with the client and giving not only information but also emotional support. They showed positive body language towards the guardians. This shows a respect for the client and the client's wishes.

During the two role-plays the participants presented knowledge of various communication strategies they could use with clients during the immunization interaction. They were friendly and talkative greeting their clients and asking them to sit and asking about their families. Some of the most common strategies were asking questions to confirm understanding, using two-way communication, using oral history to determine which shots needed to be given, giving explanations on the importance of vaccination and explaining the side effects, the need to keep the card, and the importance of completing the vaccination series. They were reassuring towards the client and made sure that it was the guardian's decision to vaccinate. All of the vaccinators felt that it was very important to explain the vaccine, what it does, what diseases it protects against along with what the side effects and benefits are. By focusing on the importance of communicating the information during the role-plays the communication itself also improved.

These role-plays were very interesting to watch. However, what was demonstrated in the role-plays was very different to what I observed in the vaccination room at ICDDR, B. As discussed in chapter nine, an average immunisation encounter in the vaccination room at ICDDR, B lasted about one and a half minutes. The vaccinators sometimes greeted the guardians, there was little to no information given by the vaccinator. The exception to this was when to come back for the next vaccination and information about the injection site for the BCG vaccine. The atmosphere was rushed and the room was usually crowded with people. The room was always crowded with supplies. (See pictures in chapter seven)

The other major difference was in the perceived power structure of the people involved. During the role-play the interaction was between approximate equals, vaccinator-vaccinator, even though a vaccinator was playing the role of a guardian. In the vaccination room at ICDDR, B the interaction is most frequently between the vaccinator and a guardian who she perceives as being poor and most likely illiterate. In the social hierarchy the vaccinator in this case is placed above the guardian. In instances where the vaccinator perceived the guardian as being at a similar level in the hierarchy the interaction was different. The vaccinator would spend more time with the guardian and be friendlier, greeting them etc. In these situations the vaccinator is demonstrating her position of power by not interacting or acknowledging the guardian she is dealing with.

The use of power by the vaccinators at Paedicare was less obvious. I think that this was because the vaccinators and guardians were at a more similar level in the social hierarchy. Paedicare was a private clinic that charged a small fee for the EPI vaccinations. The clientele tended to be middle class and literate. The nurses at Paedicare were also younger. Many of the parents they were dealing with were older than them and may have held positions of power in the community. Another major difference at Paedicare was the environment as discussed in Chapter seven. The nurses at Paedicare felt in control of their space and their environment. The atmosphere seemed relaxed. The training the Paedicare nurses had received concerning communication was also more detailed, and more recent, than the training received by the vaccinators at ICDDR, B.

Interestingly, both groups of vaccinators used power words when talking about giving information to the guardians. They often used phrases like, “We make them understand”, or “You have to…” They were not looking to reach a decision through discussion as in the models of shared decision-making or patient centred care. Their goal was to persuade the guardian to vaccinate their child. As I do not speak fluent Bengali I cannot be sure if coercion, and if so how much, was used. They want the guardians to understand that the vaccines will benefit their children. Another key argument was the cost that the family would bear if the child did fall sick. The final argument was always that the child needed a completed immunization card to attend public school or receive a passport. This is how one vaccinator described her interactions with women about the tetanus toxoid vaccine during workshop #2.

> “*I didn’t want to say anything but, out of 10 mothers some don’t understand anything. Sometimes they ask, “Did you stop our birth process?”(Pregnancy). Then we make them understand that this (TT vaccination) is profitable for the mother and also for the child.”* Vaccinator, ICDDR, B, HWFC Workshop #2

This health worker wants to help the mothers she is dealing with who don’t understand vaccination. Many people who don’t understand vaccination believe that the vaccines do more or different things than they are supposed to. It is common for a mother to believe for example, that the tetanus toxoid vaccine may maker her labour easier or end her pregnancy.(77) The Health workers really believe that all children should be vaccinated and want to convince parents of this fact. Another central argument used in persuading parents as well as in the tikka talks is the cost associated with disease. This is an especially potent and emotional argument at ICDDR, B where the mothers are in the hospital with their sick children and are experiencing first hand the cost of the illness on their family. Most of the families in ICDDR, B are poor. This cost is both financial and emotional. In the following quote a vaccinator explains the arguments she uses to convince guardians to vaccinate.

> *“We always make them understand about the vaccination process. They see that it is good for the health not bad and that it is for his/her child. They (the child) won’t suffer from the big diseases. If someone suffers from a big disease then they have to spend a big amount of money. But if they take the vaccines then the child only suffers for fever and that is not permanent. When they understand this then they feel really very happy.”* Vaccinator, ICDDR, B, HWFC Workshop #2

Finally, the role-plays that took place at ICDDR, B could have been impacted by the fact that the vaccinators felt like they were putting on a show. They probably wanted to show their colleagues, and me, the knowledge they had. From the first workshop there had been an indication that the actions of the vaccinators in the vaccination room did not match the knowledge they held. This came up in the discussion of the informed consent form to participate in the workshops. At this point I had already been observing at the clinic for ten days. After reading the informed consent form one participant stated,

> *“Actually, you have written here that your objective is to explore how we share information between vaccinator and the parents. So, it’s a mandatory part of our immunization program. So already WHO, immunization program, recommends it. So why did you think that you need to do that?”* Vaccinator, ICDDR, B, HWFC Workshop #1

This participant did not see the need to explore how information was communicated during the vaccination process because it was required in the WHO guidelines. She believed that having it written down was enough to make everyone communicate with their clients. In reality, communication in the vaccination room at ICDDR, B was very limited and the guidelines she was referring to were, for the most part, not being followed. I did not have time during the workshops to discuss the differences between the role-plays and what was happening in the clinic in depth with the vaccinators. If time had not been a constraint this would have been an interesting discussion to have with the participants.

The use of power words and power during the interactions lead to a lack of communication between the vaccinators and guardians. This became very apparent during the interviews when I started asking both vaccinators and parents what they felt the most important piece of information about vaccination was. The majority of the parents responded that they wanted to know about the side effects of the vaccines and how to deal with them. When I asked vaccinators the same question the majority responded by saying that the completion of the vaccination series and keeping the vaccination card in a safe place were the most important pieces of information they needed to give to parents. In this quote one of the vaccinators from Paedicare describes what she thinks the most important information to give guardians is.

> “ *(The most important information is) that they keep the vaccination card in a safe place. Because when the child is going to be admitted in school or wants his/her passport then it’s necessary to show the vaccination card. Also, parents must come on time for the vaccines. Those are the important things.”* VP1

For the vaccinator at Paedicare keeping the vaccination card safe and following the vaccination schedule were for her the most important pieces of information to give to parents. A vaccinator at ICDDR, B had a similar point of view, which she presents below.

> *“The most important information, in my opinion…All side effects are not important information. The most important information is that you will finish…(Heather: Complete dose?) Complete the dose…complete all the vaccines on schedule. I think that complete the doses on schedule is the most important.”* VI2

This focus on completing the vaccination schedule sometimes lead to vaccinators giving misinformation, especially during the tikka talks. It was often said during the tikka talks that you had to complete all of the vaccinations for the series to be effective. Guardians were told that the vaccinations would only be effective after receiving the measles vaccine. It is true that for the pentavalent and oral polio vaccine to be the most effective you have to receive all of the doses. However, for BCG and measles the child only receives one injection.

The disconnect between the information wanted by parents and the information that vaccinators thought was the most important was also visible in the tikka talks. During the talks the health worker would explain about the diseases the vaccines protected against but did not mention any of the side effects from the vaccines or how to treat them.

The final demonstration of power that was apparent from the role-play was asking permission before giving the vaccine to the child. In both role-plays the vaccinator asked permission of the guardian before giving the vaccination. I never saw this happen in the vaccination room. Asking before giving a vaccination shows trust and respect for the guardian involved. It also helps to balance out the power differential between the two parties. Asking before vaccinating will be discussed further in section 10.2.

10.1.4 Balancing power during vaccination interactions

As mentioned above there are a number of ways in which vaccinators can use power in a positive way to help balance the relationship between the vaccinator and the guardian. These included greeting the guardian, giving information during the encounter, appearing relaxed and welcoming and thanking the guardian for coming to the vaccination clinic. In the balanced relationship presented in the role plays as well as the more equal power balance between vaccinators and guardians at Paedicare these signals were often present. The presence of questions from the guardian and discussion between the vaccinator and the guardian are symbols of a more equal power relationship where both parties are listening to what the other has to say. They also acknowledge the beliefs and knowledge of the other person.

Another way that power was balanced at ICDDR, B was through the group education sessions on vaccination. During the tikka talks one health worker would present to a number of mothers. When I asked the mothers at ICDDR, B if they liked the group education sessions they felt it was nice to learn in groups. In the following quote a guardian interviewed at ICDDR, B talks about how she likes to receive information.

> *"I like the health worker visits (at her home) but I really enjoy the group learning."* GI7

Having more mothers in the group than health workers helped to balance the power within the group. During group discussions and teaching the women asked more questions and became more animated. They took courage from each other. This was also seen in the vaccination room on occasion. The few times when women spoke up in the vaccination room to ask questions or ask for advice the women outnumbered the vaccinators. This was also the experience I had when I did interviews on the ward at the children's bedside. This was sometimes necessary, as the mothers could not leave their children. When I did bedside interviews the neighbouring women would also become involved. The woman I was interviewing seemed to become braver with the support of the women around her. It would have been fascinating to be able to do some group interviews or focus groups with these women.

In this section I have presented the different ways in which power is used and affects the immunization encounter. How power is used also effects the trust and respect in the vaccinator-guardian relationship. This will be explored in the next section.

10.2 Discussion: The effects of power on trust and respect in the vaccinator-guardian relationship

Power and the use of power have a direct impact on trust and respect in relationships. In his article Power, trust and risk: Some reflections on an absent issue, Grimen argues that an analyses of trust that neglects power is naïve and analyses of power that neglect trust are shallow. He regards the two as interconnected in health care. He believes that trust is transactional. In the case of health care the patient readily gives their trust to the health worker who they feel knows more than them. This puts the patient in a position of inferiority to the health care provider. This creates a situation where trust and power can easily be abused.(78) When someone uses his or her power in an interaction, like when a vaccinator does not greet a guardian, this can affect the trust and respect that the guardian has for the vaccinator. In chapter seven, I discussed how guardians would visit a number of clinics until they were satisfied with the treatment and environment at a clinic. How the guardian was treated had a large impact on whether or not they decided to return. Guardians appreciated being treated well and being informed during the vaccination interaction. In some situations, the vaccinator did not abuse the power they held and trust was exchanged between the two participants. In these situations, to use Grimen's terminology, the guardian's position of inferiority to the vaccinator was mitigated by the vaccinator's behaviour.(78)

In my final interview a guardian raised the issue of the vaccinator asking before giving the injection to her child.

> *"I would like for the nurse to ask before giving the injection."* GI11

She felt that if the vaccinator asked before giving the injection they were showing respect. It also increased her trust in the provider as she was being treated as an equal. As mentioned above vaccinators did ask permission during their role-plays but did not do this in the vaccination room. By not asking permission the vaccinator shows dominance over the guardian. Asking before giving a vaccination also has deeper ethical implications. As discussed above, it is socially required for children to be vaccinated in order to attend public schools and obtain a passport. The government controls access to the right to education through vaccination. It is important from a moral and ethical perspective that if guardians feel that they don't have a choice to vaccinate that they are informed about the vaccinations they are receiving. This is the legalistic argument of unidirectional informed consent. It is an important one, however as I have argued throughout this thesis communication in the vaccination room needs to come from both parties involved, not just the vaccinator. Information needs to be exchanged not just given.

P.H. Streefland has been one of the biggest proponents for the need for informed consent in vaccination. He discusses the importance of informed consent in immunization in two of his articles; Patterns of vaccination acceptance,(29) and Public doubts about vaccination safety and resistance against vaccination.(3) He discusses the fact that immunization is a provider driven model of health care. It has become a widely accepted medical intervention and as such has become very stable. However, there is a variation in the extent to which promotion, pressure, intimidation and even coercion are used to convince parents to immunize their children. He worries about the ethical and societal implications of immunization programs that do not require the informed consent of the participant. He concludes his article on public doubts by stating,

> *"In developing countries the pursuit of high quality standards, particularly though of course not only in the way clients are treated, should always characterize vaccination campaigns and routine vaccination. In practice this means that informed consent is an obligation, as is the strict avoidance of rudeness and intimidation by health professionals."*(3)

This argument is especially salient in the vaccination programs I was observing. These clinics are beginning to strive for higher quality standards in their vaccination programs. These include improvements in communication however there is still a fair ways to go to meet ethical and human rights standards. Asking before giving an immunisation, informed consent, as requested by GI11 would include the parent in the decision making process in the clinic. In turn this would give them an opening to speak and ask questions, to begin a dialogue with the vaccinator. This would re orient consent from an assumed tacit consent to an express consent procedure as recommended by Verweij and van der Hoven.(8) The difference between approval and consent must also be recognized. Kleining argues that for approval to be transformed into consent some form of authorization must be given. This authorisation, the consent, needs to be formally recognized and recorded for it to be valid.(23) Asking for the guardian's consent and then recording it on the vaccination card would provide this transformation from approval to consent.

Braddock et al. (1999) conducted a study of observation on informed decision making in outpatient care. The authors agree with the call for a shift in informed consent away from the legal interpretation of giving the required information to a participant towards a more meaningful dialogue between the client and provider. In their view, this move from a uni-directional to multi directional dialogue is the move from informed consent to informed decision-making. Braddock et al, argue that the old form of informed consent satisfies legal requirements for liability. However, informed decision-making allows for a meaningful process to foster patient involvement in their care.(79) In a way I think that this is what GI11 was asking for. She wanted the vaccinator to ask before vaccinating her child not only to demonstrate respect for her as a mother but also to give her the final decision and power over the choice she was making for her child. This means to place the decision to immunize back in her hands before the vaccine was given. It would allow the guardian a more active role in the vaccination encounter, requiring them to speak and opening the door to possible further communication.

Another observed practice that could adversely affect the trust between vaccinators and guardians was the misinformation sometimes given during tikka talks. This practice could seriously damage the trust between the two groups if intentional misinformation was discovered by the guardians. This could be especially damaging if the information came out through the mass media and was presented as if the guardians were intentionally being misinformed. This could impact on the trust that guardians have in the vaccination program resulting in a decrease in the number of vaccinations. Paul and Dawson raise the issue of trust in the article concerning the OPV campaign in India. They found a policy of non-disclosure being used in the WHO Polio eradication campaign. Advocates of the eradication campaign believed that if they informed parents about the risks and side effects of the OPV then many would choose not to participate. This raised an ethical dilemma for the authors who feel the only valid reason for withholding information and consent is if the greater good from the vaccine outweighs the risk to the public. The authors were not sure if this was the case. They also worried that if the policy of non-disclosure became public then the public’s trust in the programme would collapse.(13) There was no policy of non-disclosure in Bangladesh and some information was given to guardians. Nevertheless, some of the information that was being given was incorrect and could lead to a loss of trust in the vaccination program if publicized in the wrong way.

A further demonstration of the disconnect in communication over wants and needs between guardians and vaccinators was the different information each party felt was the most important to give/receive. Guardians felt like the information concerning side effects and how to deal with them was the most important. On the other hand the vaccinators felt that the focus should be placed on the importance of completing the vaccination series and keeping the vaccination card in a safe place. Arntson and Philipsborn describe a similar finding in their article

Paediatrician-parent communication in a continuity-of-care setting. They found that doctors and patients matched their interaction styles to one another during an encounter. Encounters were more successful the stronger the relationship between the doctor and the patient. However, a disconnect was found in the way doctors and patients thought about and viewed the child's disease. Both the parents and guardians felt that it was important to talk about the symptoms the child was experiencing. The disconnect occurred in how each group felt the symptoms should be discussed. When discussing the child's symptoms the doctors would focus on the environmental factors they thought were contributing to the symptoms. Conversely, when parents would discuss symptoms they would focus on medication and professional treatment. The parents were not as concerned about the environmental factors. The authors' felt that this disconnect in communication between the two groups was based in the role inflexibility between the two groups. Part of the inflexibility was fostered through a doctor/active, patient/passive relationship.(80) This is the same inflexible communication structure that was seen in the vaccination interactions in Bangladesh. I think that this role inflexibility was compacted by the hierarchical structure of the vaccination encounter. Vaccinators found it more difficult to step out of their concrete roles and interact with their clients on an equal level.

This mismatch in information wants was not present in an American study by Davis et al. They found that on average health workers spent three minutes discussing with clients before giving a vaccination. The most common questions health workers were asked by parents were about side effects. When the authors asked the health workers what parents needed to know 79% of them responded information about side effects.(37) It is clear from this study that the more the vaccinators can communicate with guardians the more they become attuned to the guardians information needs. This is why it is essential that guardians be able to ask questions and interact with their vaccinators.

Finally, the role of the state in the vaccination interaction cannot be overlooked. The state uses its power to, in a way, coerce guardians into vaccinating their children. The fact that vaccination is needed to enter public schools and obtain a passport is a strong influencing factor in the decision to immunize. Even though the vaccinations are not mandatory the repercussions of not vaccinating your child are socially crippling. Not only would the child be left exposed to disease, a very real possibility in Bangladesh, but you would be severely handicapping their future by eliminating the option to attend public school. For most parents this is not a choice. The vaccinator is the incarnation of this state power in the vaccination interaction.

Nordfeldt and Roalkvam argue a similar point in their article entitled, Choosing vaccination: Negotiating child protection and good citizenship in modern India. They state that, "*vaccines and vaccinators give a concrete form to a state that would otherwise remain a conjured abstraction. Vaccination becomes a profound manner in which citizenship is negotiated and expressed*."(81) The same can be argued for Bangladesh where citizenship, as represented by the right to education and the right to obtain a passport, are only accessible through a completed vaccination card. Vaccinators are the representatives of the state and are asked by the state to reach vaccination and other public health intervention quotas. Nordfeldt and Roalkvam observed that in India vaccination was integrated into the mother child health program, which also includes birth control.(81) There was a push to convince mothers that to be a good mother, and a good citizen, it was important to have a small family. This link between state vision of a good citizen and being a good mother was also present in the tikka talks given at ICDDR, B. Health workers stressed that a good mother had less children, was not lazy and brought them for vaccination. A mother who vaccinates her child is modern. A modern woman accesses birth control and has a smaller family.

Within the state framing of vaccination vaccinators feel that they have to make guardians understand about vaccination. This can take many forms such as scolding, coercion or simply just ordering them to vaccinate. In no way is this process a multi directional dialogue between equal and consenting parties. So how, in a place where the concept of shared/informed decision making and patient centred care are so far from being realized, can we improve the informed decision making capacity of parents and improve the communication interactions in the vaccination room? How can we bridge informed consent with informed decision making within the vaccination clinics of Dhaka? This will be discussed in chapter twelve.

Chapter 11: Conclusions to the study findings

Image 11.1 Local men with little girl in Uttara Sector 10

In the previous four chapters the four main findings from the fieldwork in Dhaka were presented. The broad scope of the findings, from clinic environment to trust and respect, help to show the large spectrum of events that can effect communication and information exchange in the vaccination interaction. Each of these aspects that effect communication and interaction has an impact on the ethical and human rights off those receiving the vaccination. Each Guardian and child has a right to information, which concerns his or her health. If this information is not provided in a situation where vaccination is not required by law ethical dilemmas appear.

Ethics, in general, has two objectives. The first is to instruct us in how we should act in a given situation. The second is to provide us with the reasons and arguments for doing so.(65) If this is applied to vaccination these objectives provide information to vaccinators about how they should act in a vaccination scenario. They should be professional, welcoming and trustworthy. They should provide information to the guardians coming for vaccination and make sure that they understand the decision they have taken. There are many reasons why the vaccinators should behave in this way. First of all, the vaccinator has a moral duty to inform the guardians about the vaccinations. Secondly, in giving this information they are protecting the human rights of the guardian by making sure they have access to information as well as safe and affordable health care. If we extend this argument further into the principles of biomedical ethics the vaccinator should live up to the expectations of autonomy, beneficence, non-malfeasance, and justice. They must respect the guardians' autonomous decision to vaccinate. They must not coerce or pressure guardians into vaccination and by no means should the vaccination be given without the guardians consent.

Vaccination in itself provides a protective service to the child. Some argue that it is unethical not to vaccinate children once a vaccine has proved beneficial.(13) However, in countries where vaccination is not required by law it is still the guardians' independent decision whether or not to vaccinate their children. The government and health workers job is to support parents in making an informed decision around vaccination. This becomes complicated in Bangladesh where it is not legally required to vaccinate but seems to be socially required due to the restrictions placed on education. A child must be fully vaccinated to attend public schools and obtain a passport. This thesis explored how information was communicated in the vaccination room, where guardians get their information about vaccination from and how they make the decision to vaccinate. The findings presented in the previous four chapters presented concrete and abstract impediments to communication in the vaccination room and the decision making process of parents.

In chapter seven the effect of the environment of the vaccination room on the vaccination interaction was discussed. A busy, crowded environment seems to make vaccinators feel rushed and limit communication. A calm, spacious vaccination room seems to make the vaccinators feel more relaxed so they feel they can take their time and communicate with the client. Environment also effects satisfaction with the vaccination experience as demonstrated by the guardians who said it was one of the influencing factors determining whether they would return to a clinic. Finally, the environment of the vaccination room had a negative impact on the job satisfaction of those working there.

Job satisfaction, and its impact on communication in the vaccination encounter was presented in chapter eight. At ICDDR, B the crowded and small vaccination had a negative impact on job satisfaction. However, it was not the only influencing factor on the apparent job satisfaction of vaccinators. The vaccinators at both clinics are motivated by their wish to help people and protect children from the vaccine preventable diseases. All of the vaccinators wanted to be able to communicate with their clients. However, the main obstacles to communication are limited time and the amount of paperwork that is required. These pressures, along with a felt lack of respect, have lead to a decrease in job satisfaction in the vaccinators at ICDDR, B. These same pressures influence interactions with patients. A rushed vaccinator who feels the stress of multiple administrative tasks and who does not feel appreciated in her work will not be motivated to take the time to interact with her clients to make sure they are informed about the vaccinations they are receiving.

Chapter nine discussed findings surrounding who decided to immunize the children, how this decision was made and the information used in this decision making process. Communication and information exchange were found to play an important role in the decision making process of guardians about vaccination. Parents seek information from a variety of information sources. Those parents who are literate and have higher socioeconomic status have access to more independent sources of information such as the Internet. Those parents who have lower levels of education and fewer economic resources are more dependent on the information received from health workers and family and friends. Family members often play an important role in the decision making process. The majority of parents interviewed felt like they had enough information to make a decision about vaccination but would like to learn more. It was observed that theories of shared decision making and patient centered care are not applicable to the current situation in Bangladesh. Two-way information exchange, and or multidirectional information exchange is weak in both clinics. A broader focus needs to be placed on the content of information and how it is exchanged. A major indicator of the success of two-way communication in the vaccination room will be in the number of guardians asking questions during the vaccination encounter.

This limited focus on two-way communication has important repercussions on the ethical ideal of informed decision-making. If the guardian is not able to participate in conversations and question asking with informed health professionals then their ability to fill gaps in their vaccination knowledge is limited to the information they receive from the one-way information sources. Two-way communication is an aim of the tikka talks given at ICDDR, B. The question answer format with interactive learning is meant to involve guardians in the learning procedure. However, these talks are often rushed and fall far short of this ideal. Information exchange and informed decision making are interaction based. With the current focus on one-way information in vaccination these ethical ideals are not being fulfilled. As a result many guardians are not having their information needs addressed.

The final findings chapter explored the effect of power, trust and respect in the vaccination encounter. Power and how it is used has a direct impact on trust and respect between all the parties involved in vaccination. Trust is essential in health care where the health workers hold more information than the patients. Trust in health care is also transactional. The guardian gives trust and respect to the vaccinator when they allow them to vaccinate their children. Trust, respect and power in Bangladesh are also based on a strict local hierarchy, which governs how people interact with each other. Asking before vaccinating a child can also serve an important purpose in balancing the power and increasing trust and respect in a vaccination encounter. When a vaccinator asks before immunizing a child she demonstrates respect for the guardian. Asking before immunizing also covers legal and ethical points in countries where vaccination is voluntary. One of the main findings in this chapter was the disconnect in the communication between vaccinators and guardians over which information is the most important to be exchanged during the vaccination encounter. This disconnect results in vaccinators giving different information than the parents feel they need. This problem could be solved with better communication between the two groups. Finally, the power of the state in the vaccination program cannot be ignored. Although vaccination is not mandatory in Bangladesh the government has made it socially required for young children to be vaccinated by making it a caveat to attending public schools and obtaining a passport. This places a lot of social pressure on parents to vaccinate their children.

All of the findings mentioned above have an impact on communication. Any impact on communication and interaction between vaccinators and guardians can have an implication on the informed decision making process of guardians. Two-way communication is essential to this decision-making. In order to have a successful multi-directional interaction time is also needed. This lack of time was one of the biggest commonalities between the findings from all of the chapters. In both vaccination clinics vaccinators felt rushed. This was far more evident at ICDDR, B than it was at Paedicare.

The lack of time or sense of feeling rushed was the biggest barrier to achieving successful communication during the immunization encounter. The ethical implications of this lack of time are that guardians are not receiving much if any information during the vaccination encounter even though both the vaccinators and guardians thought that vaccinators were the easiest source for obtaining vaccination information. This sense of feeling rushed also limits the amount of time the vaccinator spends interacting with the client and so they do not get a sense of the knowledge the guardian has about vaccination. This lack of time along with an acceptance of tacit consent in the vaccination room can lead to coercion in the vaccination process. From my observations once a guardian had entered the vaccination room it was very difficult for them to leave without being vaccinated. Many of the women looked scared and unsure of what was going on as they had been brought to the ICDDR, B vaccination room after the morning tikka talk by the health workers.

It is important that vaccination programs around the world operate within an ethical and human rights framework. That the guardians bringing their children for vaccination have the chance to interact with the vaccinators and ask questions to clarify any doubts they may have. Vaccinators in turn need to be educated and understand how vaccines work, what the side effects are and be given training in two way communication. Both guardians and vaccinators need to be responsible for information concerning vaccination. Guardians receive information from outside of the vaccination clinic from a variety of sources including the mass media. Guardians are also starting to gain experiential knowledge of vaccination as the first generation to be vaccinated in Bangladesh are now vaccinating their children. The vaccinator needs to be responsible for exchanging information with guardians in the vaccination room. However, it needs to be clear during the vaccination encounter that it has been the guardian’s decision to vaccinate. That they have made an autonomous, informed choice.

Is the choice to vaccinate informed? A qualitative study on information exchange in the vaccination encounter in Dhaka, Bangladesh

Chapter 12: Bridging informed decision making and informed consent in vaccination

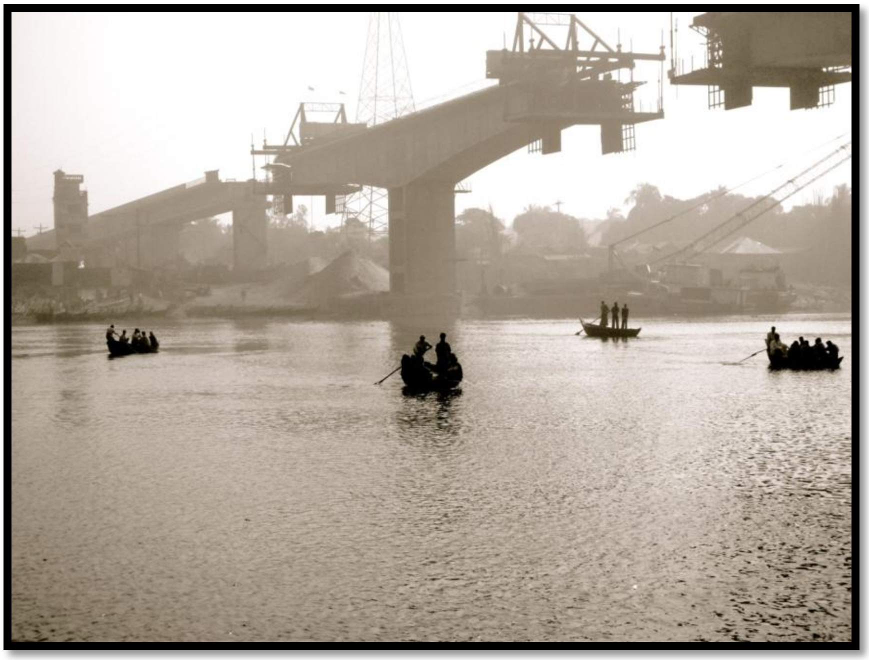


Image 12.1 Building a new bridge just outside of Dhaka City

In the previous chapters on the findings from the study it was presented that the amount of communication in the vaccination process is limited. With the limited two-way communication in the vaccination encounter guardians must rely on outside, often one way, communication sources for their vaccination information. These outside sources include the mass media, and friends and family. The majority of both vaccinators and guardians felt that the easiest way to get information about vaccination was from the vaccinators. However, since this was not happening in the majority of cases, especially at ICDDR, B, many guardians felt like they needed or wanted more information about vaccination in order to facilitate their decision to immunize.

This lack of communication in the vaccination encounter leads to moral, ethical and judicial consequences. Morally, the vaccinator should inform guardians about the vaccinations their children are receiving. It is a choice to immunize and as such the vaccinator has a moral and ethical duty to inform parents about immunization and its side effects. Judicially, if law does not require vaccination, a vaccinator should be asking permission before injecting a child to clarify that they have the guardian’s permission to go ahead. Assuming consent from guardians who enter the vaccination room does not cover this responsibility. However, with the limited time available for the vaccination encounter in the two clinics it seems unreasonable at this point in time to ask each vaccinator to have a long conversation with each parent to clarify understanding and give all of the information necessary. So what can be done?

In this chapter I will present my thoughts on using informed consent and informed decision making to standardize the information exchange between vaccinators and guardians in the vaccination room. This will be similar to the informed consent procedures presented in chapter two from British Columbia, Canada. Secondly, I will argue that informed decision-making on the part of the guardians plays an important role in this encounter. The guardians must take the responsibility to be informed when coming for vaccination. Informed decision-making will become the process, which leads to informed consent during the vaccination encounter. Both the vaccinator and the parent should be responsible for information. The vaccinator will be responsible to inform during the vaccination encounter. The guardian will be responsible for information seeking outside of the vaccination clinic.

The majority of the focus around autonomy and consent in biomedical research concerns informed consent. This focus exists to meet the legal and judicial requirement to protect the researcher and the participants. However, in biomedical encounters the doctrine of informed consent does not go far enough towards ensuring an informed decision from those it targets.

Within biomedical practice there has been a trending towards shared decision making. This change in focus has been the result of debate around the shortcomings of informed consent in the biomedical ethics community.(20)(22) New concepts such as shared decision making, informed decision-making, and patient centred care have been proposed to help bridge the perceived gaps in the informed consent doctrine.(20)(26) The main goal of all of these concepts is a shift from disclosure of information to a discussion and understanding of the information. This focus helps to protect patient autonomy when it comes to health care decisions. These various positions and arguments were presented in detail in chapter two and so I will not go into detail again here.

After performing the literature review and experiencing the situation in Bangladesh I came to the realisation that most people were looking at informed consent and informed decision-making in the medical encounter separately. I perceived that in the literature these two concepts are sometimes being placed one against the other in an either or argument.(20)(25) Often the argument is that informed consent does not go far enough and needs to be replaced with a more interactive and proactive concept such as informed or shared decision-making. However, once I started analyzing my experience from Bangladesh I realised that making them work together could strengthen both concepts. This is especially true in countries such as Bangladesh where the idea of patient centred care or shared decision making are not being practiced in most medical encounters. However, informed consent is still very relevant due to the time crunch experienced in most clinics. Informed decision-making is relevant to the process the guardians go through before arriving at the vaccination clinic and during the vaccination encounter. It addresses the process they go through in making the decision to immunize.

Informed consent can be viewed as a static event. It happens at one point in time and the respondent gives a ‘yes’ or ‘no’ answer. In the context of vaccination this would be the vaccinator asking if it is ok to give the vaccination to the child and the guardian responding ‘yes’ or ‘no’. Informed consent in this aspect is seeking explicit consent from the guardian that they accept the vaccination of the child. This is important from a judicial perspective if law does not require vaccination. From a moral perspective it shows respect for the guardian in the vaccination encounter.

Informed decision making, on the other hand, can be viewed as a process. It is the process the guardian goes through before arriving at the clinic and sometimes continues throughout the vaccination encounter if more information is needed or the guardian is unsure. It is how they decide to immunize their child and the information they get and use to make this decision. In the majority of cases guardians have made the decision to immunize their child before arriving at the clinic. This is the reason why there is an argument for the acceptance of tacit consent in vaccination. This view is based on the idea that if a guardian brings their child to a vaccination clinic they are consenting to the vaccination. In my view the argument for tacit consent has a number of shortcomings. It does not give the vaccinator an opportunity to question the guardian to make sure that they understand what vaccination is, that they have the right to vaccinate the child, and limits their opportunity to give guardians information about vaccination and its side effects. When tacit consent is used, such as in the clinics in Bangladesh, it removes a communication opportunity in the majority of cases between vaccinators and guardians. The whole encounter is based on an assumption that the guardian understands vaccination, knows the side effects and how to treat them and is consenting to have their child vaccinated. Such assumptions can be unfounded. It was clear from fieldwork during this study that some guardians did not really understand vaccination and were vaccinating their child because they were told to do so.

Many studies in Bangladesh have shown that there is a lack of knowledge around vaccination in Bangladesh.(43)(52)(54)(77)(82) In my study I encountered parents who wanted to know more about vaccination. Some were even unsure about what exactly the benefits were. All of the guardians felt like vaccinating their child was something they were supposed to do, and that it would be good for the child’s health. I think that many guardians did not realise they had a choice in the matter. I did not directly ask the guardians if they new that vaccination was voluntary. I did not want to introduce any anxiety into their decision to vaccinate. Introducing the fact that vaccination is voluntary to guardians was found to cause anxiety in parents in a study from the UK.(9) The social pressure to vaccinate is quite strong in Bangladesh with a completed vaccination card needed to entre public schools and receive a passport. Due to this pressure it is very important that guardians understand the process of vaccination and its benefits as well as side effects.

As stated above, in the majority of cases, the guardian has consciously made the decision to immunize their child before coming to the vaccination clinic. In this study I found that the guardian makes this decision mostly based on outside sources of information such as mass media. Guardians felt that without this information they would not have been able to make a decision at all. Making an informed decision was very important to many of them. However, many still felt that they wanted more information about vaccination then they had before vaccinating their child. So whose responsibility is it to provide the information and how could this be done?

Jointly, it is the responsibility of the guardian to seek out information, which should be provided in an easily accessible form by both the government and the health care system. Most guardians stated that the easiest source of outside information in the city was television and newspapers followed by radio and miking. Guardians also accessed information from the health sector, the community and close family and friends. A few participants also mentioned experiential knowledge of vaccination. The most accessible sources for information would be considered weak ties if we apply Granovetter's strength of weak ties theory mentioned in chapter nine.(57) This information from weak ties forms the foundation of the information used to make the decision to immunize. This information is then discussed and compared with information from family members and personal experience, strong ties, to come to a final decision. The problem in this scenario is the lack of information being received by guardians from the weak ties in health care, especially the vaccinators. Guardians have to be provided with and/or seek out enough information to make an informed decision.

In most cases, the guardian makes the preliminary decision to immunize before going to the vaccination clinic. They arrive at the clinic with this preliminary decision. At the clinic it should be the responsibility of the vaccinator to ensure an informed decision and consent by using a seven-step informed consent procedure. (These seven steps are based on the seven steps to informed consent being used in British Columbia (40))

Step 1: Make sure that the guardian who has brought the child to be vaccinated has the authority to do so.

Step 2: Confirm that the guardian understands vaccination in general.

Step 3: Provide information concerning that day's vaccination.

Step 4: Confirm understanding of the information given

Step 5: Provide an opportunity for questions

Step 6: Ask for the guardians consent for the child to be vaccinated

Step 7: Record the vaccination on the vaccination card

During the vaccination encounter it is the vaccinators responsibility to question the guardian to make sure that they understand vaccination, the potential side effects, the schedule and the importance of keeping the vaccination card in a safe place. They must also make sure that the guardian has the right to immunize the child they have brought for vaccination. If the vaccinator believes that the guardian understands vaccination and what is expected then they can proceed with giving the information about the vaccination the child will be receiving that day. If the vaccinator feels that the guardian does not understand vaccination then they should at this point take some time to explain and discuss with the guardian before proceeding to the next step.

The basic information that would be included in this static informed consent procedure at the vaccination site would be the vaccination being given that day and which diseases it protects against, the possible, common side effects (fever and rash), how to treat them, and when to come back for the next shot. The vaccinator would then ask the guardian a question to confirm understanding of when to come back and ask if the guardian had any other questions. Next they would ask the guardian if it was ok to give the child the vaccination. After the guardian confirms with a 'yes' the vaccination would be given and recorded on the vaccination card.

In think the above scenario would work well in Bangladesh. Vaccinators do not have much time to interact with each client. By limiting the amount of information they need to give to four simple points (which vaccination, side effects, how to treat side effects, and when to come back) will shorten the interaction. If a vaccinator feels that a guardian does not understand the basics of vaccination then they will need to spend a little more time with them to explain. I believe that this static check for information and consent at the clinic will also encourage communication between guardians and vaccinators by giving the opportunity for guardians to ask questions. This is an important missing piece in the vaccination encounter as seen during observations in the vaccination clinic.

This static informed consent procedure to be performed by vaccinators is also reasonable as I found that the majority of guardians receive their information about vaccination from outside sources. The majority of guardians had also made the decision to immunize before arriving at the clinic so in most cases the vaccinator will just have to confirm understanding and not spend a long time educating parents. The vaccination encounter will be the last step in the informed decision making process. In this interaction the vaccinator will clarify that the guardian understands the vaccination process and that they wish to proceed with the vaccination. This encounter will give the chance for vaccinators and guardians to engage in active two-way communication to answer the guardians remaining questions. The taking of the informed consent to vaccinate is the final step in the informed decision-making process, which begins at home and ends when the vaccination is given. Asking for permission to vaccinate in a voluntary vaccination program serves many purposes. It shows respect for the guardian's role in the vaccination, can potentially open the door to increase communication and legally makes sure, using explicit consent, that the guardians has agreed to the vaccination.

The major limiting factor in communication in vaccination found in the two clinics where I was observing was the limited time of the interactions, especially at ICDDR, B. At Paedicare the clinic was already working on a system similar to the one I am suggesting. The vaccinators spent considerably more time with parents during the first vaccination encounter explaining about vaccination and what to expect, side effects, schedule etc. Each consecutive appointment became shorter as the vaccinators just checked for previous side effects, explained the vaccination being given that day with a quick explanation of fever and then gave the vaccination. After vaccinating they filled in the card and told the parent when to come back. The only part of the seven steps they did not cover was explicitly asking consent to vaccinate. This demonstrates that the model can work in Bangladesh. The consecutive appointments at Paedicare took about two minutes. This is only thirty seconds longer than the average vaccination time at ICDDR, B, one and a half minutes. However, at ICDDR, B little to no information was exchanged during the vaccination encounter. By applying the informed consent procedure to the vaccination the information to be given would be standardized and the guardians would have an increased opportunity to ask questions which they found was lacking in the current system.

I think that applying this combined perspective of informed decision-making and informed consent in the vaccination process has many advantages. It distributes the responsibility to be informed and inform over both vaccinators and guardians. This is important in a health system that has limited time and has not yet adopted ethical perspectives of shared decision-making and patient centred care. In a system where vaccination is not legally required it is the responsibility of the parents to be informed and make the decision for their children. However, morally and ethically the vaccinator has a duty to check and make sure that the guardians have made an informed decision and understand what is happening to their child. Applying a systemized approach to informed consent and informed decision-making in the vaccination room would help to standardize the information, which is given to parents. Perhaps more importantly it will open the floor for communication between vaccinators and guardians and show respect to the guardians by asking before vaccinating their children. In order, for this proposed system to work there would need to be an increased amount of information given to guardians both inside and outside of the vaccination clinic. Vaccinators will need training in communication strategies as well as how to use the vaccination checklist. A focus of the communication training should be on the importance of giving vaccination information to the guardians before giving the injection.

This information would have to be tailored to the local population in order to be effective. As seen in the findings of this study middle and upper class guardians have more access to independent vaccination information whereas illiterate guardians are dependent on miking and communication with health workers. It is this illiterate, female portion of the population that needs to be especially targeted with increased communication.

Chapter 13: Conclusions and recommendations

Image 13.1 The participants in the Health Workers for Change Workshops at ICDDR, B

The aim of this study has been to explore the communication and interaction, which occurs during a vaccination encounter in Dhaka City, Bangladesh. Observations, interviews, workshops and material analysis were used to explore the interactions and perspectives on information exchange in vaccination from multiple angles. This study has attempted to employ an ethical and human rights lens to this information exchange and interaction/communication in vaccination at Paedicare Hospital and ICDDR, B to see if ethical and human rights standards are being met in this scenario, to see if guardians feel like their decision to immunize was informed, and where guardians got the information they used to make that decision.

If the seven guidelines of an ethical vaccination program presented by Verweij and Dawson are applied to the clinics I was researching in, then it can be seen that the vaccination programs fall short of meeting these ethical requirements.(7) The program in Bangladesh meets the criteria of targeting serious, life threatening diseases, the vaccines included are effective and safe, and participation is voluntary. It falls short in four aspects. Firstly, the burdens and inconveniences for participants are not as small as possible. Guardians often face long waits, rushed encounters, rude treatments and a lack of information exchange during the vaccination encounter. Guardians must also take time off work and sometimes travel long distances in order to reach the vaccination clinic. Secondly, the program's burden to benefit ratio is not more favourable than alternative vaccination schemes. The private vaccination program in Bangladesh offers a wider array of vaccinations than the EPI program. Another interesting discrepancy is that the vaccine for rotavirus is not offered in the public program and diarrhoeal disease is the number one killer of children in Bangladesh.(58) Thirdly, the distribution of benefits and burdens is unequally distributed to those who are well off, educated and live in developed city areas with good infrastructure. Those who have a lower socioeconomic status, are female, uneducated and live in a rural or slum area have unequal access to vaccination opportunities both public and private. Lastly, it can be argued that the public trust in the vaccination program is not being honoured and protected by the misinformation and lack of communication present in the vaccination room.

The guidelines proposed by Verweij and Dawson provide a good base for evaluating vaccination programs. However, I think their guidelines fall short in addressing the human rights perspective of right to information. Their guidelines do not explicitly address communication or information exchange. They say nothing about what should happen during the actual vaccination encounter. I also think that the guidelines do well in addressing the fact that vaccination should be voluntary and should be the choice of the guardian but fall short of stating that if vaccination is voluntary, then consent should be required.

The research performed for this thesis has demonstrated the importance of information in the informed decision making process of guardians. Many felt that it was because of the information that they received that they were able to make the decision to vaccinate. A number of guardians and vaccinators also expressed that it was due to lack of information that many parents did not vaccinate their children or dropped out of the program. This is important information in a country where immunization rates remain low.(10) Both vaccinators and guardians felt that information exchange in the clinic was important and that guardians had a right to receive this information. However, for a number of reasons information exchange and communication is coming up short in the vaccination encounter. Some of the reasons for this were explored in the findings of this research. The environment of the vaccination clinic, vaccinator job satisfaction, and the use of power can all have an impact on the amount of information exchanged. (Please refer to the summary of the study findings in chapter eleven)

In chapter twelve, I attempted to address how informed decision making could be combined with an informed consent policy to standardize which information is given during the vaccination encounter. This involved parents seeking information outside of the vaccination clinic to make a preliminary decision to vaccinate. After arriving at the vaccination clinic the informed decision making process would continue through a seven step process during which the vaccinator would check for understanding and give a standardized set of information to the guardian. This informed decision-making process would then culminate in giving consent to the vaccinator to immunize the child. I think that this seven-step process would open the floor for questions and communication during the vaccination encounter. It could also potentially help in fostering trust and a more equal power balance between the vaccinator and the guardian.

13.1 Recommendations

During this study a number of recommendations were suggested by the participants for improving the quality of the vaccination program. I also formulated some recommendations during analysis of the data.

13.1.1 Recommendations for ICDDR, B

- At ICDDR, B health programming should be shown on the televisions on the wards. Even without sound this would be well watched by the captive audience of mothers sitting at their children's bed -sides.
- A vaccination counselling team should be implemented at ICDDR, B to give pre and post vaccination counselling.

- All family members should be included in group education at ICDDR, B.
- The vaccination room should be a clean, organized space, which is well ventilated. There should be chairs for those who are waiting and a bed on which to put children.
- There should be educational material displayed on the walls of the vaccination clinic. The vaccinators thought that this would help to stimulate discussion about vaccination.
- Teaching aids at ICDDR, B should be updated to reflect the new pentavalent vaccine.
- A question and answer session should be added to the end of the tikka talks at ICDDR, B.

13.1.2 General recommendations

- Vaccinators should be given more opportunities for career advancement and education as well as recognition for their work within the hospital environment.
- Vaccination clinics should consider training an office assistant that would be in charge of paperwork. This would free up vaccinators time to interact and communicate more with patients.
- There should be an increased focus in the mass media on EPI vaccination not just on the national immunization days
- Information about vaccination should be given for all vaccinations administered in the vaccination clinic. This information should be given before the injection takes place.
- Vaccinators should receive training in communication techniques not just technical practice.
- A standardized set of information should be given before vaccination such as the one recommended in chapter twelve.
- Vaccinators should ask permission of the guardian before vaccinating the child.

13.2 Suggestions for further research

This thesis was limited in its scope. Only two vaccination clinics were observed. Both were in Dhaka City. This thesis did not explicitly explore whether and how guardians understood the information they were being given about vaccination. Further research on this topic should look at rural and slum areas as well as continuing in other urban environments.

It would also be beneficial to measure the vaccination knowledge of Bengali guardians. This information should be measured both before and after a vaccination encounter. I would recommend a mixed methods approach. A quantitative approach to measuring vaccination knowledge and a qualitative follow up to see how guardians feel about the information and the vaccination encounter.

More closely related to the specific findings of this study further research on how the clinic environment affects the vaccination encounter would be valuable in the planning and renovation of vaccination clinics.

Finally, similar research into the exchange of information and the vaccination encounter could be done in other countries. Vaccination is a worldwide program and yet there is little information on what actually happens during a vaccination encounter and if the vaccination programs in the world are meeting current ethical and human rights guidelines. Research could also be done into the effectiveness of existing informed consent policies in Canada and the UK.

Is the choice to vaccinate informed? A qualitative study on information exchange in the vaccination encounter in Dhaka, Bangladesh

Appendix 1: Maps

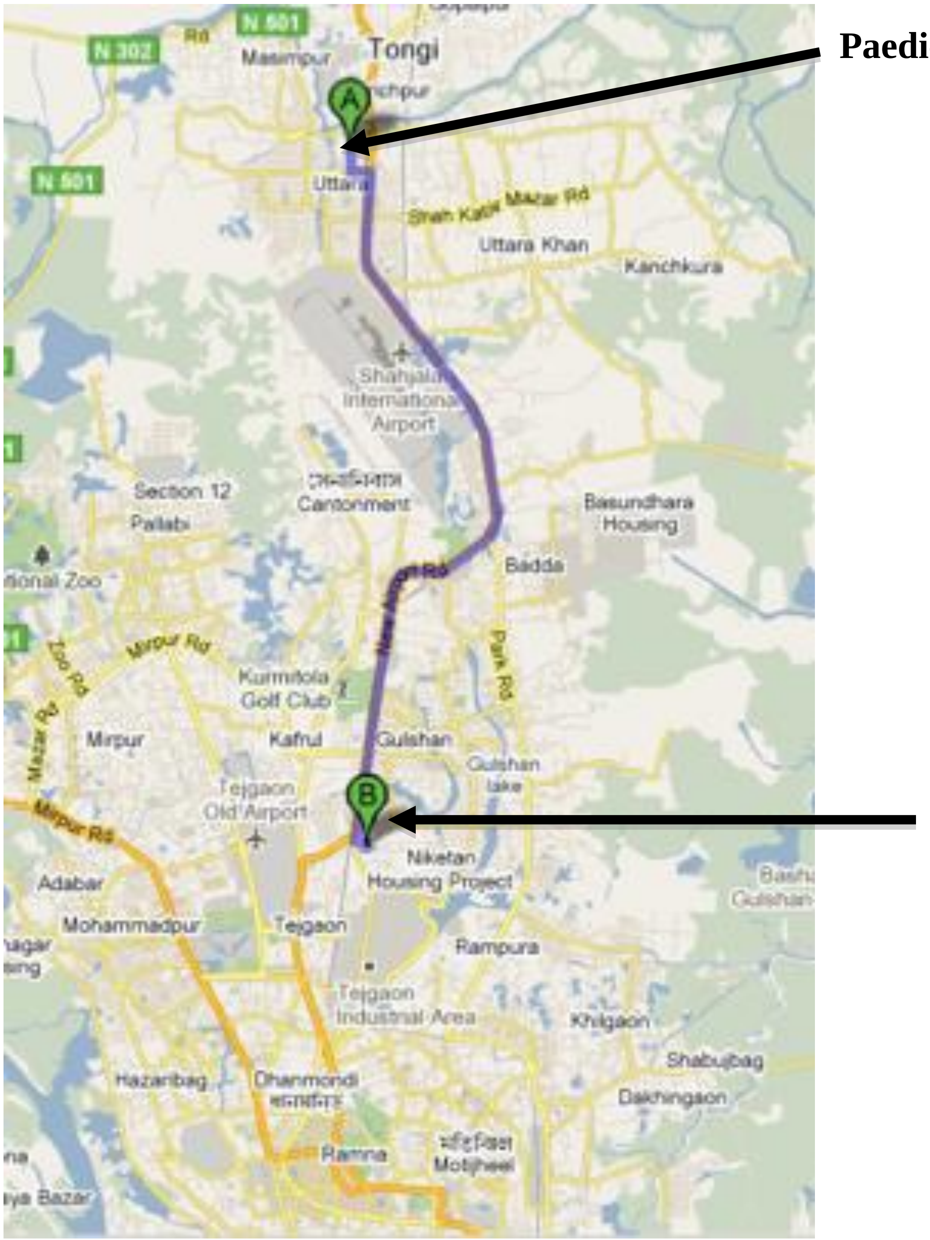
Geographic maps of Bangladesh:

(83)

(44)

Bangladesh

Map of Dhaka City with the location of the two research sites



Paedicare Hospital

ICDDR, B

(84)

Appendix 2: Semi structured interview guide for guardians

- Greetings are exchanged over how they are feeling and the health of their children.
- Is this your first child?
- Have your other children been immunized? (If they had other children)
- Can you tell me about how you made the decision to immunize?
    - Who made the decision to immunize?
    - Did your family support the decisions?
- Can you tell me about your first vaccination experience?
    - How did this experience make you feel?
    - Did you feel you could ask questions?
    - Can you tell me about any information you were given?
    - How did you feel about the amount of information you were given?
- How did your experience today compare with your previous vaccination experiences?
- Can you tell me about the sources from which you get information about vaccination?
- Can you tell me about why this information is important to you?
    - What about vaccination would you like to know more about?
- Which source is the easiest for you to get information from?
- Is there anything that you would like to see changed in the vaccination process?

Appendix 3: In depth interview guide for vaccinators

- Greetings are exchanged.
- Can you tell me about how you became a health worker?
- How did you start working in vaccination?
    - How long have you been working at this vaccination clinic?
- Can you tell me about the training you received when you started working with vaccination?
    - Did you feel that this training prepared you for what you do in the vaccination room?
- Can you walk me through a typical vaccination encounter in this clinic from the time the mother arrives until she leaves?
- Can you describe a typical patient to me?
- How many patients a day do you see on average in this clinic?
- Do you enjoy working in vaccination?
    - Can you tell me about your favourite part?
    - Your least favourite part?
- How is information about vaccination given in Bangladesh?
- How do you feel about giving information during vaccination?
- Which information do you think is the most important for parents to know?
- What do you think is the easiest source of information for parents?
- Is there anything that you would like to see changed in vaccination in this clinic?

Works Cited

1. Bonanni P. Demographic impact of vaccination: a review. Vaccine. 1999 Oct 29;17 Suppl 3:S120-125.

2. Manfredi P, Posta PD, d'Onofrio A, Salinelli E, Centrone F, Meo C, et al. Optimal vaccination choice, vaccination games, and rational exemption: An appraisal. Vaccine. 2009 Dec 10;28(1):98-109.

3. Streefland PH. Public doubts about vaccination safety and resistance against vaccination. Health Policy. 2001 Mar;55(3):159-172.

4. UNICEF - Immunization - Introduction [Internet]. [cited 2011 Mar 14];Available from: http://www.unicef.org/immunization/index.html

5. GAVI – The Global Alliance for Vaccines and Immunisation [Internet]. [cited 2011 Mar 14];Available from: http://www.gavialliance.org/index.php

6. United Nations Millennium Development Goals [Internet]. [cited 2011 Mar 14];Available from: http://www.un.org/millenniumgoals/childhealth.shtml

7. Verweij M, Dawson A. Ethical principles for collective immunisation programmes. Vaccine. 2004 Aug 13;22(23-24):3122-3126.

8. Verweij MF, van den Hoven MA. Influenza vaccination in Dutch nursing homes: is tacit consent morally justified? Med Health Care Philos. 2005;8(1):89-95.

9. Sporton RK, Francis SA. Choosing not to immunize: are parents making informed decisions? Fam Pract. 2001 Apr;18(2):181-188.

10. WHO. Bangladesh 2008 EPI Fact Sheet. New Delhi: 2008.

11. Streefland PH, Chowdhury AM, Ramos-Jimenez P. Quality of vaccination services and social demand for vaccinations in Africa and Asia. Bull. World Health Organ. 1999;77(9):722-730.

12. Chowdhury N. Quantitative study on the impact of primary care providers and other factors contributing to incomplete immunization among children 18-24 months of age in a slum area in urban Bangladesh. 2003;

13. Paul Y, Dawson A. Some ethical issues arising from polio eradication programmes in India. Bioethics. 2005 Aug;19(4):393-406.

14. The Universal Declaration of Human Rights [Internet]. [cited 2010 Nov 22];Available from: http://www.un.org/en/documents/udhr/

15. Fine PEM. Herd Immunity: History, Theory, Practice. Epidemiologic Reviews. 1993 Jan 1;15(2):265 -302.

16. Reluga TC, Bauch CT, Galvani AP. Evolving public perceptions and stability in vaccine uptake. Math Biosci. 2006 Dec;204(2):185-198.

17. Castillo FA. Limiting factors impacting on voluntary first person informed consent in the Philippines. Dev World Bioeth. 2002 May;2(1):11-20.

18. O'Neill O. Autonomy and Trust in Bioethics. Cambridge University Press; 2002.

19. Open Training Platform: Guide No. 1 - Establishing Bioethics Committees [Internet]. [cited 2011 Apr 8];Available from: http://opentraining.unesco-ci.org/cgi-bin/page.cgi?g=Detailed/281.html&tab=basic;d=1

20. Manson NC, O'Neill O. Rethinking Informed Consent in Bioethics. 1st ed. Cambridge University Press; 2007.

21. Office of Human Subjects Research [Internet]. [cited 2010 Nov 11];Available from: http://ohsr.od.nih.gov/guidelines/nuremberg.html

22. Beauchamp TL, Childress JF. Principles of Biomedical Ethics (Principles of Biomedical Ethics. 6th ed. Oxford University Press, USA; 2008.

23. Miller F, Wertheimer A. The Ethics of Consent: Theory and Practice. 1st ed. Oxford University Press, USA; 2009.

24. Andanda P. Module two: informed consent. Dev World Bioeth. 2005 Mar;5(1):14-29.

25. Cook RJ, Dickens BM, Fathalla MF. Reproductive Health and Human Rights: Integrating Medicine, Ethics, and Law. 1st ed. Oxford University Press, USA; 2003.

26. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med. 1997 Mar;44(5):681-692.

27. McMurray R, Cheater FM, Weighall A, Nelson C, Schweiger M, Mukherjee S. Managing controversy through consultation: a qualitative study of communication and trust around MMR vaccination decisions. Br J Gen Pract. 2004 Jul;54(504):520-525.

28. Tenrreiro KN. Time-efficient strategies to ensure vaccine risk/benefit communication. J Pediatr Nurs. 2005 Dec;20(6):469-476.

29. Streefland P, Chowdhury AMR, Ramos-Jimenez P. Patterns of vaccination acceptance. Social Science & Medicine. 1999 Dec;49(12):1705-1716.

30. Murphy D, Dandeker C, Horn O, Hotopf M, Hull L, Jones M, et al. UK armed forces responses to an informed consent policy for anthrax vaccination: a paradoxical effect? Vaccine. 2006 Apr 12;24(16):3109-3114.

31. Krantz I, Sachs L, Nilstun T. Ethics and vaccination. Scand J Public Health. 2004;32(3):172-178.

32. EPI Bangladesh. EPI Book Bangladesh.

33. Wakefield A. Autism, inflammatory bowel disease, and MMR vaccine. The Lancet. 1998 May 2;351(9112):1356.

34. Eggertson L. Lancet retracts 12-year-old article linking autism to MMR vaccines. CMAJ. 2010 Mar 9;182(4):E199-E200.

35. Deer B. How the case against the MMR vaccine was fixed. BMJ. 2011;342(jan05 1):c5347-c5347.

36. Peltola H. Good performance of vaccination by education. Biologicals. 1997 Jun;25(2):237-239.

37. Davis TC, Fredrickson DD, Arnold CL, Cross JT, Humiston SG, Green KW, et al. Childhood vaccine risk/benefit communication in private practice office settings: a national survey. Pediatrics. 2001 Feb;107(2):E17.

38. Plumridge E, Goodyear-Smith F, Ross J. Parents and nurses during the immunization of children—where is the power? A conversation analysis. Family Practice. 2008 Feb 1;25(1):14 -19.

39. Aubel J, Rabei H, Mukhtar M. Health workers' attitudes can create communication barriers. World Health Forum. 1991;12(4):466-471.

40. Immunization [Internet]. 2010 Jul 22 [cited 2010 Nov 19];Available from: http://www.bccdc.ca/dis-cond/comm-manual/CDManualChap2.htm

41. Information letter No. 3: Vaccination during childhood and adolescence - Folkehelseinstituttet [Internet]. [cited 2011 Mar 31];Available from: http://www.fhi.no/eway/default.aspx?pid=233&trg=MainLeft_5670&MainArea_5661=5670:0:15,3353:1:0:0:::0:0&MainLeft_5670=5544:70174::1:5675:1:::0:0

42. Stefanoff P, Mamelund S-E, Robinson M, Netterlid E, Tuells J, Bergsaker MAR, et al. Tracking parental attitudes on vaccination across European countries: The Vaccine Safety, Attitudes, Training and Communication Project (VACSATC). Vaccine. 2010 Aug 9;28(35):5731-5737.

43. ICDDR,B. Barriers to immunization among women and children living in slums of zone 3 of Dhaka City, Bangladesh: A qualitative assessment. Health and Science Bulletin [Internet]. 2009 Jun;7(2). Available from: http://www.icddrb.org/publication.cfm?classificationID=56&pubID=10393

44. CIA - The World Factbook [Internet]. [cited 2010 Nov 23];Available from: https://www.cia.gov/library/publications/the-world-factbook/geos/bg.html

45. Hadley MB, Blum LS, Mujaddid S, Parveen S, Nuremowla S, Haque ME, et al. Why Bangladeshi nurses avoid "nursing": social and structural factors on hospital wards in Bangladesh. Soc Sci Med. 2007 Mar;64(6):1166-1177.

46. UNICEF - Publications - Immunization Summary: The 2007 Edition [Internet]. [cited 2011 Mar 14];Available from: http://www.unicef.org/publications/index_38256.html

47. Chowdhury AMR, Bhuiya A, Mahmud S, Abdus Salam AKM, Karim F. Immunization divide: who do get vaccinated in Bangladesh? J Health Popul Nutr. 2003 Sep;21(3):193-204.

48. WHO. World Health Organization, Bangladesh EPI. WHO;

49. GAVI. Bangladesh GAVI. 2008.

50. Khan A. Programmatic and non-programmatic determinants of low immunization coverage in Bangladesh. Mumbai, India: 2005.

51. Chowdhury F, Khan AI, Hossain MI, Malek MA, Faruque ASG, Ahmed T, et al. Young children non-immunized against measles: characteristics and programmatic implications. Acta Paediatr. 2006 Jan;95(1):44-49.

52. Rahman M, Obaida-Nasrin S. Factors affecting acceptance of complete immunization coverage of children under five years in rural Bangladesh. Salud Publica Mex. 2010 Apr;52(2):134-140.

53. Uddin MJ, Larson CP, Oliveras E, Khan AI, Quaiyum MA, Chandra Saha N. Child immunization coverage in rural hard-to-reach Haor areas of Bangladesh: possible alternative strategies. Asia Pac J Public Health. 2009 Jan;21(1):8-18.

54. Quaiyum MA, Tuñon C, Hel Baqui A, Quayyum Z, Khatun J. Impact of national immunization days on polio-related knowledge and practice of urban women in Bangladesh. Health Policy Plan. 1997 Dec;12(4):363-371.

55. Hesse-Biber SJ (Janice) N, Leavy PL. The Practice of Qualitative Research. Second Edition. Sage Publications, Inc; 2010.

56. Silverman PD. Doing Qualitative Research. Third Edition. Sage Publications Ltd; 2009.

57. The Strength of Weak Ties - a Network Theory Revisited - Mark Granovetter [Internet]. [cited 2011 Mar 16];Available from: http://www.scribd.com/doc/24761271/The-Strength-of-Weak-Ties-a-Network-Theory-Revisited-Mark-Granovetter

58. ICDDR,B: Home Page [Internet]. [cited 2010 Nov 23];Available from: http://www.icddrb.org/index.cfm

59. Onyango-Ouma W, Laisser R, Mbilima M, Araoye M, Pittman P, Agyepong I, et al. An evaluation of Health Workers for Change in seven settings: a useful management and health system development tool. Health Policy Plan. 2001 Sep;16 Suppl 1:24-32.

60. Fonn S. Health Workers for Change; A manual to improve quality of care. WHO; 1995.

61. Immunization Coverage [Internet]. 2009 Jun 16 [cited 2011 Mar 20];Available from: http://www.bccdc.ca/imm-vac/BCImmunizationCov/default.htm

62. Letter: Castlegar’s medical health officer speaks to local Pertussis outbreak and immunizations | The Boundary Sentinel [Internet]. [cited 2011 Mar 20];Available from: http://boundarysentinel.com/node/4651

63. Denzin NK, Lincoln YS. The SAGE Handbook of Qualitative Research. 3rd ed. Sage Publications, Inc; 2005.

64. The abductive theory of method - Psychlopedia - psych-it.com.au [Internet]. [cited 2011 Apr 2];Available from: http://www.psych-it.com.au/psychlopedia/article.asp?id=264

65. Schüklenk U. Module one: introduction to research ethics. Dev World Bioeth. 2005 Mar;5(1):1-13.

66. WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects [Internet]. 2008 Oct 22 [cited 2010 Nov 22];Available from: http://www.wma.net/en/30publications/10policies/b3/index.html

67. Texts of guidelines [Internet]. [cited 2011 Mar 21];Available from: http://www.cioms.ch/publications/guidelines/frame_guidelines.htm

68. The Universal Declaration of Human Rights [Internet]. [cited 2010 Nov 22];Available from: http://www.un.org/en/documents/udhr/

69. Persky S. Employing immersive virtual environments for innovative experiments in health care communication. Patient Education and Counseling [Internet]. [cited 2011 Jan 19];In Press, Corrected Proof. Available from: http://www.sciencedirect.com/science/article/B6TBC-51XNX7K-1/2/e0ac8c7e6d1f803da2b0fdf81f8f2da8

70. Low SM, Lawrence-Zunigais D. The Anthropology of Space and Place: Locating Culture. Wiley-Blackwell; 2003.

71. Pettigrew KE. Waiting for chiropody: contextual results from an ethnographic study of the information behaviour among attendees at community clinics. Information Processing & Management. 1999 Nov;35(6):801-817.

72. Becker G, Kempf DE, Xander CJ, Momm F, Olschewski M, Blum HE. Four minutes for a patient, twenty seconds for a relative - an observational study at a university hospital. BMC Health Serv Res. 10:94-94.

73. BROWN LD, DE NEGRI B, HERNANDEZ O, DOMINGUEZ L, SANCHACK JH, ROTER D. An evaluation of the impact of training Honduran health care providers in interpersonal communication. International Journal for Quality in Health Care. 2000 Dec 1;12(6):495 -501.

74. Saba GW, Wong ST, Schillinger D, Fernandez A, Somkin CP, Wilson CC, et al. Shared Decision Making and the Experience of Partnership in Primary Care. Ann Fam Med. 2006 Jan;4(1):54-62.

75. Rao JK, Anderson LA, Inui TS, Frankel RM. Communication interventions make a difference in conversations between physicians and patients: a systematic review of the evidence. Med Care. 2007 Apr;45(4):340-349.

76. Fonn S, Mtonga AS, Nkoloma HC, Bantebya Kyomuhendo G, daSilva L, Kazilimani E, et al. Health providers’ opinions on provider-client relations: results of a multi-country study to test Health Workers for Change. Health Policy Plan. 2001 Sep;16 Suppl 1:19-23.

77. Basher MS. Knowledge and practice about TT vaccination among undergraduate female medical students. Mymensingh Med J. 2010 Oct;19(4):520-523.

78. Grimen H. Power, trust, and risk: some reflections on an absent issue. Med Anthropol Q. 2009 Mar;23(1):16-33.

79. Braddock CH, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: time to get back to basics. JAMA. 1999 Dec 22;282(24):2313-2320.

80. Arntson PH, Philipsborn HF. Pediatrician-Parent Communication in a Continuity-of-care Setting. Clinical Pediatrics. 1982 May 1;21(5):302 -307.

81. Nordfeldt C, Roalkvam S. Choosing Vaccination: Negotiating Child Protection and Good Citizenship in Modern India. Forum for Development Studies. 2010;37(3):327.

82. Nath SR, Mohsin M, Chowdhury AM. Health knowledge of children in Bangladesh: an exploratory study. Public Health. 1997 Sep;111(5):311-315.

83. map of Bangladesh in Asia - Bing Images [Internet]. [cited 2011 Apr 13];Available from: http://www.bing.com/images/search?q=map+of+Bangladesh+in+Asia&view=detail&id=18C4DC238E4A26FCEE92E4CC3A39B021C4D34C7A&first=61&FORM=IDFRIR

84. Sector 9, Dhaka, Bangladesh to ICDDR,B - Google Maps [Internet]. [cited 2011 Apr 13];Available from: http://maps.google.com/

Thanks for Reading