A Study on Knowledge, Perception and Attitude Towards Premarital Carrier Screening (PMCS) Among Students Attending Universities

A Dissertation Submitted to The Department of Pharmacy, East West University, Bangladesh, in Partial Fulfillment of The Requirements for The Degree of Bachelor of Pharmacy

Submitted By

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DECLARATION BY THE RESEARCH CANDIDATE

I, Sadia Noor Mithila, ID: 2014-1-70-007, hereby declare that the dissertation entitled **"A Study on knowledge, perception and attitude towards premarital carrier screening (PMCS) among students attending universities''** submitted to the Department of Pharmacy, East West University, in the partial fulfillment of the requirement for the degree of Bachelor of Pharmacy (Honors) is a genuine & authentic research work carried out by me under the supervision and guidance of Nishat Nasrin, Assistant Professor, Department of Pharmacy, East West University, Dhaka. The contents of this dissertation, in full or in parts, have not been submitted to any other institute or University for the award of any degree or Diploma of Fellowship.

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CERTIFICATION BY THE SUPERVISOR

This is to certify that the dissertation, entitled **"A Study on knowledge, perception and attitude towards premarital carrier screening (PMCS) among students attending universities''** is a bonafide research work done by Sadia Noor Mithila, ID: 2014-1-70-007, submitted to the Department of Pharmacy, East West University for the partial fulfillment of the requirement for the award of the degree Bachelor of Pharmacy is a bonafide record of original and genuine research work carried out by Sadia Noor Mithila, ID: 2014-1-70-007, in 2017 under the supervision and guidance of me.

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Dedication

This Research Paper is Dedicated to My Beloved Parents and

My Two Precious Nephews – **Farzad** and **Azraf**

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Abstract

The purpose of the study was to explore the knowledge, perception and attitude of university students of Bangladesh, regarding the concept of premarital carrier screening (PMCS). The study was conducted at different universities inside Dhaka City and near Dhaka City through a self-administered questionnaire which was distributed to 513 university going students aged 15 – 30 years. We found that, the majority of the participants (66.47%) had never heard about PMCS. After giving a brief knowledge about PMCS, mostly there was positive attitude toward the program. Almost 90.05% believed that PMCS was necessary and about 61.99% supported the view of making PMCS compulsory. But approximately one fifth (18.52%) of the participants reported that they were totally unwilling to conduct PMCS mostly because of lack of knowledge (50.51%). Overall, despite the relatively low level of knowledge about PMCS, around half of the participants (47.17%) were still willing to conduct premarital carrier screening. Such attitude calls for immediate need for community-based campaigns, Government and non-Government programs to encourage the public to educate people regarding the concept of premarital carrier screening and health issues and to encourage them to do premarital carrier screening tests.

Key Words: Premarital carrier screening, Consanguinity, Genetic disorders, Sexually transmitted disease.

Chapter 1

Introduction

1.1 Overview

In recent years the rate of genetic disorders and sickle cell diseases has increased. Among inherited genetic diseases, thalassemia and haemoglobinopathies are common and cause significant morbidity and mortality and impose a heavy financial burden on the society. Despite that hereditary diseases are widespread due to high rates of consanguineous (blood related) marriages, research regarding community awareness towards premarital carrier screening in our country is scarce. There are so many factors influencing the consanguineous marriages to occur in a high rate, specially, in the rural areas. Most of the people are ignorant of the health parameters and consequences regarding consanguinity and child birth. It is assumed that many genetic disorders that can be prevented if consanguineous marriages can be prevented or the population can be made aware of the risk factors.

Al Sulaiman *et al*, (2008) defined Premarital Screening (PMS) as a panel of tests in which couples that are going to get married are tested for genetic, infectious and blood transmitted diseases to prevent any risk of transmitting any disease to their children. The premarital carrier screening can contribute to lower the rate of consanguinity according to Bittles (2001) which is usually defined as a union between two individuals who are related as second cousins or closer. It can also help to reduce genetic and sexually transmitted diseases (STDs). But may be the barriers of religion, privacy concern, high expenses, society, lack of knowledge and awareness, unavailability of premarital carrier screening tests as packages in different Government and private hospitals are some of the reasons for the rareness of premarital carrier screening in many developing and even in developed countries.

1.2 Gene

Genes can be defined by classical genetic analysis (e.g. complementation analysis) of mutant phenotypes. Most such mutation-defined genes affect the function of a single protein. However, some mutations affect several proteins simultaneously, and some mutations affect only one of two related proteins encoded in the same region of DNA (Lodish, 2000).

Genes are special segments of DNA letters that, when read correctly by the body's proteins, can provide a specific and important instruction for the body to function properly. Researchers estimate that there are about 22,000 genes contained in the genome. Although genes are very important,

they make up only a small percentage of all of the DNA in the genome. Each gene has a specific location on one of our 23 chromosomes and is inherited, or passed down, from generation to generation as a unit. We have two copies of each chromosome and, thus, two copies of each gene. One copy is inherited from each of our parents and, in turn, pass on one of our two copies to each of our children. Each gene contains a specific set of instructions for the body. Some genes contain multiple sets of instructions. Usually these instructions make a protein. There are many different types of proteins in our bodies which can perform multiple important tasks. For example, proteins form the basis of our organ tissues, bones, and nervous system. They also guide how we digest food and medications (Illumina, 2017).

1.3 Genetic Disorders

Genetic diseases are hereditary in nature. Deoxyribonucleic Acid (DNA) is responsible for heredity in humans. DNA characteristically condenses to form chromosomes. There are 46 chromosomes in the nucleus of human cells arranged in 23 pairs. Each of the pairs consists of a chromosome of paternal origin and one of maternal origin. Each chromosome is made up of genes. Gene or set of genes control traits. The presence of defective gene in either parent and the probability of its transmission to the children can only be accessed through genetic testing. Therefore, information about couple's predisposition to certain disease and the likelihood of passing on those diseases to their unborn children is necessary before marriage is consummated (Odelola, 2013).

Although genetic factors play a part in nearly all health conditions and characteristics, there are some conditions in which the genetic changes are almost exclusively responsible for causing the condition. These are called genetic disorders, or inherited diseases (Illumina, 2017).

A genetic disorder is a disease caused in whole or in part by a change in the DNA sequence away from the normal sequence. Genetic disorders can be caused by a mutation in one gene (monogenic disorder), by mutations in multiple genes (multifactorial inheritance disorder), by a combination of gene mutations and environmental factors, or by damage to chromosomes (changes in the number or structure of entire chromosomes, the structures that carry genes). As the secrets of the human genome were unlocked (the complete set of human genes), it is learnt that nearly all diseases have a genetic component. Some diseases are caused by mutations that are inherited from

the parents and are present in an individual at birth, like sickle cell disease. Other diseases are caused by acquired mutations in a gene or group of genes that occur during a person's life. Such mutations are not inherited from a parent, but occur either randomly or due to some environmental exposure (such as cigarette smoke). These include many cancers, as well as some forms of neurofibromatosis (National Human Genome Research Institute, 2015).

Genetic disorders typically involve the inheritance of a particular mutated disease-causing gene, such as sickle cell disease, cystic fibrosis, and Tay-Sachs disease. The mutated gene is passed down through a family, and each generation of children can inherit the gene that causes the disease. Rarely, one of these monogenic diseases can occur spontaneously in a child when his/her parents do not have the disease gene, or there is no history of the disease in the family. This can result from a new mutation occurring in the egg or sperm that gave rise to that child. Most genetic disorders, however, are "multifactorial inheritance disorders" meaning they are caused by a combination of inherited mutations in multiple genes, often acting together with environmental factors. Examples of such diseases include many commonly-occurring diseases, such as heart disease and diabetes, which are present in many people in different populations around the world. Research on the human genome has shown that although many commonly occurring diseases are usually caused by inheritance of mutations in multiple genes at once, such common diseases can also be caused by rare hereditary mutations in a single gene. In these cases, gene mutations that cause or strongly predispose a person to these diseases run in a family, and can significantly increase each family member's risk of developing the disease. One example is breast cancer, where inheritance of a mutated BRCA1 or BRCA2 gene confers significant risk of developing the disease (National Human Genome Research Institute, 2015).

The genetics of each disorder are unique. In some cases, all the mistakes in a particular gene cause one specific genetic disorder. In other cases, different changes within the same gene can lead to different health or developmental problems or even to different genetic disorders. Sometimes changes in several similar genes may all lead to the same genetic disorder (Illumina, 2017).

1.4 Categories of Genetic Disorders

1.4.1 Monogenetic Disorders

Monogenetic disorders are caused by a mutation in a single gene. Single gene inheritance, also called Mendelian or monogenetic inheritance. The mutation may be present on one or both chromosomes (one chromosome inherited from each parent). Examples of monogenic disorders are: sickle cell disease, cystic fibrosis, polycystic kidney disease, hemochromatosis, Marfan syndrome, Huntington's disease and Tay-Sachs disease. Monogenic disorders are relatively rare in comparison with more commonly-occurring diseases, such as diabetes and heart disease. Single-gene disorders are inherited in recognizable patterns: autosomal dominant, autosomal recessive, and X-linked. A major distinction among monogenic disorders is between "dominant" and "recessive" diseases. Dominant diseases are caused by the presence of the disease gene on just one of the two inherited parental chromosomes. In dominant diseases, the chance of a child inheriting the disease is 50 percent. In a family situation, for example, if the parents have four children, it may be possible that two of those children inherit the disease gene. Examples of dominant diseases are Huntington's disease and Marfan syndrome. Recessive diseases require the presence of the disease gene on both of the inherited parental chromosomes. In this case, the chance of a child inheriting a recessive disease is 25 percent. In the family example, if the parents have four children, it may be more likely that only one child will develop the disease. Examples of recessive diseases include cystic fibrosis and Tay-Sachs disease (National Human Genome Research Institute, 2015).

1.4.2 Multifactorial Inheritance Disorders

Multifactorial inheritance disorders are caused by a combination of small inherited variations in genes, often acting together with environmental factors. Multifactorial inheritance, which is also called complex or polygenic inheritance. For example, different genes that influence breast cancer susceptibility have been found on chromosomes 6, 11, 13, 14, 15, 17, and 22. Some common chronic diseases are multifactorial disorders. Heart disease, diabetes, and most cancers are examples of such disorders. Behaviors are also multifactorial, involving multiple genes that are affected by a variety of other factors. Researchers are learning more about the genetic contribution to behavioral disorders such as alcoholism, obesity, mental illness and Alzheimer's

disease. Multifactorial inheritance also is associated with heritable traits such as fingerprint patterns, height, eye color, and skin color (Stoppler, 2016).

1.4.3 Chromosome Disorders

Chromosome disorders are caused by an excess or deficiency of the genes that are located on chromosomes, or by structural changes within chromosomes (National Human Genome Research Institute, 2015).

Chromosomes, distinct structures made up of DNA and protein, are located in the nucleus of each cell. Because chromosomes are the carriers of the genetic material, abnormalities in chromosome number or structure can result in disease. Abnormalities in chromosomes typically occur due to a problem with cell division. For example, Down syndrome (sometimes referred to as "Down's syndrome") or trisomy 21 is a common disorder that occurs when a person has three copies of chromosome 21, although no individual gene on the chromosome is abnormal (Stoppler, 2016).

Prader-Willi syndrome, on the other hand, is caused by the absence or non-expression of a group of genes on chromosome 15. A specific form of blood cancer (chronic myeloid leukemia, CML) may be caused by a chromosomal translocation, in which portions of two chromosomes (chromosomes 9 and 22) are exchanged. No chromosomal material is gained or lost, but a new, abnormal gene is formed that leads to formation of cancer (National Human Genome Research Institute, 2015).

There are many other chromosome abnormalities including:

- ✓ Turner syndrome (45, X0),
- ✓ Klinefelter syndrome (47, XXY), and
- ✓ Cri du chat syndrome, or the "cry of the cat" syndrome (46, XX or XY, 5p-).

Diseases may also occur because of chromosomal translocation in which portions of two chromosomes are exchanged (Stoppler, 2016).

1.5 Inheritance of Genetic Disease

Genetic disorders are typically inherited (passed down) in either a dominant or recessive manner. Each person has two copies of every gene on our 22 numbered chromosomes. In addition, females have two copies of all the genes on the X chromosome, whereas males have one copy of the X chromosome genes and one copy of the Y chromosome genes. When a disorder is dominant, the disease can occur when there are DNA mistakes in only one of the two gene copies. This means that if a parent has the DNA change, there is a 50-50 chance that it will be passed on to each child. When a disorder is recessive, there must be mistakes in both copies of the gene for the disorder to occur. This means that both parents must carry at least one copy of the specific gene change in order to produce an affected child. If both parents have one changed copy, there is a 1 in 4, or 25% chance, that a child may inherit both changed copies at the same time, causing the disorder in the child. Parents who have only one changed gene copy usually do not display any symptoms of the disorder and may not even know they carry a gene change. Researchers estimate that each person has ("carry") 6-10 recessive gene changes. Certain recessive gene changes may be more common in different population groups. For example, sickle cell gene changes are found more often in individuals with West African ancestry and cystic fibrosis gene changes are more common in individuals with- North European ancestry. In addition to the inheritance pattern, some genetic disorders may be inconsistent when it comes to whether a person develops symptoms and their severity. Penetrance refers to whether the person who has the causative gene changes actually develops any symptoms of the disorder. Expressivity refers to the symptoms that may develop and their severity (Illumina, 2017).

1.6 Hemoglobinopathies

The haemoglobin disorders are a group of autosomal recessive disorders characterized by either the reduced synthesis of one or more normal globin chains (the thalassaemias), the synthesis of a structurally abnormal globin chain (the haemoglobin variants) or in a few cases by both phenotypes (the reduced synthesis of a Hb variant, e.g. Hb E). They are the commonest single-gene disorders known and approximately 1000 different mutant alleles have now been characterized at the molecular level. The mutations are regionally specific, with each country having its own unique

spectrum of abnormal haemoglobins and thalassaemia mutations, and can occur at high gene frequencies in some ethnic groups (Weatherall & Clegg, 2001).

Haemoglobin comprises four globin chains: fetal haemoglobin (Hb F) has two α and two gamma chains (α2γ2) and adult haemoglobin (Hb A) has two α and two β chains (α2β2). Genes in the α-globin and β-globin gene clusters (on chromosomes 16 and 11) control globin-chain production. Due to spontaneous mutation, haemoglobin gene variants are present at low prevalence (carriers 1–1.5/1000) in all sizeable populations (Modell & Darlison, 2008).

1.6.1 Thalassemia

Almost 60–80 million people in the world are carriers of beta thalassemia trait. The major forms of thalassemia include thalassemia minor and thalassemia major. Individuals who have a defect in only one of their β-globin genes usually develop non-life-threatening thalassemia minor. This disease only causes mild anemia which usually does not require any treatment. But both parents who are positive for thalassemia minor trait usually give birth to off springs with thalassemia major. An individual having both genes (encoding for b-subunit) affected, usually develops beta thalassemia major. In such patients, severe anemic condition arises at few months of age, and bone marrow cavities get increased due to the overburden of hemoglobin production. This situation leads to abnormalities in bones especially in facial bones. In such individuals, abnormal hemoglobins are formed, which are unable to transport oxygen efficiently. These are termed as unstable hemoglobins which are dangerous for body because bone marrow, liver and spleen undergo stress. Due to extra pressure exerted on spleen for the eradication of abnormal blood cells from human blood circulation, splenomegaly usually takes place. The only available hope for the continuation of patients' life is frequent blood supply. Unfortunately, due to continuous blood supply, breakdown of unhealthy blood cells and unstable hemoglobin, the level of iron increases in thalassemia patients. This iron overload leads towards therapeutic option via chelation therapy (Weatherall & Clegg, 2001).

1.6.2 Glucose-6-Phosphate Dehydrogenase Deficiency

Glucose-6-phosphate dehydrogenase deficiency is a genetic disorder that occurs almost exclusively in males. This condition mainly affects red blood cells, which carry oxygen from the

lungs to tissues throughout the body. In affected individuals, a defect in an enzyme called glucose-6-phosphate dehydrogenase causes red blood cells to break down prematurely. This destruction of red blood cells is called hemolysis. The most common medical problem associated with glucose-6-phosphate dehydrogenase deficiency is hemolytic anemia, which occurs when red blood cells are destroyed faster than the body can replace them. This type of anemia leads to paleness, yellowing of the skin and whites of the eyes (jaundice), dark urine, fatigue, shortness of breath, and a rapid heart rate. In people with glucose-6-phosphate dehydrogenase deficiency, hemolytic anemia is most often triggered by bacterial or viral infections or by certain drugs (such as some antibiotics and medications used to treat malaria). Hemolytic anemia can also occur after eating fava beans or inhaling pollen from fava plants (a reaction called favism). Glucose-6-phosphate dehydrogenase deficiency is also a significant cause of mild to severe jaundice in newborns. Many people with this disorder, however, never experience any signs or symptoms and are unaware that they have the condition (Genetics Home Reference, 2017).

1.6.3 Sickle-Cell Disorders

Sickle-cell anemia is a blood related disorder that affects the haemoglobin molecule, and causes the entire blood cell to change shape under stressed conditions. In sickle cell anaemia, the haemoglobin molecule is defective. After haemoglobin molecules give up their oxygen, some may cluster together and form long, rod-like structures which become stiff and assume sickle shape. Unlike healthy red blood cells, which are usually smooth and donut-shaped, sickled red blood cells cannot squeeze through small blood vessels. Instead, they stack up and cause blockages that deprive organs and tissues of oxygen-carrying blood. This process produces periodic episodes of pain and ultimately can damage tissues and vital organs and lead to other serious medical problems. Normal red blood cells live about 120 days in the bloodstream, but sickled red cells die after about 10 to 20 days. Because they cannot be replaced fast enough, the blood is chronically short of red blood cells, leading to a condition commonly referred to as anemia (Weatherall & Clegg, 2001).

1.6.4 Haemophilia

Haemophilia is a hereditary bleeding disorder, in which there is a partial or total lack of an essential blood clotting factor. It is a lifelong disorder, that results in excessive bleeding, and

many times spontaneous bleeding, which, very often , is internal. Haemophilia A is the most common form, referred to as classical haemophilia. It is the result of a deficiency in clotting factor 8, while *haemophilia* B (Christmas Disease) is a deficiency in clotting factor 9. This illness is a sex-linked recessive disorder (Weatherall & Clegg, 2001).

1.7 Global epidemiology of haemoglobin disorders

Table 1.1: Global epidemiology of haemoglobin disorders and derived service indicators (Modell & Darlison, 2008)

WHO region	Demography 2003				% of the population carrying			Affected conceptions (per 1000)			Affected births (% of under-5 mortality)
	Population (millions)	Crude birth rate	Annual births (1000s)	Under-5 mortality rate	Significant variant[a]	α^+ thalassaemia[b]	Any variant[c]	Sickle-cell disorders[d]	Thalassaemias[e]	Total	
African	586	39.0	22 895	168	18.2	41.2	44.4	10.68	0.07	10.74	6.4
American	853	19.5	16 609	27	3.0	4.8	7.5	0.49	0.06	0.54	2.0
Eastern Mediterranean	573	29.3	16 798	108	4.4	19.0	21.7	0.84	0.70	1.54	1.4
European	879	11.9	10 459	25	1.1	2.3	3.3	0.07	0.13	0.20	0.8
South-east Asian	1 564	24.4	38 139	83	6.6	44.6	45.5	0.68	0.66	1.34	1.6
Western Pacific	1 761	13.6	23 914	38	3.2	10.3	13.2	0.00	0.76	0.76	2.0
World	**6 217**	**20.7**	**128 814**	**81**	**5.2**	**20.7**	**24.0**	**2.28**	**0.46**	**2.73**	**3.4**

Hemoglobinopathies are the most frequent inherited disorders worldwide. According to the WHO, approximately 240 million people are heterozygous for inherited hemoglobinopathies, including thalassemia and sickle cell disease. Haemoglobin disorders were originally endemic in 60% of 229 countries, potentially affecting 75% of births, but are now sufficiently common in 71% of countries among 89% of births. Table 1 shows conservative prevalence estimates by WHO region. At least 5.2% of the world population (and over 7% of pregnant women) carry a significant variant. Haemoglobin S accounts for 40% of carriers but causes over 80% of disorders because of localized very high carrier prevalence: around 85% of sickle-cell disorders, and over 70% of all affected births occur in Africa. In addition, at least 20% of the world population carry α^+ thalassaemia. Around 1.1% of couples worldwide are at risk for having children with a haemoglobin disorder

and 2.7 per 1000 conceptions are affected. Prevention is making only a small impression: affected birth prevalence is estimated at 2.55 per 1000. Most affected children born in high-income countries survive with a chronic disorder, while most born in low-income countries die before the age of 5 years: haemoglobin disorders contribute the equivalent of 3.4% of mortality in children aged under 5 years worldwide or 6.4% in Africa (Modell & Darlison, 2008).

It has been reported that among the populations at risk for beta thalassemia, some similar kinds of mutations and some rare types of mutations exist. Every mutation is thought to be associated with powerful linkage disequilibrium along with definite arrangements of the restriction fragment length polymorphism within cluster of β-globin. It has been further observed that there are approximately 80% of mutations which are in association with twenty different restriction fragment length polymorphisms. This phenomenon leads to the conclusion of independent beta thalassemia originating in various populations (Olivieri, 1999; Flint *et al*, 1993).

The carrier rates of this disease are various depending upon different areas of the world. The carrier rates of thalassemia in Indian subcontinent and China, Central Asia, South Europe (also known as North Mediterranean) and Arab Region is approximately 1%–40%, 4%–10%, 1%–19% and 3%, respectively. But in Australia, North Europe, South Africa and America, the thalassemia carrier rates are very low. In Pakistan, the annual number of infants born with beta thalassemia is the highest in Eastern Mediterranean Region as compared to other parts of the world (Angastiniotis & Modell, 1998).

Almost 70,000 infants are born with *β*-thalassaemia worldwide each year and 270 million people are carriers of haemoglobinopathies. *β*-thalassaemia is most commonly present among populations in all Mediterranean countries, as well as in Southeast Asia, India, Africa, Central America and the Middle East. However, because of migration, the carrier rate of *β*-thalassaemia is increasing in countries that previously had low prevalences. *β*-thalassaemia causes severe, blood-transfusion-dependent anaemia in people who are homozygous or compound heterozygous for mutations in the *β*-globin gene (*β*-thalassaemia major). The main complication of this therapy is that frequent transfusions lead to iron overload, as humans have no mechanism to excrete excess iron. Iron overload can cause liver cirrhosis and cardiomyopathy. Iron chelation therapy is used to increase iron excretion, which prolongs the life of individuals with thalassaemia (Flint *et al*, 1993).

According to World Health Organization technical report series (1996), Sickle cell anemia affects millions throughout the world. It is particularly common among people whose ancestors come from Sub-Saharan Africa, South America, Cuba, Central America, Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece, and Italy. In the Unites States, it affects around 72,000 people, most of whose ancestors come from Africa. The disease occurs in about 1 in every 500 African-American births and 1 in every 1000 to 1400 Hispanic-American births. About 2 million Americans, or 1 in 12 African Americans, carry the sickle cell allele. Again, due to the sex-linkage of the disorder haemophilia, there is a greater prominence in males than in females. About a third of new diagnoses are where there is no previous family history. It appears world-wide and occurs in all racial groups. About 6,000 people are affected with haemophilia in the UK. There are about 5400 people in the UK with haemophilia A and about 1100 with haemophilia B (Modell & Darlison, 2008).

1.8 Sexually Transmitted Diseases

Sexually transmitted infections (STIs), also known as Sexually Transmitted Diseases (STDs), are caused by bacteria, viruses or parasites that are transmitted through unprotected sex (vaginal, anal, or oral) and skin to skin genital contact. Bacterial infections include bacterial vaginosis, chlamydia, gonorrhea, Lyphogranuloma venerum (LGV) and syphilis. Viruses cause genital herpes, Hepatitis B, Human Papillomavirus (HPV) and Human Immunodeficiency Virus (HIV). Parasites are responsible for trichomoniasis and pubic lice. STIs occur worldwide, but some infections like chancroid, LGV, and Granuloma inguinale are more common in less industrialized countries (Iamat, 2016).

1.8.1 HIV

The Human Immunodeficiency Virus (HIV) targets the immune system and weakens people's defence systems against infections and some types of cancer. As the virus destroys and impairs the function of immune cells, infected individuals gradually become immunodeficient. Immune function is typically measured by CD4 cell count. Immunodeficiency results in increased susceptibility to a wide range of infections, cancers and other diseases that people with healthy immune systems can fight off. The most advanced stage of HIV infection is Acquired

Immunodeficiency Syndrome (AIDS), which can take from 2 to 15 years to develop depending on the individual. AIDS is defined by the development of certain cancers, infections, or other severe clinical manifestations (WHO, 2016).

1.8.2 Syphilis

Syphilis is a sexually transmitted disease caused by the bacterium *Treponema pallidum* subspecies pallidum. Syphilis is divided into stages (primary, secondary, latent, and tertiary), with different signs and symptoms associated with each stage. A person with primary syphilis generally has a sore or sores at the original site of infection. These sores usually occur on or around the genitals, around the anus or in the rectum, or in or around the mouth. These sores are usually (but not always) firm, round, and painless. Symptoms of secondary syphilis include skin rash, swollen lymph nodes, and fever. The signs and symptoms of primary and secondary syphilis can be mild, and they might not be noticed. During the latent stage, there are no signs or symptoms. Tertiary syphilis is associated with severe medical problems. Syphilis can be spread by direct contact with a syphilis sore during vaginal, anal, or oral sex. It can also spread from an infected mother to her unborn baby (Centers for Disease Control and Prevention, 2017).

1.8.3 Gonorrhea

Gonorrhea, one of the common sexually transmitted diseases (STDs), is caused by a bacterium called Neisseria gonorrhoeae. Along with diseases like syphilis, chlamydia, human papillomavirus, hepatitis B, and human immunodeficiency virus (HIV), gonorrhea is spread through sexual activity. Gonorrhea can also be passed from a pregnant woman to her baby. If untreated, gonorrhea can develop into a more serious infection called pelvic inflammatory disease. Gonorrhea may not have any symptoms (Torpy, Lynm & Golub, 2013).

1.8.4 Hepatitis

Hepatitis is an inflammation of the liver. The condition can be self-limiting or can progress to fibrosis (scarring), cirrhosis or liver cancer. Hepatitis viruses are the most common cause of hepatitis in the world but other infections, toxic substances (e.g. alcohol, certain drugs), and autoimmune diseases can also cause hepatitis. There are 5 main hepatitis viruses, referred to as

types A, B, C, D and E. These 5 types are of greatest concern because of the burden of illness and death they cause and the potential for outbreaks and epidemic spread. In particular, types B and C lead to chronic disease in hundreds of millions of people and, together, are the most common cause of liver cirrhosis and cancer. Hepatitis A and E are typically caused by ingestion of contaminated food or water. Hepatitis B, C and D usually occur as a result of parenteral contact with infected body fluids. Common modes of transmission for these viruses include receipt of contaminated blood or blood products, invasive medical procedures using contaminated equipment and for hepatitis B transmission from mother to baby at birth, from family member to child, and also by sexual contact. Acute infection may occur with limited or no symptoms, or may include symptoms such as jaundice (yellowing of the skin and eyes), dark urine, extreme fatigue, nausea, vomiting and abdominal pain (WHO, 2016).

1.9 Risks Associated with Sexual Transmitted Diseases

Travelers are at high risk of acquiring sexually transmitted diseases (STDs) if they have unprotected sex outside a monogamous relationship, engage in casual sex, or use the services of sex workers (Iamat, 2016).

Truck drivers are a recognized high-risk group for STDs and HIV. Bangladeshi women living adjacent to truck stops are at greater risk for STDs (Gibney *et al*, 2001).

In Bangladesh, there are approximately 100,000 commercial sex workers (CSWs), who are distributed in urban, semi-urban, and rural areas, either organized in brothels, or working as independent sex workers (Choudhury *et al*, 1997).

Female CSWs play an important role in the heterosexual transmission of HIV. These sex workers have been considered to be the most important reservoir of STDs and a high-risk population for STDs and HIV. An etiological study of STIs was conducted by Rahman *et al* (2000) among female sex workers in Dhaka, Bangladesh; 84% were positive for STI pathogens (D'Costa *et al*, 1985).

STDs are a major public health problem in developing countries, including Bangladesh. The prevalence of reproductive tract infections (RTIs) and STDs among females in the general population and among street female sex workers (SFSWs) in Bangladesh is not well documented.

In a cross-sectional study among slum dwellers in Dhaka city, the prevalence of gonorrhea and syphilis were observed to be 1.00% and 11.50% respectively. STDs have complex social, political, and public health implications, in addition to their medical significance. Even with the introduction of effective treatments such as penicillin for syphilis more than 60 years ago, syphilis continues to remain an important disease. STDs remain among the most common infectious diseases in developed and developing countries. STDs have become more common in recent years, partly because people are becoming sexually active at a younger age, are having multiple partners, and do not use preventive methods to lessen their chance of acquiring an STD. People can pass STDs to sexual partners even if they themselves do not have any symptoms. Frequently, STDs can be present but cause no symptoms, especially in women (for example, chlamydia, genital herpes or gonorrhea). This can also occur in some men (Stoppler, 2016).

Most STDs cause relatively harmless diseases, producing few or no symptoms. However, some produce persistent and symptomatic or minimally symptomatic disease. Some people carry the disease for days or weeks, while others carry the disease for longer periods, even for life. During this time, an infected individual or carrier can spread the disease (Centers for Disease Control and Prevention, 1999).

In many cases, sexually transmitted infections can be transmitted unknowingly because a person can be asymptomatic – does not exhibit symptoms. If left untreated, sexually transmitted infections can lead to infertility, pelvic inflammatory disease, cancer, chronic liver conditions, pregnancy complications, and birth defects (Vuylsteke, 1993).

1.10 Epidemiology of Sexual Transmitted Diseases

According to WHO (2016), HIV continues to be a major global public health issue, having claimed more than 35 million lives so far. In 2016, 1.0 million people died from HIV-related causes globally. There were approximately 36.7 million people living with HIV at the end of 2016 with 1.8 million people becoming newly infected in 2016 globally. There is no cure for HIV infection. However, effective antiretroviral (ARV) drugs can control the virus and help prevent transmission so that people with HIV, and those at substantial risk, can enjoy healthy, long and productive lives. It is estimated that currently only 70% of people with HIV know their status. The remaining 30% – or 7.5 million people – need to access HIV testing services. Between 2000 and 2016, new HIV

infections fell by 39%, and HIV-related deaths fell by one third with 13.1 million lives saved due to ART in the same period. This achievement was the result of great efforts by national HIV programmes supported by civil society and a range of development partners.

More than 1 million sexually transmitted infections (STIs) are acquired every day worldwide. Each year, there are an estimated 357 million new infections with 1 of 4 STIs: chlamydia, gonorrhoea, syphilis and trichomoniasis. More than 500 million people are estimated to have genital infection with herpes simplex virus (HSV). More than 290 million women have a human papillomavirus (HPV) infection1. The majority of STIs have no symptoms or only mild symptoms that may not be recognized as an STI. STIs such as HSV type 2 and syphilis can increase the risk of HIV acquisition. Over 900 000 pregnant women were infected with syphilis resulting in approximately 350 000 adverse birth outcomes including stillbirth in 2012. In some cases, STIs can have serious reproductive health consequences beyond the immediate impact of the infection itself (e.g., infertility or mother-to-child transmission). Drug resistance, especially for gonorrhoea, is a major threat to reducing the impact of STIs worldwide (Wijesooriya, 2012).

1.11 Consanguinity

For clinical purposes, consanguinity is usually defined as a union between two individuals who are related as second cousins or closer. However, the most common form of consanguineous marriage worldwide is between first cousins, who on average have co-inherited 1/8 of their genes from one or more common ancestors (Bittles, 2009).

To a large extent the present-day distribution pattern of consanguineous marriage matches that of adherence to the Islamic faith. But there is no prescription that Muslims should marry within the family, and first cousin marriage is freely permissible in the Jewish, Christian Protestant, Buddhist and Zoroastrian/Parsi religions (Bittles and Black, 2010a).

1.12 Existing Explanatiom of Consanguineous Marriage

The existence of consanguinity between spouses can be attributed to many causes, some of which are religious or social, and others which are primarily economic (Bittles, 1994). These are reviewed below:

1.12.1 Religion

One explanation for the popularity of consanguineous marriage is the sanction that is provided to it by some religions. In Europe, Protestant denominations permit first cousin marriage in contrast to the Roman Catholic Church which requires permission from a diocese to allow them. Judaism permits consanguineous marriage in certain situations, such as for example, uncle- niece union. Islam has also permitted some types of consanguineous marriages: for example, a Muslim man is prohibited from marrying his mother or grandmother, daughter or grand-daughter, sister, niece or great niece, aunt or great aunt. A man is also forbidden to have two wives at the same time who are related to each other by consanguinity, affinity or fosterage implying that a man cannot marry sisters. However, it is often cited that the Prophet Mohammad married his daughter Fatima to Ali, his paternal first cousin which has led researchers to argue that for Muslims first cousin marriage might be permitted in practice (Bittles, 2001; Hussain, 1999).

Overall, religion may contribute to the prevalence of consanguinity in some parts of the world, yet it is not the primary driver of this practice. The religious sanctions and prohibitions around this practice are also quite diverse, and have changed over time.

1.12.2 Social Capital

Consanguinity is often regarded as a valuable tool to strengthen economic, political and social ties between members of a single family. In other words, consanguinity builds "social capital" within a family. By uniting different descent groups under patrilineal kinship rules, it strengthens ties between family members, lowers the possibility for conflict within a family, and consolidates both assets and power. It also encourages cooperation about matters relating to production decisions, household decisions, property decisions, market work and interactions with the community. If the decision to undertake a consanguineous marriage is related to landholding and/or the desire to retain economic and political power in a local community, then the larger the group that practice. Consanguineous marriage, the more powerful the group would be in a rural society. This is reinforced if consanguinity has been practiced over many generations. Recent anecdotal evidence from the Middle East suggests that the larger the group that practices consanguineous marriage,

the greater the control over resources such as land and wealth, and thus more powerful group would be in a rural society (Kuran, 2002).

1.12.3 Marriage Costs

In some cultures, marriage payments such as dowry and brideprice are customery. A family's ability to make such payments can have significant implications for a young person;s marriage prospects. In the Middle East, for example, rising levels of brideprice together with the practice of polygamy (in which wealthy men typically have more than one wife) have had the combined effect of lowering the prospects for some men, and also increasing the average age at marriage in the overall population (Mensch, Singh & Casterline, 2005).

In South Asia, where dowries are very common if not almost universal, dowry payments are well known to influence marriage decisions. This is particularly in light of the fact that dowries have escalated over time. In situations where parents feel that they are unable to afford the cost of a wedding, marriage for the daughter may be delayed. In communities where it is permitted, marriage to a relative may also be desirable (Epstein, 1973).

1.12.4 Considerations of Inheritance

The practice of consanguinity by royalty and major landowning families has often been cited as a clear indication that it is motivated by considerations of inheritance and desire to maintain control over asset holdings (Bittles, 1994).

This argument is further bolstered by the fact that in patrilineal systems, most consanguineous marriages occur between cross cousins and not parallel cousins. By bringing individuals from outside the patriline into its fold a family ensures that its assets are consolidated, This motivation for consanguineous marriage is particularly powerful in cases where women can inherit property and where land is a significant determinant of political and economic power. In the Islamic world, arranged marriages to individuals within the kinship network have helped families circumvent mandatory Islamic sharing rules for inheritances for several hundred years. Though not as powerful as the European system of primogeniture, this system helped some families to maintain control over assets for two or even three generations (Kuran, 2002).

1.13 Global Consanguinity Trends

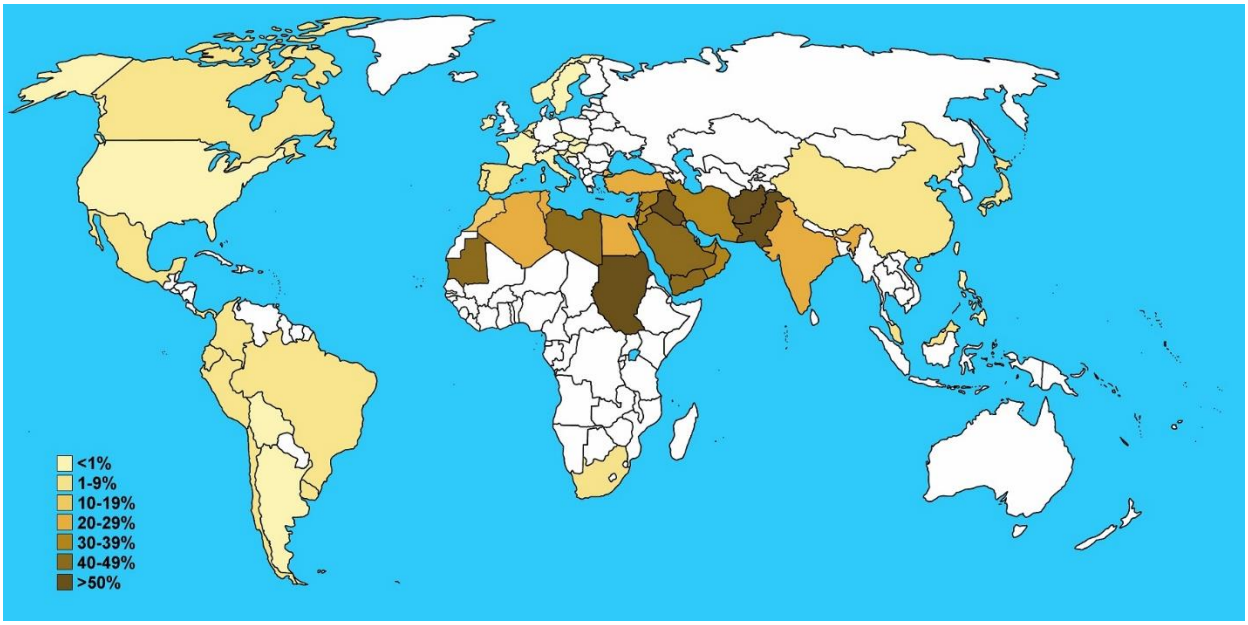

Figure 1.1: Consanguinity rate in Global Aspect (Bittles, 1990)

In populations of North Africa, West Asia and South India, consanguineous marriages are culturally and socially favored and constitute 20–50% of all marriages, with first cousin unions accounting for almost one-third of all marriages (Bittles, 2010; Tadmouri *et al*, 2009).

The prevalence of consanguinity and rates of first cousin marriage vary widely within and between populations and communities, depending on ethnicity, religion, culture and geography. Consanguineous marriages are also practiced among emigrant communities from highly consanguineous countries and regions, such as Pakistan, Turkey, North Africa and Lebanon, now resident in Europe, North America and Australia. The high consanguinity rates, coupled by the large family size in some communities, could induce the expression of autosomal recessive diseases, including very rare or new syndromes which increase the public awareness of the risks associated with consanguineous marriages. Currently, many young consanguineous couples planning to have children seek preconception genetic counseling for fear of the consequences of consanguinity on their offspring (Hamamy *et al*, 2011; Schulpen *et al*, 2006).

1.14 Consanguinity and Health Parameters

There is now considerable evidence that genetic disease and congenital malformation occur more frequently in countries with a low gross national income (GNI) per capita. There are several reasons why this might be the case, including increased rates of consanguinity and parental age, population migration, and natural selection (Christianson, 2006).

While population migration is undoubtedly the basis for the high frequency of these conditions in the richer countries, the main factors in the developing countries are consanguinity and natural selection. Consanguinity, which is known to increase the birth prevalence of autosomal recessive disease, may be acceptable to a minimum of 20% of the world's population. This practice is particularly common throughout the eastern Mediterranean, North Africa and the Indian subcontinent, and to a lesser extent in parts of South America and Sub-Saharan Africa (Bittles, 1990; Modell & Kuliev, 1989).

Health care providers and genetics specialists could consider both the negative impact of consanguineous marriage in terms of increased genetic risks to the offspring, as opposed to the potential social and economic benefits (Hamamy *et al*, 2011).

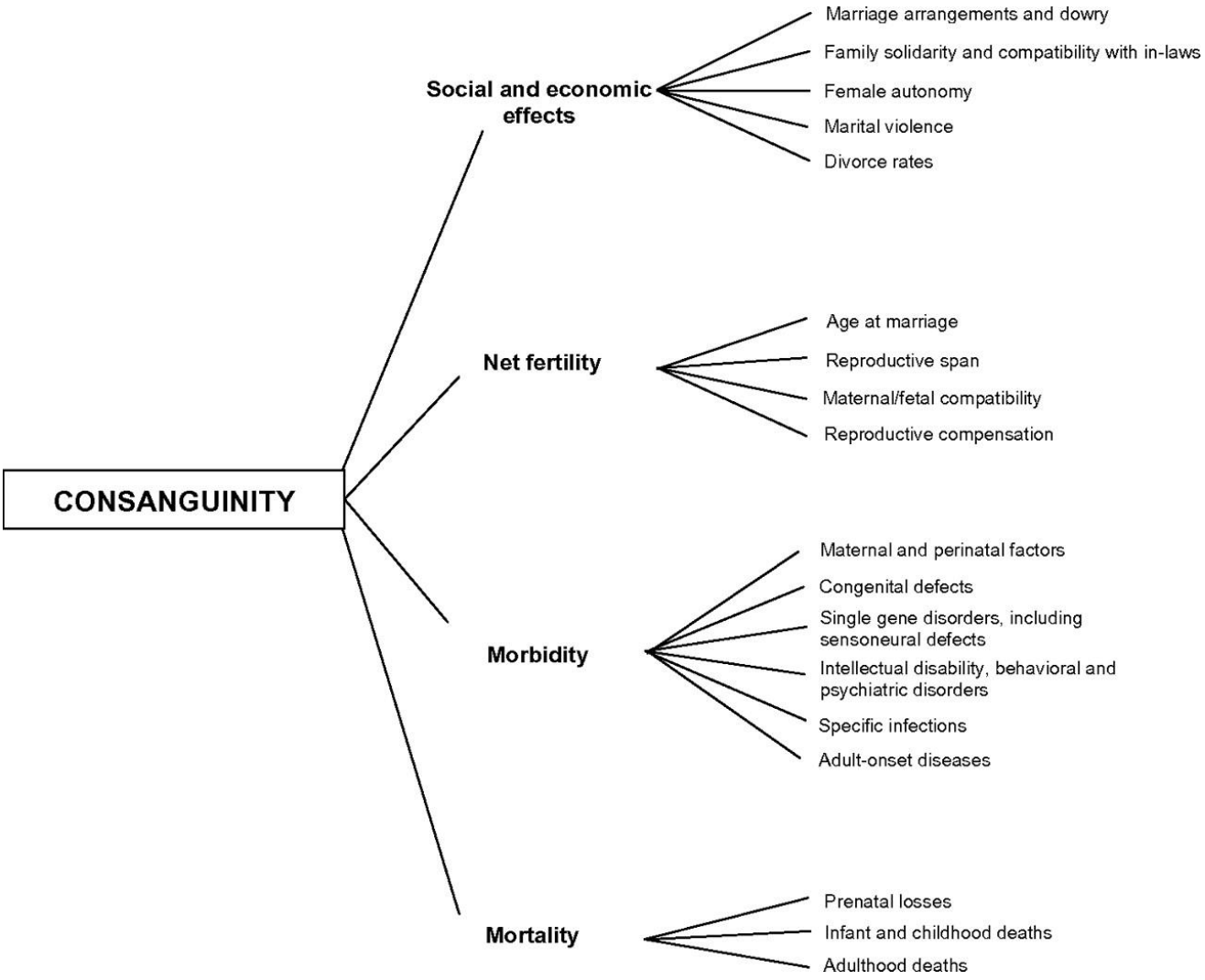

Figure 1.2: Influences of consanguinity (Bittles, 1990)

The reproductive health criteria related to consanguinity show that in first cousin marriages as opposed to nonconsanguineous marriages, fertility rate is slightly higher, abortion rate is not different, stillbirths and infant mortality rates are slightly higher and birth defects frequency is estimated to be around 2–3% points more than the background rate among newborns in the general population (around 2–3%). Furthermore, consanguineous unions lead to increased expression of autosomal recessive disorders (Bittles *et al*, 1991; Bittles & Black, 2010b; Hamamy *et al*, 2011; Tadmouri *et al*, 2009).

The offspring of consanguineous unions may be at increased risk for recessive disorders because of the expression of autosomal recessive gene mutations inherited from a common ancestor. The closer the biological relationship between parents, the greater is the probability that their offspring will inherit identical copies of one or more detrimental recessive genes. For example, first cousins are predicted to share 12.5% (1/8) of their genes. Thus, on average, their progeny will be homozygous at 6.25% (1/16) of gene loci (Bennett *et al*, 2002). In general, consanguinity does not increase the risk for autosomal dominant conditions in offspring when one of the parents is affected, nor for X-linked recessive conditions if neither parent is affected (Hamamy *et al*, 2007).

Most of the literature studying the association of Down syndrome with parental consanguinity concluded that no such association existed. The association of consanguineous marriages with late onset complex diseases such as diabetes, cardiovascular disorders, schizophrenia and cancer requires further studies to precise any existing risks because currently unambiguous evidence-based conclusions are difficult to establish (Hamamy *et al*, 2011).

In educational institutes such as schools and colleges, sex education is mostly avoided. In most of the Asian countries, marriages of couples are decided by parents. It would be a positive step if teachers would discuss the outcomes of consanguineous marriages with youngsters and their parents in order to prevent genetic abnormalities in families. Informed consent and guarantees of privacy are extremely important for the success of premarital screening programs. Premarital screening is strongly opposed by Pakistani culture and behavior of general public. For premarital screening, cultural, ethnic, religious and social issues must be resolved. Although tribal marriages are encouraged in many parts of Asia and East Mediterranean (occupied mainly by Arabs and Muslims), yet unfortunately due to inadequate knowledge, negative role of culture and poor genetic counseling, premarital screening for haemoglobinopathies, HIV, HBV and HCV for young couples is a very difficult task. It has been reported that 25%–60% of treatment of already infected patients (Waheed *et al*, 2012).

It is a well-known fact that nature has many hidden remedies against multiple disorders (cancer, cardiovascular diseases, metabolic disorders, chronic inflammation and many others). There is a strong need to discover therapeutic potentials of those natural products. It has been reported that elevated activation of various cellular proteins may cause cancer proliferation, which can be

further inhibited by potential inhibitors. But the genetic diseases such as thalassaemia are not easily treatable. The most important way to prevent such genetic disorders among families is to discourage consanguineous marriages in society. There is a strong correlation between thalassemia and consanguineous marriages (Piracha *et al*, 2014).

1.15 Premarital Carrier Screening

Premarital Screening (PMS) is defined as a panel of tests in which couples that are going to get married are tested for genetic, infectious and blood transmitted diseases to prevent any risk of transmitting any disease to their children. Nowadays premarital screening is one of the most important strategies for prevention of genetic disorders, congenital anomalies and several medical, psychological marital problems (Al Sulaiman *et al*, 2008).

As a result of the increase in the number of children affected with genetic or blood transmitted diseases, the premarital carrier screening is considered a burning issue and highly beneficial for the couples who are under the following categories:

- ✓ Couples going for consanguineous marriage
- ✓ If either/both have family history of a serious genetic condition
- ✓ If they are 'carriers' of the same faulty gene
- ✓ If they have exposure to some chemical or other environmental agent
- ✓ Any abnormalities in the chromosomes (Eastern Biotech, 2016).

Premarital testing programs should also educate couples, providing accurate and unbiased information. They should be available to anyone who want them and proper diagnostic techniques must be used. Informed consent is necessary, as well as guarantees of privacy and treatment of the affected individuals. Premarital programs are most successful when social, religious, ethnic and cultural factors are all addressed (Schumm, 2002; WHO Secretariat Report, 2006).

1.16 Tests Done in Premarital Carrier Screening

Premarital screening varies from one region to another depending on the prevalence of the diseases in that region. Generally, Premarital screenings are offered at three levels:

1.16.1 Basic package

The routine tests are done under this package to check the health status of an individual. These are the regular biochemical tests routinely done by the laboratories:

- ✓ Complete blood count (CBC)
- ✓ Blood group (ABO and Rh typing)
- ✓ Abnormal Haemoglobin studies (Hb Variants)
- ✓ G6PD- quantitative
- ✓ HIV ½ antibody screening (3rd Genration)
- ✓ Hepatitis BsAg screening
- ✓ Hepatitis C Total Antibodies to Hep C Virus
- ✓ VDRL (Syphilis) (RPR)
- ✓ Gonorrhea (Neisseria Gonorrhea) detection by PCR
- ✓ Chlamydia Trachomatis (IgG and IgA)

These tests are general routine tests to be conducted before getting married. Any abnormality will direct the couple for further analysis to an advanced level (Eastern Biotech, 2016).

1.16.2 Advanced Package

This includes the basic package with the addition of infertility testing for both male and female. It is always important to know the about the fertility status of the couple as most of the time, specially in the South-East Asia, women are condemned for not having children after years of marriage. Though it's interesting to know in many cases, the male infertility was the reason behind this (Eastern Biotech, 2016).

1.16.2.1 Male Infertility Test

Although many people still think of fertility as a "woman's problem," up to half of all cases of infertility involve problems with the man. In fact, about 20% to 30% of the time, a man's low fertility is the main obstacle to conception. A semen analysis is the most common testing procedure for determining if there is a male infertility factor. Sperm is collected into a specimen jar and

presented to a lab technician who examines the sperm under a microscope to evaluate the count, shape, appearance, and mobility. When assessing sperm count, the technician will be checking to see whether the sperm concentration is above or below 20 million sperm cells per milliliter of ejaculation fluid. If the sperm count is low, your fertility specialist will probably test the blood testosterone, FSH, LH and prolactin levels. A urinalysis may be used to look for white blood cells which may indicate an infection. The urinalysis will also determine if there is sperm in the urine, which would suggest that there is a problem with ejaculation known as retrograde ejaculation (Eastern Biotech, 2016).

1.16.2.2 Female Infertility Test

Infertility is the inability to get pregnant after a year of unprotected intercourse. About 10% of couples in the United States are affected by infertility. Both men and women can be infertile. According to the American Society for Reproductive Medicine, 1/3 of the time the diagnosis is due to female infertility, 1/3 of the time it is linked to male infertility and the remaining 1/3 is due to a combination of factors from both partners. For approximately 20% of couples the cause cannot be determined. The tests performed by the specialists involves measuring the level of the hormones, like, follicle stimulating hormone (FSH) and luteinizing hormone (LH) to establish a baseline. This is performed on the third day of cycle. Other hormones and routine analyses are also done to complement the diagnosis (Eastern Biotech, 2016).

1.16.3 Advanced Genetic Package

This is the most comprehensive package which includes basic tests, fertility tests and adds karyotyping as to analyze the chromosomes of both of them. For advanced screening, blood karyotyping is suggested by the counsellor to the couples who do not have any particular genetic conditions. When the couples show the correct number of chromosomes, there is less likely that they have any genetic abnormalities in their chromosomes (Eastern Biotech, 2016).

1.16.3.1 Blood Karyotyping

Blood Karyotyping is a test to examine chromosomes in a sample of cells, which can help identify genetic problems as the cause of a disorder or disease. This test can count the number of

chromosomes and look for structural changes in chromosomes. The sample is placed into a special dish and allowed to grow in the laboratory. Cells are later taken from the growing sample and stained. The laboratory specialist uses a microscope to examine the size, shape, and number of chromosomes in the cell sample. The stained sample is photographed to provide a karyotype, which shows the arrangement of the chromosomes. Certain abnormalities can be identified through the number or arrangement of the chromosomes. Chromosomes contain thousands of genes that are stored in DNA, the basic genetic material (Eastern Biotech, 2016).

1.16.4 Other Tests to be Considered

Couples might also consider taking specific Molecular Cytogenetic or DNA tests if he/she has family history of any genetic disease. Carrier or mutation analysis will help them to diagnose the status of the couple (Eastern Biotech, 2016).

1.17 Counselling by Genetic Counsellor

Genetic counseling is the process by which an individual or a family obtains information about a genetic condition that may affect them, so that they can make appropriate decisions about marriage, reproduction and health management. Genetic counseling protects the autonomy of the couple, fulfilling their right to be fully informed about the disorder and all valuable options (Albar, 1999; Kuliev & Modell, 1990).

Although premarital tests for haemoglobinopathies are reliable and useful, not everyone with these genes responds to counseling. Neal-Cooper and Scoot 10 reported that young couples concerned about producing a child with sickle cell disease are often offset by their strong desire to have children regardless of risk. The researchers suggested that at-risk couples should be contacted directly by counselors and encouraged to undertake education and counseling. Prevention and treatment of genetic diseases are virtually impossible (Al-Arrayed SS *et al*, 1997).

One successful approach is ‘solution-focused’ premarital counseling. Murray and Murray discuss how this focuses on a couple’s resources, helping them to develop a shared vision for the marriage. Background information about premarital counseling and solution-focused therapy provide a framework in which intervention strategies in those confined with positive status for a disease can

be developed. These solution- oriented interventions include solution–oriented questions and feedback, as well as a Couple's Resource Map (CRM) which depicts the support available to the couple from various personal relationships and contextual resources (Murray and Murray, 2004).

The available choices include avoidance of marriage, reproductive options for those who proceed with the marriage following prenatal diagnosis, adoption of the affected child, donation of sperm, ova or a pre-embryo from an unaffected individual and pre-implantation diagnosis. Choosing the best option depends on availability, cost and local regulations and religious rules. For example, in Saudi Arabia and most other Muslim countries abortion is prohibited on religious grounds and prenatal diagnosis is useless because abortion is forbidden unless the fetus is malformed. However, pre-implantation diagnosis is permitted and affordable. Thus, the success of genetic counseling depends on the approach adopted by the counselor as well as the education and attitude of the couple. Screening programmes must be equitable, accessible and understood by the target population, but most importantly they must comply with the prevailing cultural, ethnic, economic and social values (Monaghan, 2008).

In Bangladesh, there is still no recognized genetic centre where appropriate genetic counseling facility is available. Genetic counseling is or should be a part of premarital screening. Genetic Counsellor can help to decide the type of test the couple should consider. A detail of the family history, medical records and conditions of family members from both the sides need to be provided to the counsellors to have a proper advice from him (Eastern Biotech, 2016).

If the couple are informed of the possibility that they are at an increased risk of having a genetically abnormal child, they can choose to plan conceptions according to medical advice and can make use of the genetic counselling services available, such as:

- ✓ Couples may decide not to get married
- ✓ If couples decide to get married, they may not wish to have children
- ✓ If couples wish to have children, they must do the Prenatal Screening of the fetus at an early stage of pregnancy
- ✓ Couples must understand the option of termination of the pregnancy
- ✓ Couples must understand the social, economic perspectives of having children with genetic disorders (Eastern Biotech, 2016).

1.18 Role of Culture and Education in the Success of PMCS

Marriages between same tribes or extended family groups are favoured in some cultures, including those between first cousins. Consanguineous marriages are uncommon in Western countries. Marriage between first cousins is forbidden by the Orthodox Church and Roman Catholic Church, and may be seen as incestuous in the United States. Personal characteristics including socioeconomic status have implications for the outcome of premarital screening programmes. Education of the couples who are to be screened is extremely important and it is important to educate all members of the screening team consisting of laboratory technologists, nurse practitioners, physicians, counselors, outreach workers and social workers (Tosun *et al*, 2006).

According to Schmidt (1974), sufficient planning in the educational area before the first blood sample is drawn can avoid failures of the programme. The meaning of the term 'carrier status' should be made known to members of the public long before they get married. For successful public education, government and government organizations must cooperate, as well as community and religious leaders, school parent organizations and health personnel.

People who responded to information about premarital screening had favourable attitudes towards premarital counseling and examination of consanguineous marriages, possibly relating to social changes, declining illiteracy, increasing economic pressures, increasing numbers of nuclear families and longer waiting times before starting a family. People with a negative attitude towards these tests were mostly unmarried males. Religious beliefs restrict the success of screening programmes in some communities. In southern Iran, premarital screening has been made mandatory for 10 years, yet high-risk couples still get married and give birth to children homozygous for beta-thalassaemia. Often this is because of religious and traditional cultural restraints; in the case of Islam, consanguineous marriages are permitted, so thalassaemia persists in some parts of the community, making the programme redundant (Karimi *et al*, 2007).

Some people believe that their fate is determined by God and therefore accept the risk of having a sick child. A recent report in The Jordan Times showed that many Jordanians view the results of their 'unions' as fate. On the contrary, there are many teachings in the Islamic culture that promote healthy marriage and the role of counseling (Albar, 1999).

1.19 Global Aspects of Premarital Screening Programmes

Angastiniotis and Modell (1998) classified countries who deliver premarital screening programmes into three categories. First category is the endemic mediterranean countries in which preventive programmes are long-established, with success rate (preventive) of 80–100% and optimum treatment via specialist clinics. Secondly, the developed, industrialized countries in which prevalence is increasing because of migration; these countries can fund screening programmes, but find it difficult to reach immigrants with certain cultural backgrounds. Finally, the developing countries in which there are economic difficulties and other health priorities (e.g. infectious disease control) or other religious or cultural constraints.

In Cyprus, Greece and Italy, premarital screening for thalassaemia has been normal practice for a long time as because of high consanguinity. Similar preventive programmes have been introduced in Bahrain, China, India, the Islamic Republic of Iran, Indonesia, Malaysia, the Maldives, Singapore and Thailand, and recently in Saudi Arabia and United. Arab emirates. In the UK, Northern Ireland and other Northwest European countries, prenatal diagnosis is available and abortion is a prevention stratagey (WHO Secretariat Report, 2006).

In china, couples who wish to marry are extensively tested, including physical examination. They are given premarital health instructions and ‘counseling’ – in the form of watching videotapes of the type of child they may conceive – after which appropriate measures are taken. This approach has been strongly criticized in terms of human rights, control, oppression and eugenics, even though the value of vigilant premarital screening is acknowledged. In Lebanon, thalassaemia patients are managed in chronic-care centres in collaboration with the ministries of Social Affairs and Public Health. These screening programmes provide information, train health professionals and develope training materials with priority given to disseminating knowledge and public awareness (Therese, 2006).

Tosun *et al* (2006) studied the premarital haemoglobinopathies screening programmes in Mersin, Turkey, where consanguinity is 30%. If the man and the woman are both carriers, results are given confidentially and they are counseled about their options, including prenatal diagnosis. In Saudi

Arabia, premarital testing for haemoglobinopathies is mandatory. The results of at-risk couples are treated in the same way as in Turkey, prenatal diagnosis is not offered.

1.20 Premarital Screening Programmes in Asia and Indian Subcontinent

No data is available regarding premarital screening programmes in Pakistan, Nepal, Sri Lanka, Bhutan and Bangladesh. In India, a few selected private clinics are offering premarital screening testing as a package (Colah, 2008).

In Bangladesh, Pakistan, Nepal, Bhutan and Sri Lanka as well as in India, the health related problems including inherited diseases are more prevalent, so the governments of these countries should be committed to solve these problems. They are engaged to prevent the communicable and other chronic diseases. Although the governments of these countries are aware of the high prevalence of inherited and sexually transmitted diseases but because of economic constraints, they focus their attention to more common and easily preventable diseases. As the time passes, gradually these countries are achieving economic solvency and time has come to give proper attention to prevent inherited diseases. Haemoglobinopathies and beta-thalassaemia are more prevalent in these countries, so necessary measures and action plan should be formulated to reduce the incidence of these inherited diseases (Rahman et al, 2014).

Chapter 2

Literature Review

2.1 A Study on Knowledge, Attitude and Practice Towards Premarital Carrier Screening Among Adults Attending Primary Healthcare Centers in a Region in Oman

Al-Farsi *et al* (2014) aimed to investigate the knowledge and attitude towards premarital carrier screening (PMCS) in Oman. He conducted a cross-sectional study using a self-administered questionnaire which was distributed to 400 Omani adults aged 20–35 who attended primary healthcare institutions at the South Batinah Governorate in Oman. He found that, the majority of the participants (84.5%) believed that PMCS was necessary, and about half of them (49.5%) supported the view of making PMCS compulsory. On the contrary, approximately one third (30.5%) of the participants reported that they were not in favor of taking the blood screening test. Overall, unwillingness to perform pre-marital testing was associated with female gender, younger age, being single, less education, and increased income. Despite the relatively high level of knowledge, about one third of the participants were still reluctant to carry out premarital testing. Such attitude calls for immediate need for community-based campaigns to encourage the public to do premarital testing.

2.2 Young Syrian Adults' Knowledge, Perceptions and Attitudes to Premarital Testing

Gharaibeh and Mater (2009) coducted a study to identify young Syrian adults' knowledge, perceptions and attitudes about premarital testing. They stated that Syria is an Islamic country that is moving towards modernization that involves changes in social structures and urbanization of attitudes, beliefs, views and values. But still the issue of premarital testing is a controversial and complex issue. The study was conducted at a mid-sized university in Syria and descriptive, cross-sectional design was utilized. A stratified simple random sampling was used to recruit the university students in the last 2 years of their graduation. A total of 942 students participated in the study using a questionnaire developed to measure the participants' knowledge, attitudes and perception of premarital testing. They found that although university students had a considerable knowledge of premarital testing, they had a limited knowledge about certain aspects. Moreover, although they had some positive attitudes, they still had negative attitudes and perceptions towards

other aspects of premarital testing. The study results could assist in the development of health education programmes in Syria and other Arab countries to increase their awareness and influence their attitudes towards premarital testing. But according to them, the study limitation was that the sample was chosen from one part of Syria.

2.3 Knowledge and Attitude Toward the Hemoglobinopathies Premarital Screening Program in Saudi Arabia: Population-Based Survey

The study was conducted by Al Sulaiman *et al* (2008) to assess the knowledge, perception, and attitude among the Saudi population about the PMS program through a questionnaire-based survey. A total of 1,047 candidates were included, divided into three groups. Group A represented the general population, group B was composed of couples presenting for PMS, and group C represented couples who had received their results. There was a fair knowledge among participants of the three groups about the nature of the tests and the targeted disorders, with more than 80% believing that it should include both sexually and genetically transmitted diseases. The concept of genetic counseling was liked by most of the participants. The study showed that, there was a positive attitude toward the program and the majority agreed to apply the PMS program to all couples in all country regions. More than 60% of all the participants were in favor of preventing at-risk marriages.

2.4 Attitudes towards Mandatory National Premarital Screening for Hereditary Hemolytic Disorders

Al-Aama (2010) reported that, in the survey, eight hundred university students (aged 18–29) filled in a self-administered structured questionnaire. Data were analyzed using the EPI Info Statistical Package version 6. A *P*-value <0.05 was considered significant. The study was conducted to examine the attitude of young educated individuals regarding the national PMS program and its implementation. The finding appears that most students favor the PMS program but there were concerns regarding mandating the testing and interference with individual decision making. Significantly more women favored testing and coercive interference with the decision to marry. The author urged that further public education and wide spread genetic counseling prior to testing is essential for the success of the program. Screening singles on admission to university prior to

any commitment may be preferable than screening immediately before the marriage certificate is issued.

2.5 Knowledge Regarding the National Premarital Screening Program among University Students in Western Saudi Arabia

The study was conducted by Al-Aama (2008) **t**o explore the knowledge of university students in Jeddah, western Saudi Arabia, regarding the national premarital screening (PMS) program. A self-administered questionnaire was distributed to a sample of 800 students at King Abdulaziz University KAU, Jeddah, Kingdom of Saudi Arabia during the first semester of the academic year 2005-2006. This included questions regarding socio-demographic data, personal history of hereditary disease, or premarital screening, knowledge on hereditary diseases, and on the national PMS program. Data were analyzed using the Statistical Package for Social Sciences version 13. A p-value less than 0.05 was considered significant. According to Al-Aama (2008), eighty-five percent of the students believed that gene mutations may lead to hereditary disorders, and 84% of the respondents believed that consanguinity can increase the risk for genetic diseases. Fifty-six percent were aware that hereditary disease could affect any body system. Less than onethird of the students knew which disorders are tested for by the PMS, and 54% of the students thought that PMS detects all hereditary diseases. Only 35% knew what a non-compatible test result meant, while 59% believed that a compatible result meant freedom from all hereditary diseases. Most of the students at KAU have good general knowledge concerning hereditary diseases, but had inadequate knowledge in relation to the national PMS program. The majority did not know which diseases were tested for, and what the test result meant. Public education regarding the disorders tested for, and the implication of screening is essential for the success of the premarital program.

2.6 Attitude towards Pre-Marital Genetic Screening Among Students of Osun State Polytechnics in Nigeria

In this study Odelola *et al* (2013) investigated the attitude towards pre-marital genetic screening among students of Osun State Polytechnics. Descriptive survey design was used for the study. The instrument for data collection was self-developed and structured questionnaire in four- point Likert scale format. Descriptive statistics of frequency count and percentages were used to describe the

demographic data, while the parametric statistics of t-test and ANOVA set at 0.05 alpha level were used to test the hypotheses. A total number of one thousand, one hundred and sixty-five (1,165) Higher National Diploma (HND) students served as respondents for the study. Multistage sampling technique was used in three stages to select the respondents, namely: purposive sampling technique was used to select the schools; stratified sampling technique was used to select the Faculties and Departments, while proportionate sample of 25% was selected from each stratum. Three hypotheses were formulated to guide the study. The following were the values obtained by Odelola *et al* (2013): Difference in Attitude towards Pre-Marital Genetic Screening (Crit-t = 1.96, Cal.t = 1.310, df = 1163, P>.05); Difference in Attitude Due to Religion (F2,1162) = .689, P>.05) and Difference in Attitude Due to Course of Study (F5,1159) = .585, P>.05). Conclusions were drawn based on the findings of the study. The author recommended, among other things, that religious organizations should serve as useful channels to disseminate health information since people always have respect for places of worship and religious leaders. Also, Health Education should be incorporated into the curriculum of Polytechnics.

2.7 Between Acculturation and Ambivalence: Knowledge of Genetics and Attitudes towards Genetic Testing in a Consanguineous Bedouin Community

Raz *et al* (2003) reported that a questionnaire was presented to 61 teachers and 40 school children as part of guided interaction in small groups, conducted in Bedouin schools between 1999 and 2001. Susceptibility as well as knowledge of genetics were found to correlate with a positive attitude towards the genetics program among both teachers and pupils. It was found that pupils had a lower knowledge index as compared to teachers, and their attitudes were slightly less positive. Raz *et al* (2003) discussed the difference between teachers and pupils in the context of the latter's acculturation, which contradicts tradition and parental authority and can generate ambivalence. They further discussed the attitudes in the context of the Health Belief Model and the complex interplay of tradition, Islam, cousin marriage and biomedicine.

2.8 Knowledge and Attitude of University Students towards Premarital Screening Program

This study was conducted by Al Kindi *et al* (2012) to explore the knowledge and attitude of Sultan Qaboos University students towards premarital screening program. They did a cross-sectional study at the students' clinic from January to April 2011. Distributed a self-administered questionnaire to 590 unmarried Omani students of both genders. The questionnaire consisted of 3 main parts; the first part was based on socio-demographic data, the second part dealt with the students' knowledge about the premarital screening program while the third part explored their attitudes towards the screening program. Most of the participants (n=469; 79%) were aware about the availability of premarital screening program in Oman. The main sources of information were: school/college (n=212; 36%), media (n=209; 35%), family and friends (n=197; 33%), and/or health services (n=181, 31%). The vast majority of the participants (n=540; 92%) thought it is important to carry out premarital screening and agreed to do it. Around half of the participants (n=313; 53%) favored having premarital screening as an obligatory procedure before marriage and about one third (n=212; 36%) favored making laws and regulation to prevent marriage in case of positive results. The study concluded that even though the majority of the participants thought it is important to carry out premarital screening; only half favored making it obligatory before marriage and one third favored making laws and regulations to prevent marriage in case of positive results. This reflects the importance of health education as a keystone in improving knowledge and attitude towards premarital screening program.

2.9 Knowledge and Attitude Regarding Premarital Screening for Sickle Cell Disease among Students of State School of Nursing Sokoto

Isah *et al* (2016) included in the study that about 5% of the world's population carries genes responsible for hemoglobinopathies and each year about 300 000 infants are born with major hemoglobin disorders including more than 200000 cases of sickle-cell anemia in Africa. Sickle cell anemia is a very common disorder in Nigeria with birth rate of about 1 in 50 and about 150,000 children are born annually with sickle cell anemia in Nigeria alone. They conducted the study to explore the knowledge and attitude of nursing students about premarital screening for sickle cell disease. A descriptive, cross-sectional study was conducted using self-administered semi-

structured questionnaire among 176 students. The finding was majority of respondents knew sickle cell disease and also knew their genotype 97.6% and 71% respectively, although up to 9.1% selected blood group as their genotype. More than half of respondent (51.7%) said sickle cell disease can be transmitted through blood, 55.1% of respondent said they think government should prohibit marriage between incompatible couples with regard to sickle cell disease, only about one third (34.1%) of respondent have good knowledge of SCD, and 34.3% of respondent have good knowledge of premarital screening for SCD, more than half (55.4%) of respondent have good attitude regarding premarital screening for SCD. According to the authors, the study shows that the respondents have poor knowledge of sickle cell disease and premarital screening though more than half of the respondent have good attitude towards premarital screening. They concluded that the importance of health education as a keystone in improving knowledge and attitude towards premarital screening for sickle cell disease.

2.10 Premarital Screening and Genetic Counseling program: Knowledge, Attitude and Satisfaction of Attendees of Governmental Outpatient Clinics in Jeddah

Ibrahim *et al* (2013) reported that a cross-sectional study was conducted from January to April 2009. Individuals who attended three governmental hospital outpatient clinics on the day of the interview and agreed to participate in the study were recruited. The three hospitals were the two hospitals in Jeddah that offer the PMSGC programs and the King Abdulaziz University Hospital. Ethical considerations were followed and data were collected through an interview questionnaire that had been constructed for the study. Ibrahim *et al* (2013) asked in their questionnaire for personal and socio-demographic data and for responses, on a 5-point Likert scale, to 30 knowledge items and 14 attitude statements. Individuals who participated in the PMSGC program were asked questions regarding the services and activities of the program to ascertain their satisfaction with the program and their recommendations for program improvement. The statistical analysis was performed using SPSS version 16 (SPSS Inc., Chicago, IL). The sample included 655 participants, of whom 38.8% completed the PMSGC program. The finding was the participants' knowledge about the program was generally low. Education was the first predictor of a high knowledge score; individuals having ≥ university degree obtained a higher score (aOR. =2.73; 95% CI: 1.77-4.20).

The second predictor was the nationality of the participants, with Saudis gaining a higher score (aOR. =2.04; 95% CI: 1.002-4.16). The third predictor was monthly income. Regarding attitudes, the vast majority of participants (96.0%) strongly agreed on the importance of the program. Concerning the satisfaction levels of those who benefited from the program, 80.0% gave an excellent or very good score for program confidentiality, whereas lower scores were given for counseling. Counseling before the tests was conducted for only 11.7% of the study participants. The majority of participants recommended adding testing for other genetic diseases and STDs as well as additional topics for counseling. They concluded that the knowledge in the general population about the PMSGC program was low. Implementation of school and university educational campaigns is important. Improved counseling and adding new topics for counseling on genetic, chronic, and psychiatric problems; building healthy families; reproduction and fertility are recommended.

Significance of the Study

Consanguinity between spouses can occur in society due to many reasons, some of which are religious, social and others which are primarily economic. But healthcare providers and genetics specialists emphasize on the negative impact of consanguineous marriage in terms of increased genetic risks to the offspring, as opposed to the potential social and economic benefits (Bittles 1994; Hamamy *et al*, 2011).

In populations with high consanguinity rates and common inherited blood disorders, community programs for premarital screening to detect carriers of hemoglobinopathies such as thalassemia and sickle cell anemia are in progress in many countries. Carrier detection and genetic counseling programs have been very successful in reducing the birth prevalence of inherited disorders in some of those populations (Hamamy, 2011).

Although in Bangladesh the health related problems such as beta-thalassaemia and haemoglobinopathies are more prevalent, but because of economic constraints, the government of the country focus its attention to more common and easily preventable inherited and sexually transmitted diseases. As the time passes, gradually the country is achieving economic solvency and time has come to give proper attention to initiate the premarital carrier screening and also genetic counselling programmes to prevent consanguinity related inherited disease, sexually transmitted diseases and other genetic diseases in broader spectrum. There must be awareness raising programmes as the population concept about the premarital screening is not sufficient (Rahman *et al*, 2014).

These programs are most successful when they are sensitive to the cultural backgrounds of populations in which they are applied. The attitude of the screening programs is dependent on the knowledge, religious point of view, privacy concern, expenses, social and cultural acceptancy and many other stereotypes believes of selected populations. According to Khoury and Massad (1992), the consanguinity marriage in many countries is regarded as a family decision and not just the couple's decision, although the frequency of arranged marriages may be declining in recent years due to the increasing number of females reaching university level education which gives them a broader choice of marriage partner.

To our best knowledge, research on the knowledge and attitude on premarital carrier screening has never been done earlier in Bangladesh. In fact, the concept of premarital carrier screening which is important to reduce the inherited diseases in consanguineous marriages or spread of infectious or genetic diseases is not well recognized among the general population in our country. According to Colah (2008), no data is available regarding premarital screening programmes in Bangladesh. So the present study may have significant impact upon Government and general populations regarding the premarital carrier screening programs. This study may open a new window in the medical sector as well.

Objective of the study

Objectives of the study were:

- ✓ To determine the knowledge level of young generations in Bangladesh about premarital carrier screening.
- ✓ To assess the level of perception about the premarital carrier screening.
- ✓ Their perception of mode of preventions and control of genetic, inherited and infectious diseases.
- ✓ Their attitude towards practicing premarital carrier screening.
- ✓ To determine the availability of consanguineous marriages and genetic disorders.

Chapter 3

Methodology

3.1 Type of the Study

It was a survey based study.

3.2 Study Area

The survey was conducted in different universities inside Dhaka City which included North South University, International University of Bangladesh, South East University, Bangladesh University of Business and Technology, BRAC University, Ahsanullah University of Science and Technology, University of Liberal Arts Bangladesh, United International University and also in different universities near Dhaka City which included Jahangirnagar University and Islamic University of Technology.

3.3 Study Population

The targeted group was students of different universities in Bangladesh. The survey was conducted among 513 university going students including male and female of young age within the range of 15 - 30.

3.4 Inclusion Criteria

- ✓ Both male and female university going student

3.5 Exclusion Criteria

- ✓ Anyone not current student of any university

3.6 Data Collection Method

The data was collected through questionnaire that is formed in English language and also some of the information are given in both English and Bangla for better understanding. It consists of multiple choice type questions to find out the knowledge and attitude about Premarital Carrier Screening among university going students. The data was collected by face to face interview.

3.7 Development of the Questionnaire

The questionnaire was developed based on different findings in available journal and research paper on this topic.

3.8 Sampling Technique

In this study, convenience sampling was followed.

3.9 Data Collecting Period

The duration of data collection was about four months that started from June 2017 to September 2017.

3.10 Data Analysis

After collecting, all the data were checked and analyzed with the help of Microsoft Office Excel 2016.

Chapter 4

Results

4.1 Demographic Information

4.1.1 Age Distribution

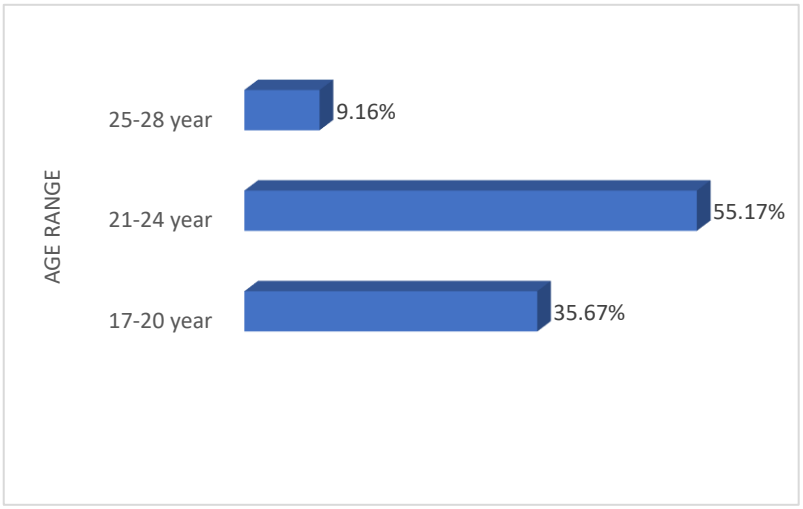

Figure 4.1.1: Age Distribution

In this survey, maximum participation (55.17%) of the students was from the age range 21-24 years and lowest participation (9.16%) was from the age range 25-28 years.

4.1.2 Gender distribution

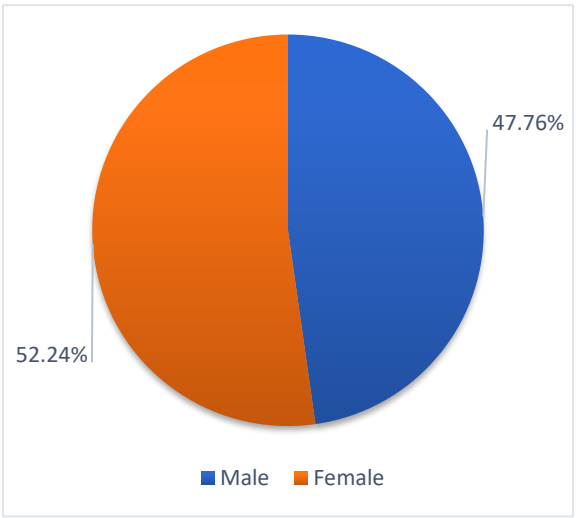

Figure 4.1.2: Gender distribution

In this study, the participation of male and female was almost similar. It was found that about 52.24% of population were female and 47.76% were female.

4.1.3 Department of Study

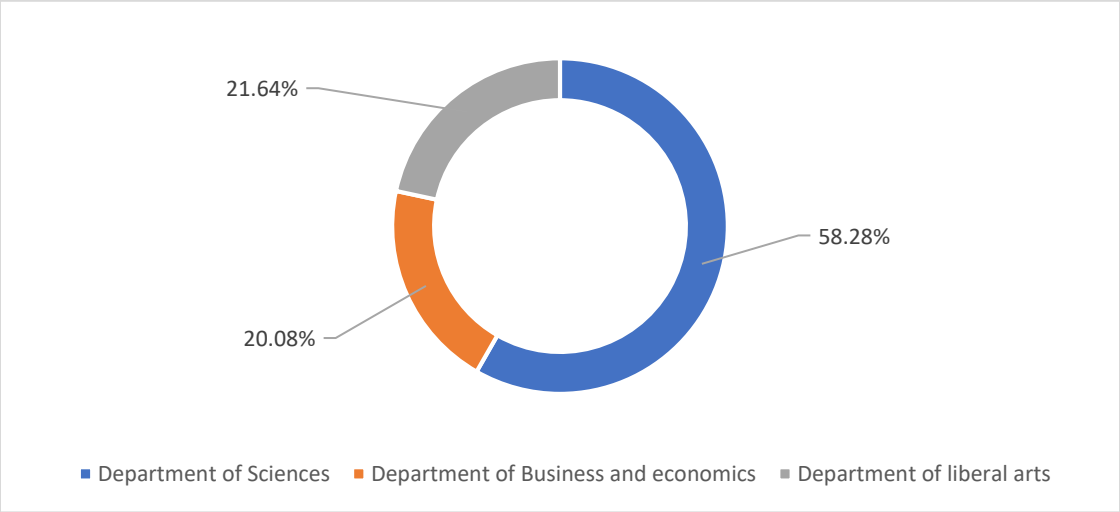

Figure 4.1.3: Department of Study

Significant number of students (58.28%) were from science departments. Among other students, 21.64% were from department of liberal arts and 20.08% were from department of business and economics.

4.1.4 Year of Study

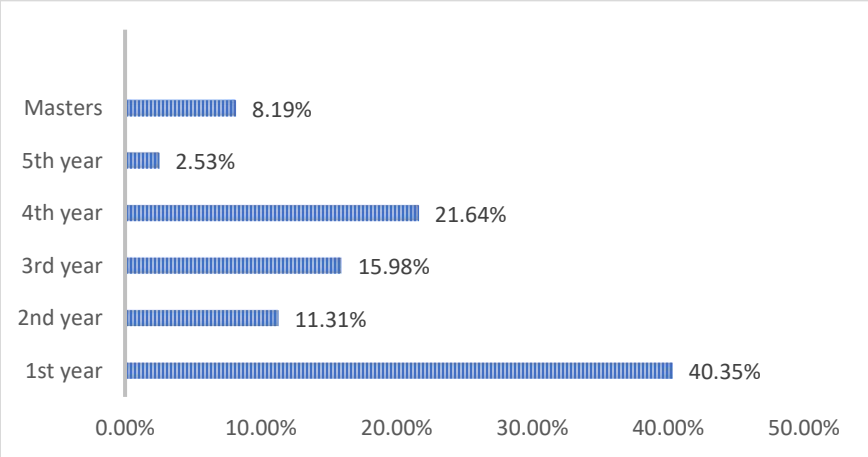

Figure 4.1.4: Year of Study

Most of the study populations (40.35%) were students of 1st year. The participation of 5th year (2.53%) and masters (8.19%) students was very low.

4.1.5 Marital Status

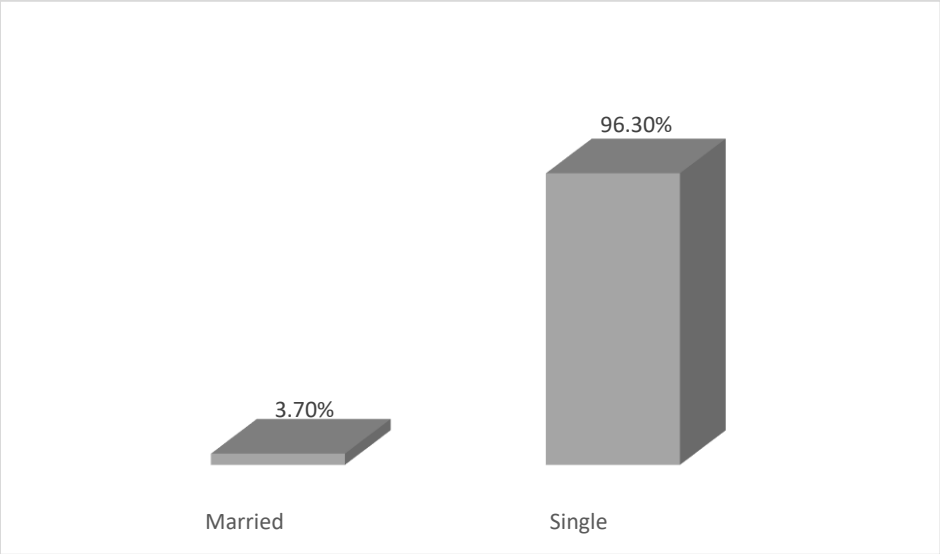

Figure 4.1.5: Marital Status

Most of the students (96.30%) of this study were single. Only 3.70% were married and there was no consanguinity in the married population.

4.1.6 Consanguinity in Parents

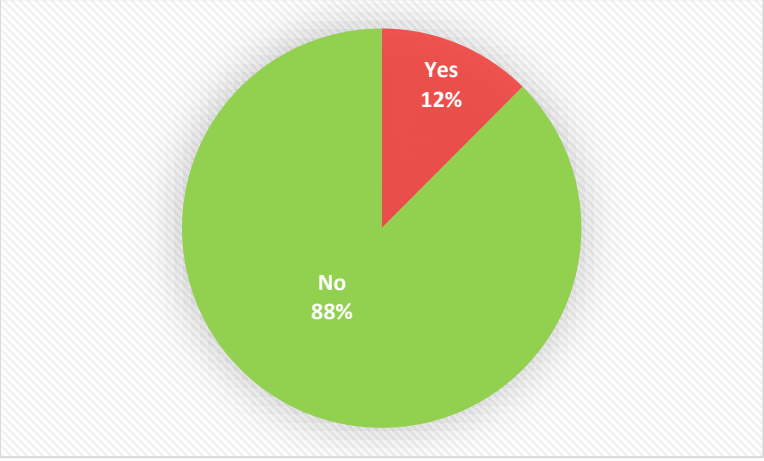

Figure 4.1.6: Consanguinity in parents

Consanguinity in parents was not very common (only 12%) in the study population.

4.1.7 Family History of any Genetic Disease

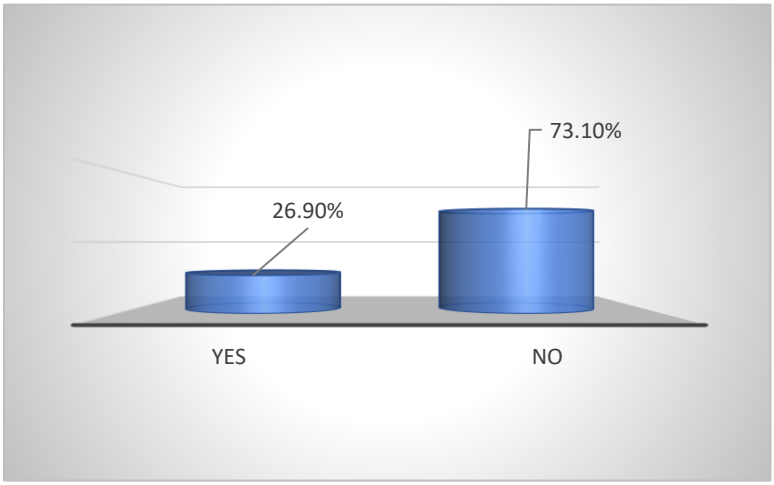

Figure 4.1.7: Family history of any genetic disease

It was found that only 26.90% of study population had some genetic disease in the family.

4.1.8 Kind of Genetic Disease (N=138)

Here, N is the number of population answered this question which was selective only for those population who had any genetic diseases in family.

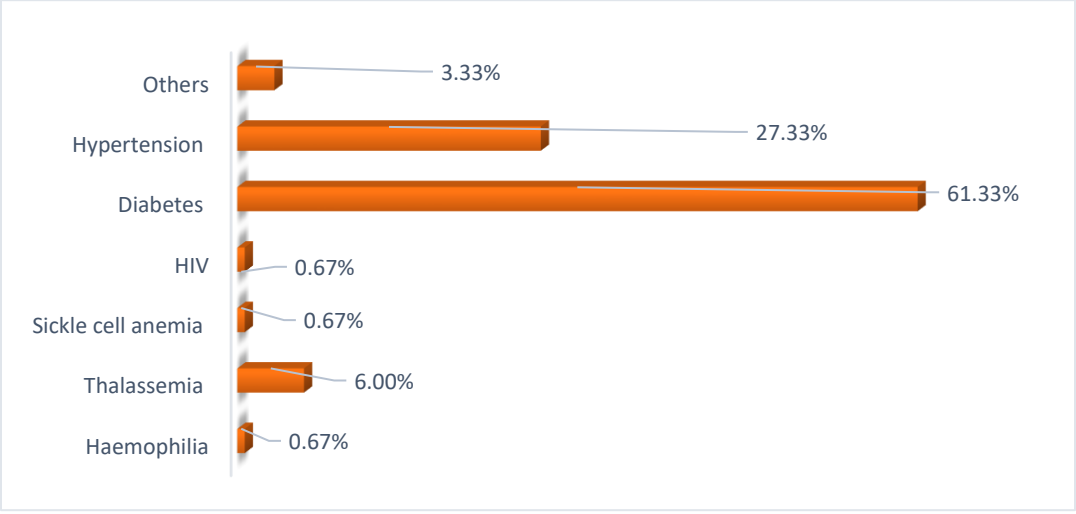

Figure 4.1.8: Kind of Genetic Disease

The most prevailing genetic disease in the selected population was diabetes (61.33%). Second most prevailing disease was hypertension (27.33%).

4.2 Knowledge about PMCS

4.2.1 Ever Heard about PMCS

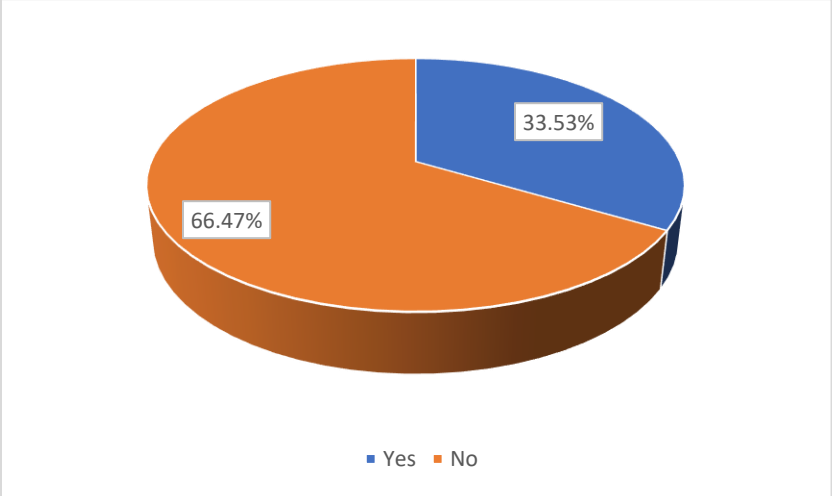

Figure 4.2.1: Ever heard about PMCS

A big portion of the study population (66.47%) had never heard about PMCS. They were totally ignorant of the concept.

The following three questions were asked only to those populations **(N=172)** who were not totally ignorant of the concept of PMCS and have heard about it.

4.2.2 Source of Knowledge

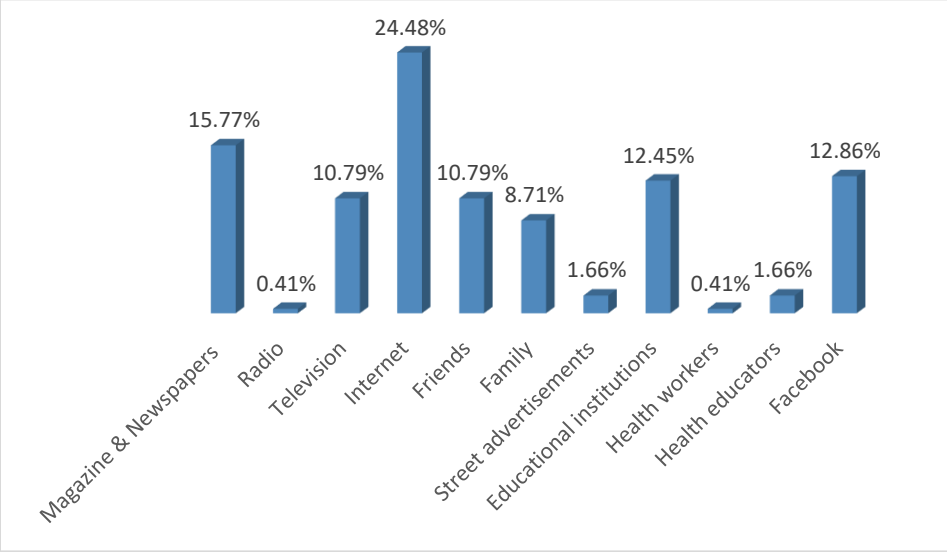

Figure 4.2.2: Source of Knowledge

Internet was found to be the major source of information (24.48%). Among the other sources, the magazine and newspaper (15.77%), Facebook (12.86%), educational institutions (12.45%), friends (10.79%), television (10.79%) were also common.

4.2.3 PMCS Reduce Genetic Diseases and STDs

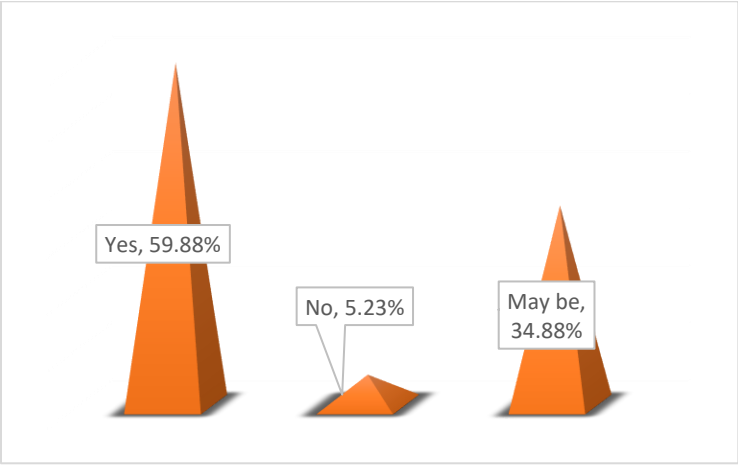

Figure 4.2.3: PMCS reduce genetic diseases and STDs

Among the selected population, majority of the students (59.88%) were aware that PMCS can reduce genetic diseases and STDs. A very little amount (5.23%) gave totally the opposite opinion. Some of the students (34.88%) were not clear about this concept.

4.2.4 Ever Conducted PMCS

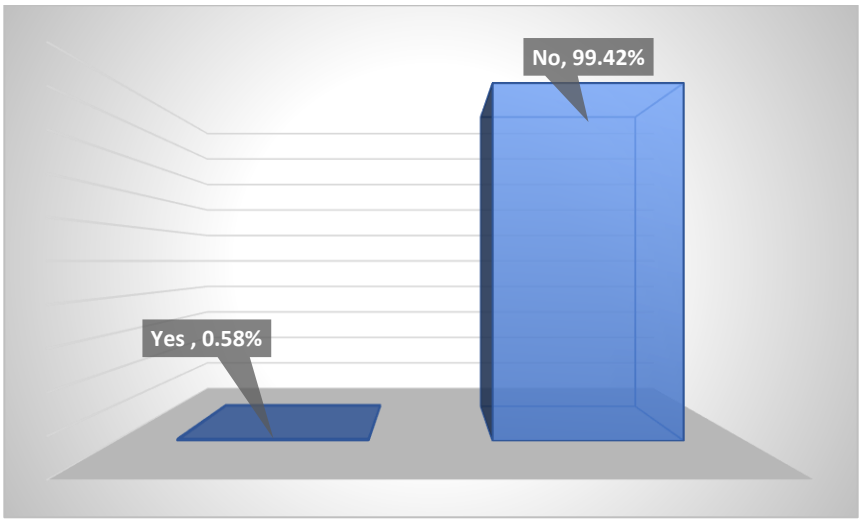

Figure 4.2.4: Ever conducted PMCS

More than 99% of the population never conducted PMCS. Less than 1% population conducted PMCS.

4.2.5 Genetic Disease Causes Psychological Burden

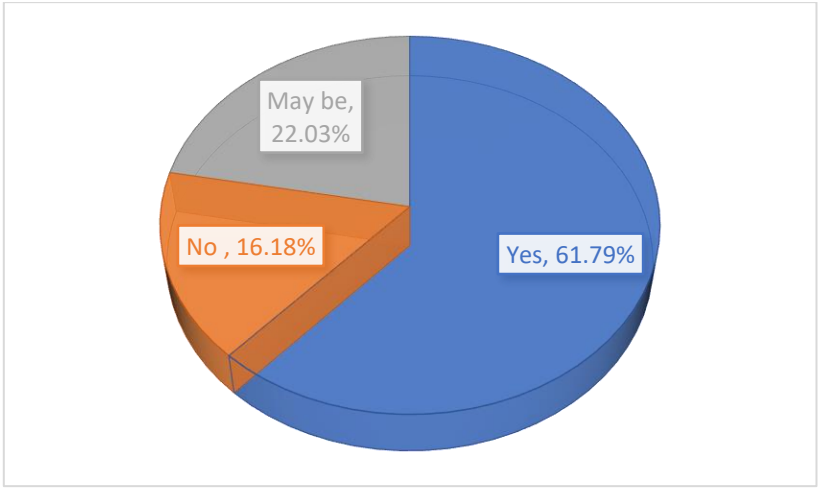

Figure 4.2.5: Genetic disease causes psychological burden

Most of the population (61.79%) gave their opinion that genetic disease causes huge psychological burden whereas 22.03% were confused.

4.2.6 Consanguinity Leads to Genetic Disease

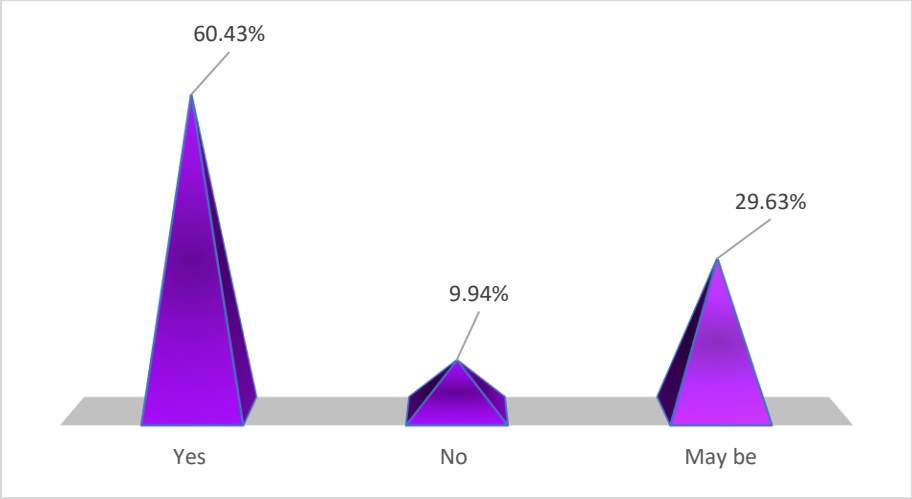

Figure 4.2.6: Consanguinity leads to genetic disease

Approximately 61% were aware that consanguinity leads to genetic disease and 29% were confused. The remaining 10% disagreed upon the fact that consanguinity leads to genetic disease.

4.2.7 Heard about Following Diseases

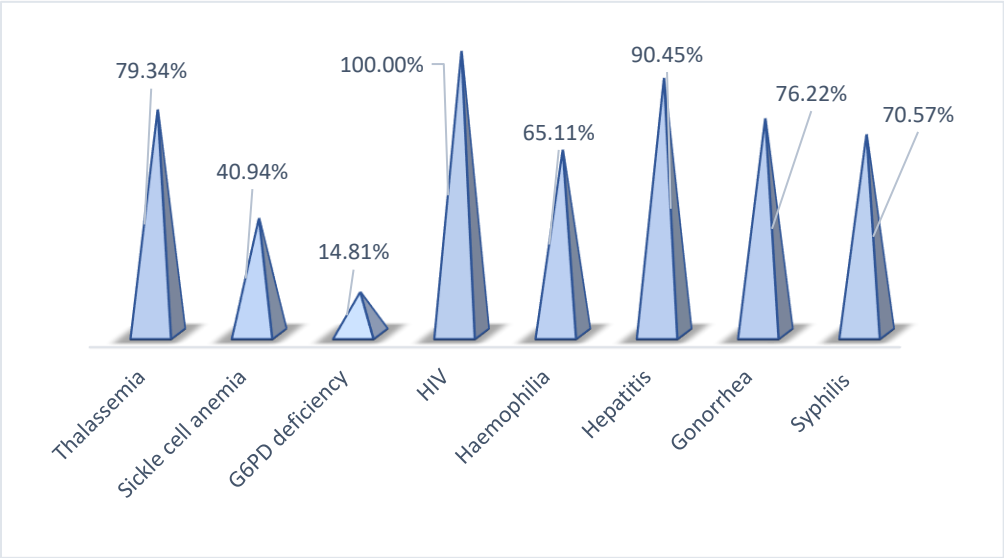

Figure 4.2.7: Heard about following diseases

Every student upon whom the survey was conducted have heard about the genetic disease HIV whereas only 14.81% have heard about G6PD deficiency. Other than G6PD deficiency, other diseases such as hepatitis (90.45%), thalassemia (79.34%), gonorrhea (76.22%) etc were known comparatively more to the students.

After giving a brief idea about what PMCS is, the next two sections - perception and attitude of students toward PMCS were done.

4.3 Perception about PMCS

Table 4.1: Perception about PMCS

Statement	***Strongly agree***	***Agree***	***Neutral***	***Disagree***	***Strongly disagree***
PMCS is important	46.39%	43.66%	9.55%	0.19%	0.19%
It is necessary to raise awareness about PMCS before marriage	49.12%	42.50%	7.80%	0.39%	0.19%
PMCS breaks personal privacy	6.82%	20.66%	41.13%	27.10%	4.29%
PMCS stands against religion	3.70%	10.33%	37.04%	34.50%	14.42%
There should be law that obligates all future couples to do PMCS	24.17%	37.82%	30.99%	4.87%	2.14%

The highlighting part of our study is that majority of the study population showed positive perception towards PMCS. A very few population denied the fact that PMCS is important, awareness regards PMCS must be raised and there should be law to make PMCS compulsory. But when it comes about whether PMCS stands against religion or breaks personal privacy, most of the population were in neutral position. But in both cases, the second highest population disagreed.

4.4 Attitude towards PMCS

4.4.1 Willingness to Do PMCS

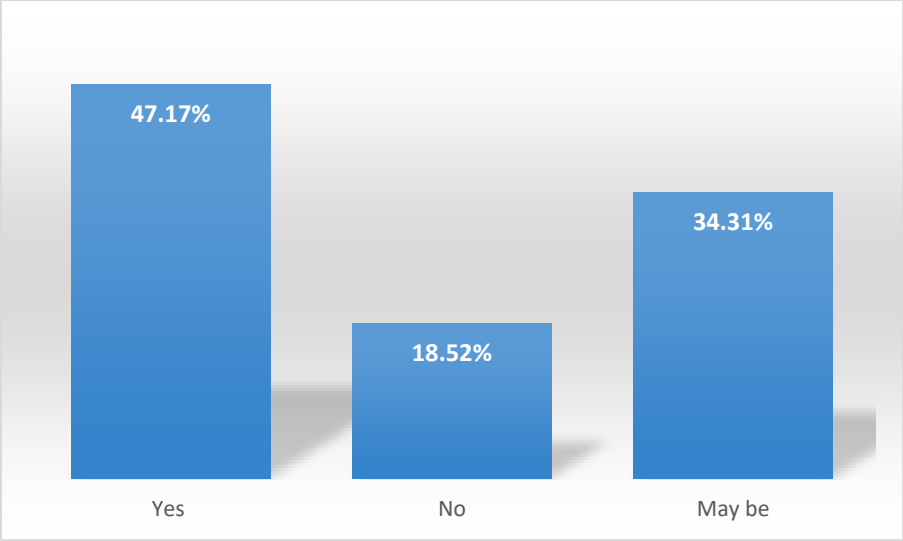

Figure 4.4.1: Willingness to do PMCS

In this study, 47.17% study population showed willingness to conduct PMCS, 18.52% were totally unwilling and 34.31% were confused.

4.4.2 Reasons for Unwillingness (N=95)

Here, N is the number of population answered this question which was selective only for those population who showed unwillingness to conduct PMCS.

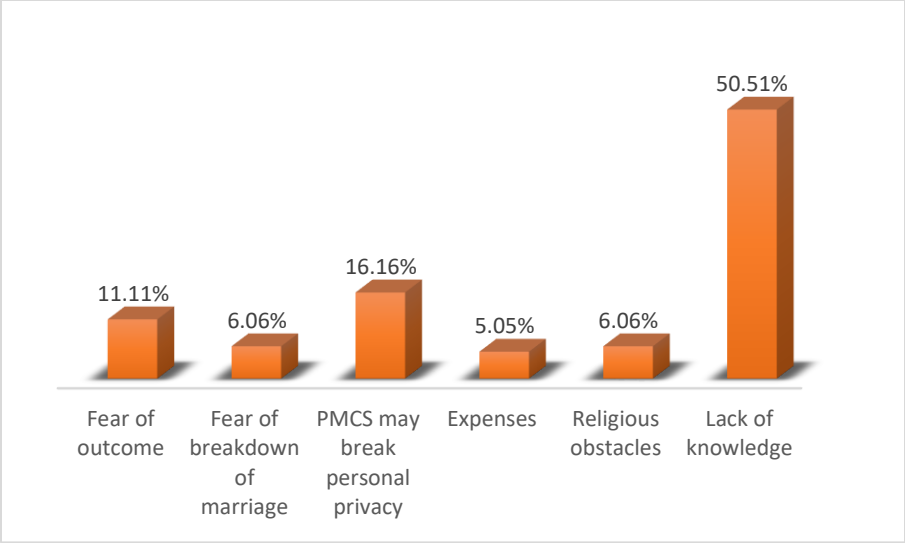

Figure 4.4.2: Reasons for Unwillingness

The lack of knowledge (50.51%) was the most prevailing reason behind the unwillingness to conduct PMCS. There were also other reasons for their unwillingness like breaking of personal privacy (16.16%) and fear of outcome (11.11%) etc.

4.4.3 Prefer to Marry a Blood Relative

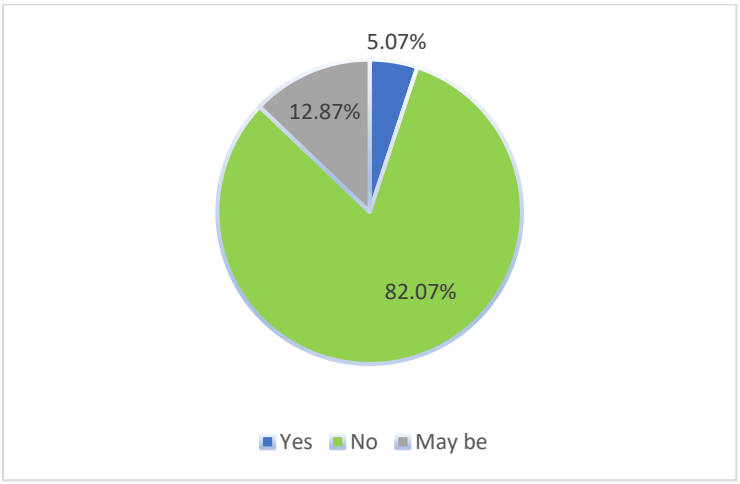

Figure 4.4.3: Prefer to marry a blood relative

Most of the study population (82.07%) did not prefer to marry blood relatives whereas 12.87% were confused. Only 5.07% showed preference to marry a blood relative.

4.4.4 Advise Future Spouse to Conduct PMCS

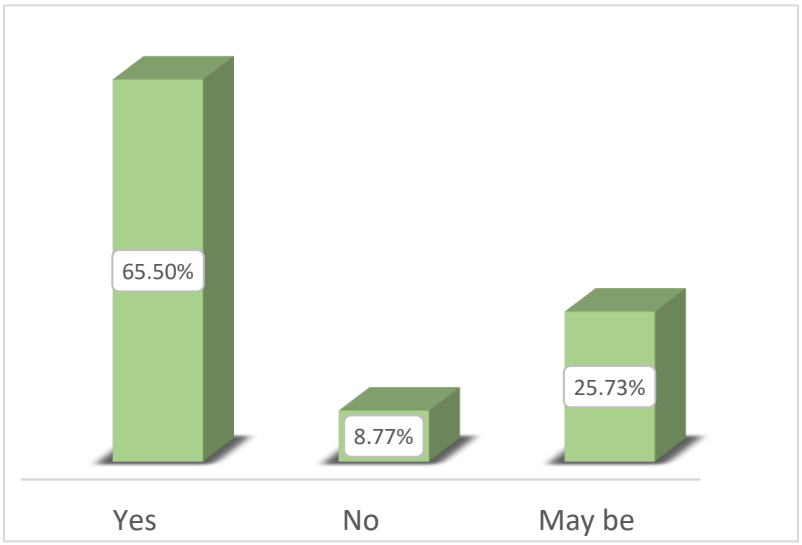

Figure 4.4.4: Advise future spouse to conduct PMCS

Most of the study population (65.50%) will advise future spouse to conduct PMCS. But 25.73% were confused about the decision.

4.4.5 Still Go for Marriage if Spouse is a Carrier of Genetic Disease

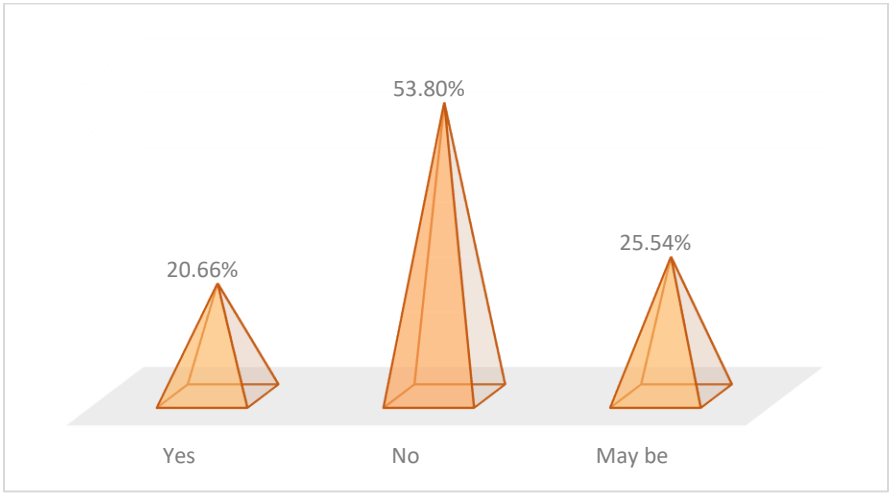

Figure 4.4.5: Still go for marriage if spouse is a carrier of genetic disease

In spite of finding genetic disease in spouse, 20.66% will still go for marriage and in contrast, 53.80% will not go for marriage. The remaining 25.54% were confused about their decision.

Chapter 5
Discussion and Conclusion

5.1 Discussion

The survey was based on the knowledge, perception and attitude towards PMCS among students attending universities. Our study conducted onto 513 university going students. Most of them were in the age range between 17-30 years (35.67%), 21-24 (55.17%) and 25-28 years (9.16%). In our study, there was participation of both male (47.76%) and female (52.24%) and most of them (96.30%) were single. Only 3.70% were married.

During this study we came to know that consanguinity in parents was not very common in the study population (12%) and percentage of genetic disease in family was not very high (26.90%). But Shawky *et al* (2013) reported in their study that consanguineous marriage was found in 54.4% of the studied group compared with 35.3% in the controls. Also, it was higher in rural areas (59.9%) than in semi-urban (23.5%) and urban areas (17.7%). Again, in their study consanguineous marriage was reported in 78.8% of patients with autosomal recessive disorders compared to 21.2% in nonconsanguineous patients. In Jordan, Hamamy (2011) stated that consanguinity rates among parents affected with autosomal recessive diseases were 85%. Here we can see the connectivity between the consanguinity and genetic disorders. As the consanguinity rate in parents found in our study was very low (12%), it may be a reason for which the rate of the genetic disease in family was not very high (26.90%). Besides, in our study no consanguinity was found in married population (3.70%).

Among those genetic diseases, the most prevailing disease was diabetes (61.33%). Second most prevailing disease was hypertension (27.33%). Thalassemia and Sickle cell anemia were found 6% and 0.67% respectively. Al-Aama *et al* (2008) found in their study that 34.9% reported having hereditary disease in one or more of their family members. Among these, the reported disorders were Sickle cell anemia (1.1%), thalassemia (0.4%), glucose-6-phosphate dehydrogenase deficiency (0.4%), and hemophilia (0.2%). The remainder considered diabetes mellitus (18.8%), or allergy (4.6%) as hereditary disorders.

In our study, a big portion of the study population (66.47%) had never heard about PMCS. They were totally ignorant of the concept. About 34% respondents knew about the concept of PMCS. An opposite view has emerged from a study done by Oluwole *et al* (2010) in South-West Nigeria. They have reported that 90.5% of the respondents were aware of PMCS. Again, Ibrahim *et al*

(2013) reported that, vast majority of population (93.7%) had heard about PMCS program. May be the difference is because of the lack of structured package of PMCS in various public and private hospitals. In our country, we have conducted a little survey in different public and private hospitals before commencing the study to see if there was any structured package of PMCS available or not. But unfortunately, there was no such packages. But the tests were available in scattered form and also most of them were very expensive for the general populations.

Some questions were asked only to those selected populations (N=172) who have ever heard about PMCS. There are so many sources found from where the population have heard about PMCS. The peak source was found media, educational institutes, friends. Very few learned about PMCS from health institutions. Similar finding was observed in the study conducted by Al-Aama *et al*. (2008) where they found that the major sources of knowledge regarding PMCS were the media, followed by friends. Only 7% reported learning anything, regarding the PMCS from medical professionals.

Among the selected population, majority of the students (59.88%) were aware that PMCS can reduce genetic diseases and STDs. As the concept of PMCS was not well known to the population, many of them (34.88%) were not clear about this fact. Al-Farsi *et al* (2014) reported that 90.3% endorsed the view that PMCS has the potential to limit the spread of hereditary diseases. A similar finding obtained by Al-Aama *et al* (2008) reported that about 95% of the population believed that PMCS would have limited the spread of hereditary disease. More than 99% of the selected population never conducted PMCS. Less than 1% population conducted PMCS. May be because of the lack of structured packages, expenses or the major reason may be, most of the populations in this study were unmarried. So, the rate of conducting PMCS is this much low.

In our study, majority of the populations were agreed upon the fact that PMCS is important and it is necessary to raise awareness about PMCS before marriage. Similarly, Al-Farsi *et al* (2014) and Al-Aama *et al* (2008) stated in their studies that about 86% and 96% of the participants respectively believed that PMCS is important. Al-Farsi *et al* (2014) reported that the majority of the participants (84.5%) believed that PMCS is necessary and about half of them supported the view of making PMCS compulsory.

On the point of giving opinion about PMCS stands against religion and breaks personal privacy, most of the population remained in the neutral position. But reports from Islamic country Southern

Iran by Karimi *et al* (2007) provided evidence that religious beliefs could be obstacles to the success of pre-marital screening programs, regardless of other factors such as education level.

In this study, 47.17% study population showed willingness to conduct PMCS, 18.52% were totally unwilling and 34.31% were confused. The lack of knowledge (50.51%) was the most prevailing reason behind the unwillingness to conduct PMCS. There were also other reasons for their unwillingness. Most of the study population (65.50%) will advise future spouse to conduct PMCS. Al-Farsi *et al* (2014) reported that the majority would advise their spouse to take the premarital medical test. Also, more than 60% of the participants reported that they would consider results of PMCS prior to marrying a partner. Nearly one third (30.5%) of the participants reported that they were not in favor of taking the test; whether married or single. Lack of awareness, as the most common explanation, was reported among the married participants who did not perform the test. This constituted 36% of the participants. Others indicated that lack of testing centers (13%), no interest (10%), or lack of hereditary disease in the family (9%), not important (7%), or no relationship with partner (6%) as the reasons behind their failure to have sought PMCS.

Only 5.07% showed preference to marry a blood relative. Most of the study population (82.07%) did not prefer to marry blood relatives where 5.07% were in the support of consanguinity. But 25.73% were confused about the decision. In spite of finding genetic disease in spouse, 20.66% will still go for marriage and in contrast, 53.80% will not go for marriage. The remaining 25.54% were confused about their decision. Isah *et al* (2008) found in their study that 13.3% of respondent said for sure they will go ahead with their marriage when they are not compatible with their partner, 22.4% also said they may go ahead with their marriage when they are not compatible with their partners, this is similar to finding in Sultan Qaboos University Oman by Al-kindi (2012) where 26% of the respondent said they will go-ahead with their marriage even if their couples are not compatible for various reasons.

5.2 Conclusion

Based on all the facts, it can be concluded that the selected population in our study do not hold a satisfactory level of knowledge about the concept of PMCS. But their attitude and perception towards the implementation and importance of PMCS is positive and satisfactory. So useful and informative media campaigns, Government and non-Government programs like seminar, workshop etc. should be arranged to educate people regarding the beneficial health consequences of PMCS. Combined approach is strongly needed for creating knowledge and awareness regarding PMCS among general population of Bangladesh. If all could develop a better knowledge about PMCS among the mass population, it will be easy to implement this program in our country. It is however needed to mention that this research was conducted on selected population in a very small scale as it was a purposive survey based study. So, it doesn't reflect the whole idea. Therefore, it is suggested that if a conclusive result and more accurate scenario about the knowledge and awareness about PMCS is desired, further largescale researches should be conducted.

Chapter 6
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