

**FACTORS AFFECTING ATTITUDES TOWARD PRENATAL
DIAGNOSIS AND MEDICAL TERMINATION OF PREGNANCY
AMONG BETA THALASSAEMIA CARRIERS IN SH. BILEHFAHI**

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May, 2013

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CARRIERS IN SH. BILEHFAHI**

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A Project submitted in partial fulfillment of the requirements for the
degree of Bachelors in Primary Health Care

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MAY, 2013

DECLARATION

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I hereby declare that this project is the result of my own work, except for quotation and summaries which have been duly acknowledged.

Signature:

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ABSTRACT

A cross-sectional descriptive study was conducted to reveal the attitude towards Prenatal Diagnosis (PND) and Medical Termination of Pregnancy (MTP) among 18 to 25 years unmarried beta thalassaemia carriers in Sh. Bilehfahi, Maldives. A pre-structured questionnaire was used to interview 34 beta thalassaemia carriers in the island. Analysis was done to calculate the frequency and percentage of age, sex, relationship characteristics, family income, level of education and knowledge. Chi-square test was used to examine the association of these factors and attitudes toward PND and MTP.

The result showed that 52.9 % of the carriers have negative attitudes toward PND and MTP. 44.1% of the carriers had adequate knowledge. The knowledge was found to be strongest predictor of attitudes toward PND and MTP when compared with other factors. Among the study participants those who have an adequate knowledge about PND and MTP; 80% of them were having a positive attitude while only 20% said they had a negative attitude. Among the people who do not have an adequate knowledge regarding PND and MTP; 78.94% have negative attitude while only 21.1% have a positive attitude. The knowledge had a significant association with attitudes toward PND and MTP (p -value = 0.001).

It is recommended that knowledge has to be improved in order to develop a positive attitude toward PND and MTP among the beta thalassaemia carriers in the island. In addition, promotion of health education by providing appropriate information about PND and MTP is highly needed.

Keywords: Prenatal diagnosis, Medical termination of pregnancy, Knowledge, Attitude, Carrier

ACKNOWLEDGEMENTS

I would like to express my deepest appreciation to all those who provided me the possibility to complete this research project. A special gratitude to all the voluntary enumerators helped me to conduct interviews to fill the questionnaires. Furthermore I would like thank all my friends in Sh. Bilehafhi, who provide help and support during data collection. I would also like to thank all my class mates and colleagues, those who helped me to complete this project. Special thanks should go for all my family members, especially for mom.

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LIST OF ABBREVIATIONS

DNP – Department of National Planning
MTP – Medical Termination of Pregnancy
NGO – Non-governmental organization
NTC – National Thalassaemia Center
PND – Prenatal Diagnosis
SHE – Society for Health Education
TOP – Termination of Pregnancy
UN – United Nations
USA – United State of America
WHO – World Health Organization

CHAPTER 1

INTRODUCTION

1.1 Background to the Study

The prevalence of beta thalassemia among the population of Maldives is 18.1%; 1 in 5 people are carriers of the disease and 1 in 120 live births are estimated to be thalassaemia major (National Thalassemai Center, 2012). Currently, there are more than 726 thalassemia major patients who require regular blood transfusions, and as a result, 60% of the blood utilization of the Maldives treats these patients (Society for Health Education, 2012).

Maldives has the highest beta thalassaemia prevalence rate in the world. Around 18.1% of the Maldivian population is found to be carriers for hereditary blood disorder, beta thalassaemia. This prevalence level leads to a birth of a thalassaemic child (thalassaemia major) in every 120 births. At the end of the year 2002, nearly 504 thalassaemia majors were registered at the National Thalassaemia Center (NTC). It has been estimated that for the eight-year period 1990-1998 more than 50% of the thalassaemic children born in Maldives would have died in infancy or before their third birthday (Ministry of Planning and Development, 2006). Thalassaemia deaths toll still contribute to 5-10 % of the child mortality in Maldives (Ministry of Health and Family, 2011).

The current Thalassaemia Prevention Program in the Maldives, comprise, health education, population screening and genetic counseling. Due to the impact of emerging issues of thalassaemia and its direct and indirect impact to the community, today the Maldives is in need of more effective and efficient interventions such as prenatal diagnosis (PND) with establishment of molecular biology laboratory in the country. Moreover the facilities should be developed for selective cases to conduct medical termination of pregnancy (MTP) in Maldives to combat the current crisis of nationwide thalassaemia problem.

PND and MTP appears to be a distant vision in the Maldives. Most of the countries in the region and other thalassaemia endemic countries in the world have adopted PND and selective abortion by MTP to reduce number of thalassaemia major newborn (Bozkurt, 2007). PND and MTP are not yet available in the Maldives, may be due to religious and cultural beliefs reinforce people lack of autonomy and decision making capacities to selective abortion thus putting their children's lives at risk on regular blood transfusion and its related complications.

A number of studies, particularly in the recent past have looked at the issue of the public acceptability of PND and safe MTP services to reduce the thalassaemia major new born and to reduce the overall thalassaemia related costs. The general knowledge regarding PND and MTP services plays an important role to change public attitude towards service. This study explores the factors which influence the attitude toward PND and MTP among the beta thalassaemia carries in Shaviyani Bilehfahi. A questionnaire was planned to assess the factors which may affect the attitudes towards PND and MTP as a method of prevention while these services is not yet available in Maldives. This study would help to identify the factors which may leads to negative and positive attitude towards PND & MTP. Thus it would assist to develop programs and strategies to change the public attitudes toward PND & MTP. Moreover, it may contribute and paves the way to guiding principle for the prevention of thalassaemia for the sustainable development of health sector in the country in favor of establishment of PND and MTP service in Maldives.

1.2 Problem Statement

As Maldives was ranked as the highest thalassaemia prevalence rate in the world. So far the only available preventive options for thalassaemia, for Maldivian were premarital screening and discontinue the relationship if the both partners were positive for thalassaemia carries. The screening services are available only in the capital city. Due to the difficulties in getting access to the service, most of the couples do not screen for thalassaemia in their earlier stage of relationship. They often go for screening after engagement and when marriage was already finalized; therefore most of the couples proceed with the marriage. Though the screening facilities were available in Maldives, most of the young couples do not wants to separate even if

both were diagnose as thalassaemia carrier thus leads to keep continuously increasing the prevalence rate of thalassaemia major new born and consequences of it became a major public health concern which also adversely affect the socio-economic status of the country too. Today Maldives is in need of an effective thalassaemia prevention method. PND and selective abortion are considered as the most effective way for thalassaemia prevention, which was experienced in the most prevalent countries such as Cyprus and Greece and have a better outcome as well (Vadolas, 2002).

Even though PND and selective abortion was proven as the best way to reduce the burden of thalassaemia in most of the countries in the world, the government of Maldives faced problems in establishing the service in county due to issues in public acceptability and attitudes towards the concept of MTP. As the Maldives is a 100% Muslim state, the concept of abortion was greatly criticized and it was believes that the majority of the people are against it in any circumstance, even when pre-know sever congenital defect in fetus. However, PND and MTP is allowed and practiced for thalassaemia in many Muslims state such as in Saudi Arabia, Iran, Egypt, and Kuwait (Alsulaiman & Hewison, 2006). The public attitude towards PND and MTP may affect due to inadequate knowledge regarding service, level of education, income and other factors. Before introducing any kind of services, if which involves any sensitive issues such as an abortion, requires the view of the general public regarding the services. It is important to have a better understanding about the public knowledge and attitudes toward the new service to make it successful. The public acceptability and their attitude is compulsory in order to have a successful outcome from any public services. This study will explore attitude (positive or negative) of the beta thalassaemia carriers in Sh. Bilehfahi towards PND and MTP, and factors affecting it. Most importantly this study would help to understand the association between knowledge level and other factors which affect the attitude toward PND among the beta thalassaemia carriers in the island.

1.3 Objectives of the Study

In order to provide any preventive health care service effectively and efficiently, it requires the public attitude and acceptability to make the program successful. Understanding the public

knowledge is important to build up a positive attitudes towards new intervention will play a vital role in developing effective intervention and methods, to optimize health outcomes. PND and selective abortion are considered as one of the best way to reduce thalassaemia prevalence rate and which was successfully implemented in some thalassaemia prevalent countries in the world (Banton, 2005). Even though Maldives ranked as the highest prevalence rate of beta-thalassaemia in the world, still there are no facilities yet to provide PND and MTP service in the country. So far the government of the Maldives have not properly attempt to plan to develop such facilities in Maldives. It was believed that the general public of Maldives is not willing to accept the religiously controversial issue on selective abortion. So far there was no public advocating programs to PND, and attitude of the public was not properly assessed in any part of the country. The factors associated with attitude needs to be identify in order to plan and conduct effective public advocating programs about the service.

Today, as increasing the public awareness regarding the health impact and its complication of thalassaemia, most of the Maldivian may have positive attitude towards PND and MTP to prevent their children from thalassaemia and its complications.

The main objective of the study is to determine public attitude towards PND and MTP, and what are the factors associated with their attitude. And determine the most significantly associated factors with the attitude toward PND and MTP among the beta thalassaemia carries in Sh. Bilehfahi.

1.4 Research Questions and Hypotheses

The research questions of this study include;

1. What are the factors which affect the attitudes toward PND and MTP among beta thalassemia carriers in Sh. Bilehfahi?
2. How much the carrier population is having an adequate knowledge about PND and MTP?
3. Are there statistically significant association between knowledge level of the respondents and their attitude?

Statement - Factors affecting attitudes toward prenatal diagnosis and medical termination of pregnancy among beta thalassaemia carriers in Sh. Bilehfahi.

Alternative hypothesis – *Carriers those who have a good knowledge about PND & MTP have a positive attitude toward PND and MTP.*

Null hypothesis – *There is no significant association between knowledge and attitude towards PND and MTP.*

1.5 Significance of the Study

Social scientists have been studying public attitudes toward abortion for more than 30 years. PND and selective abortion has been an important and divisive issue in Maldives. The question of whether the couple has, or should have, the right to terminate a pregnancy intentionally has been a source of intense controversy for over a generation. The abortion issue has been what Amy Fried (2001) has termed a “condensational symbol,” involving questions of moral theology, human life, gender roles, and sexual morality. The issue has inspired marches and murder, and spawned a set of competing interest groups that have mobilized tens of millions of dollars a year to influence public opinion around the world (Fried, 2001).

The earliest case of thalassaemia diagnosed in Maldives goes back to early 1970s. During 1970 – 1980 few cases registered in Government Hospital where there was no proper regimen for transfusion and proper management of this disease. During 1980 -1990 there was dramatic increase of thalassaemia patients in the country, due to this special clinics for these patients were been made in the paediatric ward of the hospital (Society for Health Education, 2012). The impact of Thalassaemia and its social stigma has been recognized by the government and many experts from various countries have been brought in collaboration with World Health Organization (WHO) during 1980s. Ever since 1992 one of the leading NGO in the country, Society for Health Education (SHE) working towards well-being of Maldivian’s health has started one of its essential element, Thalassaemia Prevention Program, comprising ,health education , population screening and genetic counseling .During 1993 National Thalassaemia

Program has been formulated and in December 1994 National Thalassaemia Centre has been inaugurated with 17 bedded ward , blood banking facilities and a diagnostic laboratory services.

The enormous contribution of many people in both Government and NGOs across the country, thalassaemia awareness has increased dramatically and now the word thalassaemia is a house hold story amid all the alliance of communities. The combine effort of these institutions has screened thalassaemia and other hemoglobinopathies over 30 % of the entire population in the archipelago using modern diagnostic methodologies, including hemoglobin electrophoresis, automatic cell counting and quantification of hemoglobin. In particular, thalassaemia major is the most common life-threatening non-infectious disorder of childhood in Maldives where a substantial proportion of affected children do not survive beyond adolescence. PND and MTP may bring the ultimate solution to thalassaemia crisis in Maldives. The development of PND and MTP facilities in the country may provide better health outcomes. Long term consequent to this, PND and MTP would be resulting in less cost to already strained public health budgets in Maldives.

Research has shown that the wording of abortion questions does matter. Many citizens would neither allow abortion nor forbid it. There is evidence that the public distinguishes between types of abortions, including a new distinction between medical and surgical abortions, suggesting that how an abortion is performed. In this study, it will assess the carriers (beta thalassaemia) knowledge and their attitude towards PND and MTP among thalassaemia carriers Sh. Bilehfahi, Maldives.

1.6 Scope of the Study

Thalassaemia is one of the major public health problem in Maldives. To achieve the success in the prevention and control of thalassaemia, PND and MTP is now required. It is expected that with optimal collaboration and support, effective prevention and control of thalassaemia can be achieved. This will lead to a healthier new generation which enjoys a better overall quality of life free from thalassaemia.

By understanding of the public attitude regarding PND and MTP would help to contribute to develop better public awareness programs. Abortion opinion is interesting for a many reasons in Maldives, essentially, for PND and MTP in beta thalassaemic couples. Abortion is not an easy issue about which people can easily form opinions without great knowledge and proper understanding on the reason for it. For all of these reasons, public attitude on PND & MTP is of interest to many social scientists.

The purpose of this study is to lay out some avenues for future research on public attitudes toward PND & MTP. This study do not seek to provide an encyclopedic review of the literature, but rather it intend to highlight some of the more important findings concerning public attitudes toward PND and MTP, and what are the factors which influence the attitude of the beta thalassaemia carriers in Sh. Bilehfahe. And also it would suggest to further research on public knowledge and attitude regarding PND and selective abortion in other regions of Maldives.

1.7 Definitions of Terms

Prenatal diagnosis (PND)

Theoretical definition – Prenatal diagnosis or prenatal screening is testing for diseases or conditions in a fetus or embryo before it is born. The aim is to detect birth defects such as neural tube defects, down syndrome, chromosome abnormalities, genetic diseases and other conditions, such as spinal bifida, cleft palate, Tay Sachs disease, sickle cell anemia, thalassemia, cystic fibrosis, Muscular dystrophy, and fragile X syndrome.

Operational definition – In this study prenatal diagnosis (PND) was referred as testing for thalassaemic condition of fetus or embryo before it is born.

Medical termination of pregnancy (MTP)

Theoretical definition – Medical or surgical procedures used to terminate pregnancy by removal or expulsion of fetus or embryo prior to viability.

Operational definition – Medical of surgical procedures used to terminate pregnancy by removal or expulsion of thalassaemia major fetus or embryo prior to viability.

Knowledge

Theoretical definition – Knowledge is a familiarity with someone or something, which can include facts, information, descriptions, or skills acquired through experience or education.

Operational definition – In this study, knowledge was defined as familiarity with prenatal diagnosis and medical termination of pregnancy, which includes facts and information about prenatal diagnosis and medical termination of pregnancy.

Attitude

Theoretical definition – An attitude is an expression of favor or disfavor toward a person, place, thing, or event.

Operational definition – In this study, attitude was defined as either favor or disfavor toward prenatal diagnosis and medical termination of pregnancy.

Carrier

Theoretical definition – A carrier is a person or other organism that has inherited a genetic trait or mutation, but who does not display that trait or show symptoms of the disease. They are, however, able to pass the gene onto their offspring, who may then express the gene. This phenomenon is a direct result of the recessive nature of many genes.

Operational definition – In this study, the word ‘carrier’ was defined as the person(s) who have a beta thalassaemia carrier trait.

CHAPTER 2

REVIEW OF LITERATURE

The current thalassaemia preventive program in Maldives focuses on discouraging the marriage of carriers to one another, thus increasing the number of carriers throughout the country (Department of National Planning, 2011). And in Maldives where the social circles are small, the probability of intermarriage of carriers is high. And their carrier status should not be a restriction to getting married or having children. Some of these carriers may continue to take the risk and hope for that 75% chance of having a normal baby. The approach of discouraging the marriage of carriers to one another has not helped in reducing the number of new cases as most of the children with thalassaemia are being born unhappily. According to the recorded registered cases of National thalassaemia center, on average 28 new cases of major thalassaemia were being registered each year over last seven years (National Thalassemai Center, 2012). Most of these cases were from couples those who know their carrier status at the time of marriage, and from those who already have a child with thalassaemia major. This is an important reflection that needs to be addressed in the prevention program as just the mere knowledge of the risk has not prevented couples from having thalassaemia major children. The adequate knowledge about alternative options for prevention should be provided to the carriers those who are having risk of getting an abnormal child.

Thalassaemia is the most common single-gene disorder in the world, with the highest prevalence in Southeast Asia, where roughly 55 million are carriers (Wong HB, 2011). The burden of this disorder in many regions is of such an extent that it represents a major public health concern. Maldives has the highest incidence of beta thalassaemia carrier in the world with a carrier rate of 18.1% of the total population (Department of National Planning, 2012). To date a total of 726 cases have been registered at National Thalassaemia Center. The number of new cases registered has not declined over the last five years, with about 28 new cases on average being registered

over the last 7 years. Last year saw an increase to 39 in fact (National Thalassemia Center, 2012). Role of genetic counseling in increasing public awareness of thalassemia problems is the important step in prevention of thalassemia major prevalence. However, in Maldives it is not effectively controlled as compare to other endemic countries in the world. Thalassemia is one of the most often considerable public health issue in the Maldives. It is estimated that about 80 pregnancies in Maldives are at risk of thalassemia major each year (Ministry of Health and Family, 2011). In addition to that, a total of 140 of those registered have died so far, and from 1997 to 2007 each year about 8 children have died at the average age of 8 years. This young average age at death should be a matter of concern in a country where all aspects of treatment are free of cost and where treatment is readily available.

In some endemic countries in the Mediterranean region, long-established thalassaemia control programs of PND and selective abortion for thalassaemia major have achieved 80-100 percent prevention of newly affected births (Banton, 2005). Introduction of PND and MTP service in Maldives might probably be the best solution for current thalassaemia problem in the country. However, the introduction of such technology into service delivery should be based on the target population's attitudes toward prenatal diagnosis (PND) and medical termination of pregnancy (MTP). However, there is no research done in Maldives about the attitude towards the service and public acceptability of such technology among the risk age group of beta thalassaemia carriers in the Maldives.

2.1 Previous Studies

In Maldives, there is no published research, on the assessment of the relationship and association of attitude toward PND & MTP and its related factors among thalassaemia carrier population in the country. However, several researches were conducted in other countries. These studies had proved that there were a relationship between the level of knowledge and attitude toward PND and selective abortion. The people who have better knowledge regarding PND and selective abortion may be more accepting of PND and MTP (Pauisri, Saksiriwuttho, & Ratanasiri, 2011). According to study conducted by three Pakistani researchers in 2007 have shown that overall, those who have an adequate knowledge have a positive attitude toward PND and MTP than those

who have an inadequate knowledge (Ahmed, Saleem, & Sultan, 2007). According to the study, most expressed erroneous beliefs about PND and MTP, describing it as medically dangerous, emotionally damaging and widely illegal. In the Maldivian population may also have similar types of misunderstandings about PND and MTP due to lack of adequate knowledge. Furthermore these misunderstanding may result to develop a negative attitude towards PND and MTP among the people. A focus-group study of beta thalassaemia carrier from cities across the United States also revealed that they lacked accurate knowledge about PND & MTP and the laws governing it increase the negative attitude among the respondents (Stone & Waszak, 2001).

2.2.1 Factors affecting the attitude towards PND & MTP

There are many factors which may influence the public attitude towards PND & MTP among the beta thalassaemia carriers. Some of these factors include age, sex, education level, income, certain relationship characteristics and knowledge regarding PND and MTP.

Some studies stated that there was no gender difference in attitudes toward PND and MTP, the most plausible and supported statement is that the genders have same feelings towards PND and MTP (Helena, 2003). However, two Saudi researchers said that the women are more likely to feel abortion morally wrong than the man (Alsulaiman & Hewison, 2006). They provide justification for this by saying that the women have more at risk when becoming pregnant; they have to carry the baby and must deal with most of the consequences. Therefore, if the baby has an insufficient home life or no life at all they are to blame for making the decisions leading up to the event. A research conducted in USA revealed the women may be more likely to believe that it is a woman's choice to have MTP (Gadow & Petracchi, 2009). But the research conducted in Canada stated that most of the Canadian continue to think there should be a legal protection of human life at some time before the point of birth (Environics Research Group, 2006).

The literature supports the idea that people who live a more liberal lifestyle have more liberal attitudes overall, including attitudes towards prenatal diagnosis and abortion (Gursoy, 2006). The attitudes towards termination of pregnancy were proven to have an association with socio-cultural norms and values, influenced by religion, and the legal environment (Nyanzi & Bessie, 2005).

As previously mentioned, some researchers said the religion and faith plays a role in attitudes towards PND and selective abortion. Those who are more religious, especially scholars, are more disapproving of abortion in Pakistan (Ahmed, Sharif, Sheridan, & Taylor, 2012). However, a group of Iranian researchers had shown that there were no association between religious believe and attitude toward PND and MTP among Muslims (Ghasemi, Ayatollahi, & Masaddegh, 2007). A Saudi researcher, Ayman Alsulaimai was also stated that there were no association of religion and attitudes toward PND and MTP among the Sunni-Muslims (Alsulaiman, 2004).

The level of educational attainment may have an association with attitude of PND and MTP among the thalassaemia carriers. Those who have had completed a higher level of education were having a positive attitude towards MTP (Jelen, 2001). While the negative attitude toward PND and MTP were high among uneducated people. And two Canadian researchers said those whose parents, especially mothers, have higher education experience tend to have more positive attitude towards MTP (Osborn & Silkey, 1999).

The level of income is an important factor which may associate with attitudes toward PND and MTP. According to study conducted in Turkey revealed that there were more negative attitude among carriers from low income families (Gursoy, 2006). Whilst it more positive among the carriers from high income families. The Iranian researcher was also stated that there were more negative attitudes toward PND and MTP in low income families.

The certain relationship characteristics of unmarried adolescent beta thalassaemia carriers in Canada have a significant association with the attitude towards PND and MTP (Environics Research Group, 2006). These characters includes whether the, partner was screened for thalassaemia and whether the carriers were having another carrier as his boyfriend or girlfriend.

2.2.2 Association between attitudes and knowledge of PND &MTP

During the past 20 years, there have been several researches revealed that there was known association between the knowledge level and the attitude towards PND and selective abortion, despite the fact that socio-economic factors were also proven to have some sort of relationship with peoples' attitude toward PND and MTP.

The survey results conducted by in Pakistan suggested that the attitudes toward MTP exert a major influence by level of education and the proper knowledge about the procedure (Dehkordi & Heydernejad, 2008). The research conducted in Iran to determine the association of knowledge level and attitude towards PND and MTP of beta thalassaemia carriers shown that there were positive attitude among those who have high level of knowledge about the PND & MTP (Arif, Fayyaz, & Hamid, 2009). Though the several researches have proven that the most influential factor for PND and MTP was religious issues than the other remaining factors, theological beliefs can certainly inform opinions to a certain degree. However, three Iranian researches argued that the best predictor of someone's attitude toward PND & MTP is his or her socio-economic status and knowledge level. The study was conducted in Iran on assessment of knowledge and attitude of medical student toward genetic counseling and therapeutic abortion had revealed that there was no significant association of religious view and MTP (Ghasemi, Ayatolahi, & Masaddegh, 2007). Furthermore, this study indicated that the Islam is not the main factor that influences Muslim parents' attitude toward prenatal diagnosis and termination of the pregnancy. The Saudi researcher, Ayman Alsulaiman who supported this Iranian researcher's augments. According to Ayman Alsulaiman, there were no significant association between religion and attitude of PND and MTP. However, he further stated that when there was a limited knowledge about thalassaemia among carriers at risk, then the misunderstanding occur and lead to the wrong attitude and decision of pregnancy termination (Alsulaiman, 2004).

2.2 Methodological Issues

Some of these previous researches may have suffered methodological problems. Research on some of these data collection and sampling techniques demonstrates that the measurement of public opinion on attitude towards PND may greatly affected by the design, wording and order of questions of surveys and can be manipulated to elicit skewed answers toward a more anti-choice or pro-choice stance. The most of the above cited researches included the use of non-specific questions, yielding vague answers, as well as "leading" questions eliciting particular responses.

CHAPTER 3

METHODOLOGY

3.1 Research Design

This study was a cross-sectional descriptive study, conducted among all unmarried thalassaemia carriers aged between 18 to 25 years in Sh. Bilehfahi, Maldives. A quantitative descriptive statistics were used with demographic data, scores of knowledge and relationship characteristics of their partners associated with attitude toward prenatal diagnosis and medical termination of pregnancy were analyzed.

The associating factors to attitude, which were discussed previously in this study, and were already proven to have any kind of association with attitude towards PND and MTP, were considered as independent variables. The attitude (whether positive or not) towards PND & MTP was used as dependent variable. However, the statistical association of some of independent variables such as age and relationship characteristics, which did not discussed in the literature review, were also used as an independent variables of the study. The figure 3.1 shows the study variables used in this study.

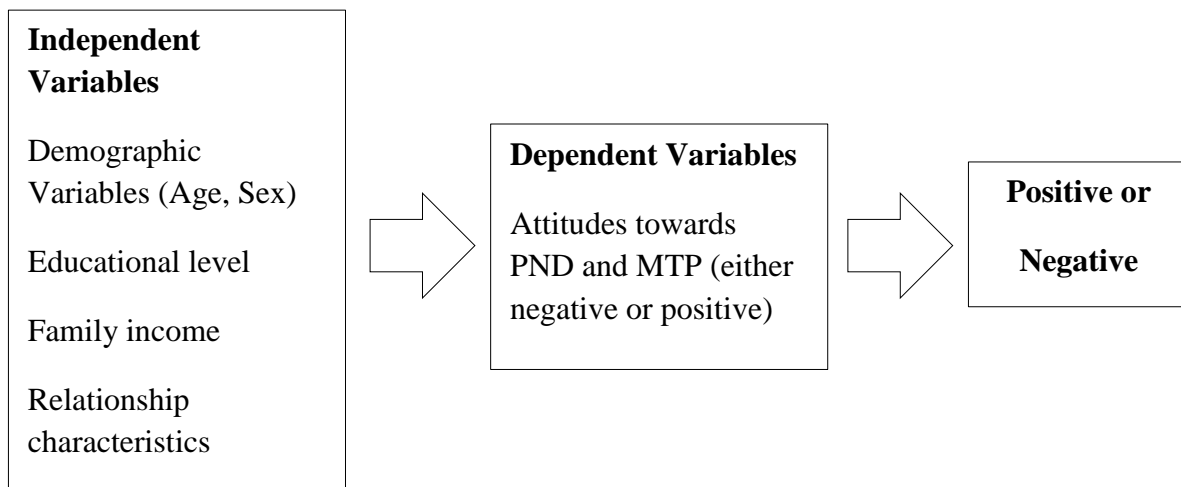


Figure 3.1: Shows the study variables.

3.2 Population and Sample

The information about the number of thalassaemia carriers in the island were collected by asking residents of the total 104 inhabitant household in the island. According to information gathered by household visits, there were total 43 beta-thalassaemia carriers screened for thalassaemia up to the date of 1st May 2013. The sample population of the study is quite small. Therefore, in order to involve as much as possible participants in the study, all the beta-thalassaemia carriers in the island were considered as an eligible study participants. All eligible study participants were included in the study sample to make strong inferential statements regarding the association of their knowledge and attitude towards PND and MTP. As all the thalassaemia carriers in the island were participated in the study, out of total 43 beta thalassaemia carriers, four carriers who do not have the thalassaemia carrier result cards were excluded from the study and three selected study participants were removed due to unable to contact them. Two selected carriers refused to participate in the study.

3.3 Instrumentation

A pre-structured, quantitative questionnaire (APPENDIX -A) was developed to collect the information. The questionnaire enquired about demographic information, relationship status, and carriers' knowledge and attitude regarding PND and selective abortion for thalassaemia major. The questionnaires consist of three parts. Part-A comprises general information included such as age, sex, educational level, average family income (Mother's income + Father's income only) and current relationship status (boyfriend/girlfriend) and certain information about their partners (boyfriend or girlfriend). This part consist total nine questions. Information about the partner includes whether he/she was screened for thalassaemia and what is the result of their screening tests. In addition to this, two questions were included in this section to understand the decision regarding the marriage if the partner is positive for thalassemia carrier. The knowledge section (Part-B), comprised information about PND and MTP. The knowledge score of the respondents was calculated from 7 items. There were four correct statements and three incorrect statements in this part. For each "correct" statement, the respondents were give one point and no points for "don't know" and "incorrect" answers. Answer scores range from 0 to -7. The total score was

classified into two categories: “adequate”: if the score was >3 ; and “inadequate” if the score was $< \text{ or } =3$.

The attitude section (Part-C) addressed respondents’ thoughts, beliefs and intention towards prenatal diagnosis and selective abortion for thalassaemia major fetus. The attitude section had 6 statements. Likert scaling was used to measure the scores. The scoring for positive statement was 5, 4, 3, 2, and 1 corresponding to “strongly agree”, “agree”, “neither agree nor disagree”, “disagree” and “strongly disagree”. The score was reversed for negative statements and categorized into two groups, “positive attitudes” (more than or equals to mean) or “negative attitudes” (less than the mean). A “positive attitude” indicated that the thalassaemia carrier would accept the PND and MTP as a preventive intervention for thalassaemia major.

The draft questionnaire was pre-tested on 18-25 Year 10 thalassaemia carriers among the carriers selected for the main study. After ten pilot interviews, the questionnaires were evaluated and checked for completeness according to the research questions. After the pretest, some questions were revised, deleted, added and amended to make the questionnaire valid and reliable. The questions were clear and understandable. Consensus was reached about the final formulation.

3.4 Data Collection Procedures

The data was collected using a developed questionnaire, after collecting information about the number of thalassaemia carriers in the island by household visits. The standardization of the questionnaire was initially performed on 10 thalassaemia carriers, and once confirmation of the questionnaire, the study proceeded. Randomly selected 10 study participants were selected for pilot interview to pretest the questionnaire. Some questions were changed and removed, and some new questions were added to increase the reliability and validity of questions.

The interviews were conducted by enumerators who have had been thoroughly trained on how to carry out the data collection procedures. Two hours training session was conducted for enumerators. During the session the technical terms in the questionnaire were explained to the enumerators. All enumerators selected for the study must have complete minimum GCE O’ Level.

Anonymous data collection was conducted during 1st to 10th May 2013. Thirty-four interviews were being carried out by six enumerators to fill out the pre-structured questionnaire. All the participants were informed about the objectives of the study. Information and the purpose of the study were explained to participants by reading information section in consent form (APPENDIX - B). Informed consents were received from all participants before the study via consent form (APPENDIX - B). Anonymity and confidentiality were guaranteed to all study participants.

3.5 Framework for Data Analysis

After completion of the questionnaires and coding them, the data were entered into statistical software, Statistical Package for Social Science (SPSS) and data were analyzed by SPSS. The SPSS version 21.0 was used to calculate all statistical analyses. Descriptive statistics were used with demographic characteristics, education level, family income level, scores of knowledge and scores of attitude were compared. The descriptive statistics were used to express the central indices (mean, variance, and median), frequency index (standard deviation, range) as well as percentage. The collected information was coded, and the anonymity of samples was preserved. Chi square test was used to determine a possible association between each independent variable to dependent variable. The significant level was considered at $p < 0.05$. The Table 3.1 represents a summary of Analytical Framework.

Table 3.1: Summary of Analytical Framework

Objective	Questions	Hypothesis	Source of Data	Types of Data	Technique of Analysis
1.Understand the demographic information of β –thalassaemia carriers in the island	Age, Sex	-	*Questionnaire Part A	Quantitative Ordinal & Nominal	Descriptive analysis
2. Understand the association of characteristics and knowledge with attitude toward PND & MTP	1. Relationship characteristics. 2. Statements to assess knowledge 3. Statements to understand attitude.	-	Questionnaire Part A, Part B & Part C	Quantitative Ordinal, Nominal & scales	Chi square test
3.Understand the association between knowledge and their attitude towards PND & MTP	Part B & Part C. <i>Dependent variable</i> – Attitude. <i>Independent Variable</i> – Knowledge	H ₁ : There is an association between carriers' knowledge and their attitude.	Questionnaire Part B & Part C	Quantitative Scales	Chi square test

* Questionnaire (Appendix – A)

CHAPTER 4

DATA ANALYSIS AND RESULTS

Majority (55.9%) of the carriers were male in this study, because two female carriers refused to participate in the study. Among these beta thalassaemia carriers 50% are above 20.5 years and the remaining were below 20.5 years. 53% of respondents were having education level at below higher secondary education and the rest of 47% were having a secondary education or university education. 64.7% of respondents answered that their family monthly income was below 10220.59 Maldivian Rufiyaa (MRF) and 35.3% were above MFR10220.59. 32.4% of the respondents were single; while 67% of the respondents were having partners either boyfriend or girlfriend. (Table 4.1)

Table 4.1 Frequency and percentage of respondents by socio-demographic characteristics, educational level, family income and relationship status.

Variable	Frequency N=34	Percent (%)
Age		
< Median	17	50
> Median	17	50
Median age = 20.5 years		
Sex		
Female	15	44.1
Male	19	55.9
Education Level		
Primary education	2	5.9
Secondary education	16	47.1
Higher secondary	8	23.5
University education	8	23.5

Table 4.1, continued.

Family income

High	12	35.3
Low	22	64.7

Mean = MRF10220.59 Minimum = MRF5000 Maximum = MVR20000

Relationship status

Single	11	32.4
Partner	23	67

Table 4.2 shows certain characteristics of the respondent's partners and their views on whether they are going to get marry if the partner is known to be a beta thalassaemia carrier. 79.4% of carriers said that they are not going to get marry with a carrier partner. Only 14.7% said that they have no problem whether their partner is a beta thalassaemia carrier or not. Those who were stated that they have a partner (n=25); 56% of their partners were screened for thalassaemia while 32% of partners where not screen and 12% of respondents don't know whether their partner is screen for thalassaemia or not. Among the screened partners, 33.3% was positive for beta thalassaemia carrier. 60% of partners got negative result in their screening tests and 6.7% don't know whether their partner was negative or positive for thalassaemia.

Table 4.2 Shows the frequency table of relationship characteristics of study participants.

Variable	Frequency n=34	Percent (%)
Not going to marry before partner get screen		
Yes	5	14.7
No	27	79.4
Don't know	2	5.9
No. of screened partners (n=25)		
Screened	14	56.0
Not screened	8	32.0
Don't know	3	12.0

Table 4.2, continued.

9 single respondents

No. of thalassaemia partners (n=15)

Positive	5	33.3
Negative	9	60.0
Don't know	1	6.7

9 single respondents, 8 did not screen, and one respondent don't know whether his/her partner is screened or not.

Table 4.3 demonstrates that 55.9% of the respondents had low or inadequate knowledge regarding prenatal diagnosis and medical termination of pregnancy. 52.95% of the carriers had positive attitudes towards PND & MTP, while 47.1% of carriers have negative attitude towards PND & MTP.

Table 4.3 The table shows the knowledge and attitude of respondents about PND and MTP (n=34).

Variable	Frequency n=34	Percent (%)
Knowledge level		
Adequate	15	44.1
Inadequate	19	55.9
Adequate = Scores more than 3, Inadequate = Scores less than 3		
Attitude		
Positive	18	52.9
Negative	34	47.1
Positive = Scores more than the mean score. Negative = scores less than the mean score. Mean score = 20.79, Minimum score = 9, Maximum score= 30		

Table 4.4 shows the associations between relationship characteristics and attitudes toward PND & MTP. There was no statistically significant association between attitude and relationship status whether the carrier was having a partner (boyfriend or girlfriend) or not. According to the data, there were no statistically significant associations between attitude with that of, whether the partners of the respondents were either screened for thalassaemia or not.

The attitude of the study participant those who have had screened their partners have significant association of their attitude towards PND and MTP (Chi-square test = 6.667, p-value = 0.036). There were stronger significant association between the opinions of the carriers, to marry a carrier partners (Do not marry, Going to marry, End relationship and Don't know) and their attitude towards PND and MTP. (Chi-square test = 16.914, p-value = 0.001).

Table 4.4 The associations between relationship characteristics and attitudes toward PND & MTP

Variable	Attitude				Chi-square test	p- value
	Positive		Negative			
	N	%	N	%		
Relationship status					2.555	0.110
Single	3	27.3	8	72.7		
Partner	13	56.5	10	43.5		
Partners screened (n=25)					4.109	0.128
Yes	9	64.3	5	35.7		
No	4	50	4	50		
Don't know	0	00	3	100		
Result of partners' screening test (n=15)					6.667	0.036*
Positive	5	100	0	0.0		
Negative	3	33.3	6	66.7		
Don't know	1	100	0	00		
When partner is a carrier (n=34)					16.914	0.001*
Do not marry	1	12.5	7	87.5		
Going to marry	10	100	0	0.0		
End relationship	3	27.3	8	72.7		
Don't know	2	40.0	3	60.0		

* Significance level p-value <0.05

Table 4.5 shows the factors which may have a relationship with attitude towards PND and MTP, these factors involves; socio-demographic factors such as family income, education level and knowledge. However, only two factors (level of education and knowledge) were known to have significant association in this study. Results showed that, there is significant relationship between educational level of carriers and attitude towards PND and MTP with a p-value of 0.024. Results also showed that the knowledge about PND and MTP among the study participants were had a greater statistically significant association between attitude towards PND and MTP, than the other factors (Chi-square test = 11.691, p-value = 0.001).

Table 4.5 The associations between socio-demographic characteristics and knowledge, and attitudes toward PND & MTP

Variable	Attitude				Chi-square test	p- value
	Positive		Negative			
	N	%	n	%		
Age (yrs.)					1.889	0.169
<Median	6	35.3	11	64.7		
>Median	10	58.8	7	41.2		
*Median Age = 20.5 years						
Sex					0.537	0.464
Male	10	52.6	9	47.47		
Female	6	40	9	60		
Education Level					5.107	0.024*
Below higher secondary	5	29.4	12	70.6		
Above higher secondary	11	68.8	5	31.3		
Family income					0.064	0.800
High income	6	50	6	50		
Low income	10	45.5	12	54.5		
High income = More than the mean income, Low income = Less than the mean income Mean income = MFR10220.59, Minimum = MVR5000, Maximum = MVR20000						
Relationship status					2.555	0.110
Single	3	27.3	8	72.7		

Table 4.5, continued.

Partner	13	56.5	10	43.5		
Knowledge level					11.691	0.001*
Adequate	12	80	3	20		
Inadequate	4	21.1	15	78.94		

* Significance level p-value <0.05

CHAPTER 5

DISCUSSION AND CONCLUSION

5.1 Summary of Main Findings

Respondents' attitudes towards prenatal diagnosis and termination of pregnancy are influenced by various factors, such as level of education, relationship characteristics and knowledge. Though there was no statistically significant association between attitude and relationship status, whether the carrier was having a partner (boyfriend or girlfriend) or not, the results showed certain characteristics of the respondent's partners and their views have a significant association with their attitude. The attitude of the study participant those who have had screened their partners have a significant association of their attitude towards PND and MTP (Chi-square test = 6.667, p-value = 0.036). There were also a strong significant association between the opinions of the carriers, to marry an another carrier partners (Do not marry, Going to marry, End relationship and Don't know) and their attitude towards PND and MTP, at p-value 0.001 (Chi-square test = 16.914)

Majority of the respondents in this study were not having an adequate knowledge regarding PND and MTP, making up of 55.9% of the total number of respondents and the remaining 44.1% were having an adequate knowledge about PND and MTP. Among the study participants those who have an adequate knowledge about PND and MTP; 80% of them were having a positive attitude while only 20% said they had a negative attitude. Among the people who do not have an adequate knowledge regarding PND and MTP; 78% have negative attitude while only 21.1% have a positive attitude. Results also showed that the knowledge about PND and MTP among the study participants has had a greater statistically significant association (Chi-square test = 11.691, p-value = 0.001) between attitude towards PND and MTP, than the other remaining factors.

There was a significant association between knowledge and attitudes towards PND and MTP with p-value 0.001 and Chi-square test = 11.691 It was similar to the study previously done by three Iranian researchers in 2009, which showed that the people those who had proper knowledge would have a positive attitude towards PND and MTP (Arif, Fayyaz, & Hamid, 2009).

5.2 Discussion

Majority of the respondents among the study participants were male (55.9%), may be due to refusal from some of the eligible female study participants. Among the study participants, 50% are above 20.5 years of age. Due to unable to get opportunity for higher secondary education, most of the study participants were having their education level at below higher secondary education. And at present, the higher secondary educations are not obtainable in the island school. 53% of the respondents were having education level at below higher secondary education and the remaining 47% were having a secondary education or above. There are less number of people working in the public service sector such as civil service and utility services. As most of the people in the island were carpenters, the main source of income comes from boat building projects which include fishing vessels and safari boats building projects. The income from tourism and fishing industry also contributes a percentile of the total income of the island. 7% of respondents said that their monthly average income for family was below 10220.59 Maldivian Rufiyaa (MRF) and 35.3% were above MFR10220.59. The most of the families depend on the fathers' income, there very few working mother in island.

Maldives defines its minor age below eighteen and couples can marry after the age of eighteen, due to this reason most of the Maldivian adolescents have either boyfriend or girlfriend at this age. Among the study participants 32.4% of the respondents were single; while 67% of the respondents were having partners either boyfriend of girlfriend.

The study result revealed that certain characteristics of the respondent's partners and their views on whether they are going to get marry if the partner is known to be a beta thalassaemia carrier. As mentioned in the literature, the thalassaemia prevention program in the Maldives focuses on discouraging the marriage of carriers to one another. As a result most of the carriers do not want to get married with a carrier. 79.4% of carriers said that they are not going to get marry with a carrier partner. Only 14.7% said that they have no problem whether their partner is a beta thalassaemia carrier or not. Due to increase in public awareness about the risk and consequences of having a carrier to carrier marriage, most of the couples get screened before marriage (National Thalassemai Center, 2012). Those who were stated that they have a partner (n=25), 56% of their partners were screened for thalassaemia whilst 32% of partners where not screen and 12% of respondents don't know whether their partner is screen for thalassaemia or not. Among the screened partners, 33.3% was positive for beta thalassaemia carrier. 60% of partners got negative result in their screening tests and 6.7%

don't know whether their partner was negative or positive. The numbers of screened partners were high may due to previous public awareness programs. But still 32% does not have yet screen, a higher percentage of these couples may end up with their partner before screening. There should be an alternative option for those who have decided to marry with a carrier partners.

The results demonstrated that 55.9% of the respondents had low or inadequate knowledge regarding prenatal diagnosis and medical termination of pregnancy. Most of the carriers in the island were not having an enough knowledge regarding PND and MTP. And majority of the carriers were having positive attitude towards PND and MTP, indicating that the 52.95% of the carriers had positive attitudes towards PND & MTP, while 47.1% of carriers have negative attitude towards PND & MTP.

The associations between relationship characteristics and attitudes toward PND & MTP showed that there were associations between some of these characters. There was no statistically significant association between attitude and relationship status whether the carrier was having a partner (boyfriend or girlfriend) or not. According to the data, there were no statistically significant associations between attitude with that of, whether the partners of the respondents were either screened for thalassemia or not. The attitude of the study participant those who have had screened their partners have significant association of their attitude towards PND and MTP (Chi-square test = 6.667, p-value = 0.036). There were strong significant statistical association between the opinions of the carriers, to marry a carrier partners (Do not marry, Going to marry, End relationship and Don't know) and their attitude towards PND and MTP. (Chi-square test = 16.914, p-value = 0.001).

The factors which had a relationship with attitude towards PND and MTP includes; education level and knowledge. However, there were no association with the family income and attitude. Knowledge and level of education were known to have significant association with attitude in the study result. Results showed that, there is significant relationship between educational level of carriers and attitude towards PND and MTP with a p-value of 0.024. As the American researche Ted Jelen stated that those who have had completed a higher level of education were having a positive attitude towards MTP. While the negative attitude toward PND and MTP were high among uneducated people (Jelen, 2001). The results also showed that the knowledge about PND and MTP among the study participants has had a greater statistically significant association between attitude towards PND and MTP, than the other factors (Chi-square test = 11.691, p-value = 0.001), as similar the result found by two Saudi researchers

(Alsulaiman & Hewison, 2006), and Iranian researchers (Ghasemi, Ayatollahi, & Masaddegh, 2007). The research conducted by Environics Research group in Canada also had revealed parallel findings (Environics Research Group, 2006).

In conclusion, majority of the carriers were not having adequate knowledge on PND and MTP in the island, may be because there were no enough public awareness programs regarding PND and MTP. Among these carriers, large number (55.9%) of the carriers had poor knowledge, while 44.1% of the carrier had adequate knowledge. Due to poor knowledge among the carriers, most of them were having negative attitudes toward PND and MTP. As hypothesized, there were statistically significant association between the level of knowledge and attitude toward prenatal diagnosis and medical termination of pregnancy among beta thalassaemia carriers in Sh. Bilehfahi. Therefore, this study proves that knowledge is important to promote positive attitudes towards PND and MTP among beta thalassaemia carriers in the island. The knowledge about PND and MTP should increase in order to promote the positive attitude towards PND and MTP among the beta thalassaemia carriers.

5.3 Implication

Based on the findings of this study, it is suggested that public awareness programs regarding PND and MTP are highly needed to improve the knowledge in order to promote positive attitudes towards PND and MTP among beta thalassaemia carriers in Sh. Bilehfahi. PND and MTP should be encouraged at national level, to mitigate the growing negative influencing factors which lead to develop a negative attitude towards PND and MTP among beta thalassaemia carrier in Sh. Bilehfahi and other island communities in Maldives. A nationwide public awareness programs regarding PND and MTP are highly recommended.

5.4 Limitations of the Study

A limitation of this study includes that small sample population. In a descriptive cross-sectional quantitative study there should be enough quantitative data to be statistically analyzed in order to provide meaningful results. The quantitative data which was analyzed in this study may not be very meaningful while the sample population is too small.

The enumerators who conducted the interview for the study were selected from the same island. hence this is a small island where everyone knows each other, the respondents may

hesitate to give correct answers for every questions especially the questions asked regarding their relationship status and information about the partner(boyfriend/girlfriend), therefore some of these questions may not be correct.

5.5 Directions for Future Research

The evidence suggests that the knowledge, education level and certain relationship characteristics had statically significant association between attitudes toward PND and MTP among the beta thalassaemia carriers in the island. Therefore, the knowledge level is not the only factors that influence the attitude of the carriers toward PND & MTP. Further investigation about factors associated with attitudes toward PND & MTP is recommended.

There are several social and behavioral factors which were not assess in this study may also have significant association with attitude towards PND and MTP. Some other factors which might influence PND and MTP were not included in this study such as how people think about premarital sex and their sexual behavior. The people who think that premarital sex is morally acceptable are very likely to have positive attitude towards PND and selective abortion (de Silva, et al., 2008).

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APPENDICES

APPENDIX - A

Questionnaire - Prenatal Diagnosis and Selective Abortion

General Information (Part A)	
1. What is your age?..... (In years)	2. Sex? <input type="checkbox"/> Female <input type="checkbox"/> Male
3. What is the highest level of education you have finished? <input type="checkbox"/> Primary school <input type="checkbox"/> Secondary education <input type="checkbox"/> High secondary <input type="checkbox"/> University education	
4. Average Family income (Monthly)..... (in Rf) (Mothers' incom + Fathers' incom Only)	5. Current relationship status? <input type="checkbox"/> Single → go to question 8 <input type="checkbox"/> Partner
6. Did your partner screened for thalassaemia? <input type="checkbox"/> Yes <input type="checkbox"/> No → go to question 8 <input type="checkbox"/> Don't know → go to question 8	
7. Is he/she positive for thalassaemia carrier? <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know	
8. Are going to marry your partner before he/she gets screened for thalassaemia? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know	
9. What you're going to do while your partner is positive for thalassaemia carrier? <input type="checkbox"/> Continue the relationship but not going to marry him/her <input type="checkbox"/> End the relationship <input type="checkbox"/> Continue the relationship and going to marry him/her <input type="checkbox"/> Don't know	
Knowledge regarding PND and MTP (Part B)	
Select the correct and incorrect statements based on your knowledge.	
1. There are number of prenatal tests to find out if an unborn baby has an inherited a genetic defect of thalassaemia major. <input type="checkbox"/> Correct <input type="checkbox"/> Incorrect <input type="checkbox"/> Don't know	
2. A safe and reliable prenatal test can be done to diagnose Thalassaemia Major in a fetus. <input type="checkbox"/> Correct <input type="checkbox"/> Incorrect <input type="checkbox"/> Don't know	
3. There are three types prenatal diagnostic test for thalassaemia. <input type="checkbox"/> Correct <input type="checkbox"/> Incorrect <input type="checkbox"/> Don't know	
4. The sample that is being tested in prenatal diagnostic test for thalassaemia is not taken from any part of the baby's body. <input type="checkbox"/> Correct <input type="checkbox"/> Incorrect <input type="checkbox"/> Don't know	
5. The prenatal diagnostic tests for thalassaemia are having 50 - 60% risk of miscarriage as a result of having the procedure done. <input type="checkbox"/> Correct <input type="checkbox"/> Incorrect <input type="checkbox"/> Don't know	
6. Medical termination of pregnancy can not be undertaken safely, if the child is affected with thalassaemia major. <input type="checkbox"/> Correct <input type="checkbox"/> Incorrect <input type="checkbox"/> Don't know	
7. Prenatal diagnostic tests can be done as early as 10weeks after conception has been developed. <input type="checkbox"/> Correct <input type="checkbox"/> Incorrect <input type="checkbox"/> Don't know	
Attitude towards PND and MTP (Part C)	
What is your opinion regarding the following statements?	
1. MTP (Medical termination of pregnancy) should not be done in any circumstance even if the unborn child is affected with thalassaemia major. <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree	
2. Thalassaemia couples in Maldives would accept and support PND & MTP services. <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree	
3. PND and MTP service should be available in Maldives for all thalassaemia couples at affordable cost. <input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree	

APPENDIX – A (Questionnaire), continued.

4. *It is forbidden religiously for Muslims to have PND & MTP for thalassemia major fetus.*

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

5. *PND & MTP services are not applicable for Maldivian societies.*

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

6. *PND & MTP intervention strategy for thalassaemia major would be long-term cost-effective than as its cost for lifelong treatment (blood transfusion and iron chelation therapy) on ill child or bone marrow transplantation.*

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

APPENDIX – B

MALDIVES NATIONAL UNIVERSITY
FACULTY OF HEALTH SCIENCES

CONSENT FORM

Factors affecting attitudes toward prenatal diagnosis and medical termination of pregnancy among beta thalassaemia carriers in Sh. Bilehfahi.

Introduction

You are asking to participate in research study conducted by Mr. Ishaam Abdul Azeez, a student of Maldives national University.

Purpose of the research

Identify the association between attitude and knowledge of prenatal diagnosis and selective abortion among the beta thalassaemia carriers in Sh. Bilehfahi.

Voluntary Participation

If you volunteer to participate in this study, we would ask you to do the following things:

If you participate in this study you will be ask to provide information regarding current relationship status, family income, level of education, knowledge regarding PND & MTP and you're attitude towards it. Furthermore, you will be it includes information about your boyfriend/girlfriend as well as your marriage preference for beta thalassaemia carrier. To complete questionnaire, around 20 minutes will be taken.

To ensure confidentiality you will be assigned the Study ID number. As a part of this study we will also access routinely collected personal and other necessary information.

Risks

You participation in this evaluation have no risk. In this study, we maintain strictly control of all the data. The Study Id is used to minimize risk.

Benefits

This study will help to determine the factors affecting the attitudes toward PND and MTP among beta thalassaemia carriers in the island. This study will provide important information to plan health promotion programs to promote positive attitude toward PND and MTP among the beta thalassaemia carriers in the island.

Consent form, continued.

Confidentiality

The information that you shared will keep as confidential until up-to complete this research project. After completion the project the questionnaires will be discarded.

Right to Refuse or Withdraw

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the Maldives national University’s Board of Ethical Consideration. If you have questions regarding your rights as a research participant, contact: **Ishaam Abdul Azeez. Phone: 7796934**

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of enumerator _____

Date _____

Day/month/year