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Social Inclusion of Children with Down syndrome in Abha City, Saudi Arabia.

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ABSTRACT

Down syndrome (DS) is popular case which is occurring greatly around the world. In this case the DS child has an extra chromosome (chromosome 21) in its genetic material, to be 47 chromosomes in each body cell, and the phenomenon is called trisomy. The cases vary from mild, moderate or severe. The condition effects on the body shape and the brain development of the baby causing mental delay and physical challenges. DS children suffer from many complications at various ages.

External appearance of DS children is very distinguishable, as they have flattened face, Brachycephaly, Almond-shaped eyes, and protruding tongue out of the gaping mouth.

Down syndrome is the most common chromosomal aneuploidy disorder affecting all countries, all races and both sexes. In Saudi Arabia, a study has been developed in Riyadh to determine the ratio of DS incidence in Saudi population, gives an incidence of 1 out of every 554 live births, with a ratio of 1.8 per 1,000. In fact, KSA is the country with the highest detected number of DS cases around the world. DS is classified into 3 types according to the type of disturbance in the genetic division into the following: Trisomy 21, mosaic, and translocation Down syndrome. Treatment of DS cases depends on the complications of every case.

The government of KSA has made several regulations to ensure that special services are presented for DS children in their early stage which is called early intervention stage. Prince Salman center for disability research in 2004 has developed some public agencies providing the training and rehabilitation services, these services include the free provision of the accurate medical, social, rehabilitation, educational and psychological services. Recommendations include avoiding consanguineous marriages and being pregnant over age of 40 years old.

Keywords: Social inclusion, children, down syndrome, behavioral intentions

INTRODUCTION

Down syndrome is a popular case occurs with high percentage around the world, in which the child has an extra chromosome (chromosome 21) in its genetic material, to be 47 chromosomes in each body cell. Children with Down syndrome have specific physical characters and mental challenges with a speaking attitude slower than normal ones. The cases vary from mild, moderate or severe.

Down syndrome (DS) is still the most common chromosomal condition diagnosed in the U.S.A, in which about 6000 babies are born every year with DS, which refers to 1 out of every 700 babies are born DS in 1980s. In 2002, 1 out of every 1000 babies are born DS ranging from 0- 19 years old, that mean that we have 83,000 children & teenagers DS.

In 2008, 1 out of every 1200 babies is born with DS, which mean that we have 250,700 DS between children, teenagers and adult. This is referring to that DS has become more common and children are living longer. The condition effects on the body shape and the brain development of the baby causing mental delay, physical challenges and some other abnormalities including heart and GIT disorders of the baby (Mayo clinic,2018)

STUDY QUESTIONS

In this study we will discuss and make answers about:

1- What are the causes of Down syndrome?

2- What are the common risk factors affecting the incidence of DS baby?

3- How to diagnose DS case?

4- What are the most common clinical signs and phenotype?

5- How to make inclusion of DS children in the Saudi society?

OBJECTIVES

This study aims to identify the main causes of Down syndrome, explaining how it occurs and the common risk factors affecting it. Identify the phenotype or the external appearance of DS children and babies, the most common signs in face and body. The study also aims to explain the different ways to make DS diagnosis during pregnancy and even before (using premarital screening program). And finally, explaining the programs and strategies to make inclusion of DS cases in childhood and adulthood.

DEFINITION

Down syndrome is a condition which is characterized by an extra chromosome (genetic disorder). Chromosomes are defined as a small group of genes found in the cells of the body, by which the form of baby is determined during pregnancy and how the baby`s body function works from conception till birth (CDC.2018)

Normally born babies have 46 chromosomes, but in down syndrome the baby will have an extra copy of chromosome 21 in a case called “trisomy”, so the baby will have 47 chromosomes (CDC,2018). This condition has resulted from abnormal cell division that resulted in an extra full or partial copy of this chromosome (Mayo clinic,2018)

Children with DS sometimes appear and act normally and similar to other people but with different abilities. IQ test (intelligence test) measured to Down syndrome shows middle-to-moderate low range IQ test result, with slower speaking than normal children and learning disabilities.

EPIDEMIOLOGY

Epidemiology is defined as the study of patterns and causes of health-related traits in certain population. Epidemiological studies of Down syndrome has begun in the mid of 1800s,

When several researchers and physicians had described group of patients suffering from mental retardation and the specific characters of Down syndrome specially the oblique eye fissures, epicanthal folds or protruding tongue.

In U.S, researchers had determined the differences in maternal-age prevalence rates in a 3 major maternal racial/ethnic groups, which are non-Hispanic white, non-Hispanic black and Hispanic. The study revealed that non-Hispanic white and non-Hispanic black has prevalence ratio 0.77, Hispanic mothers was 1.12, the differences were varying according to ethnic/racial variations as : use of pre-natal care, environmental exposure, pre-natal diagnosis, selective termination or genetic risk factors in relation to maternal age (Canfield et al.,2006).

In the worldwide, down syndrome is the most common chromosomal aneuploidy disorder affecting all countries, all races and both sexes? Incidence of DS is supposed to be relatively high in the developing countries, probably due to the higher death rate (mortality) in DS such as congenital cardiovascular defects. Improving survival of Down syndrome infants, because of the better care of cardiovascular disorders will affect prevalence ratio of DS. According to World Health Organization; the predictable incidence of DS is between 1 in 1,000 to 1 in 1,100 live births all over the world.

In the Arab world, the ratio incidence is 1 in every 800 births and related to the advanced maternal age. The name of “Mongolism” is still used in the Arab countries, hence the offensive and misleading term is not used around the world. Some medical professions use the term “Mongolian Idiocy” referring to the most prominent physical symptoms and the impaired cognitive development (World Down Syndrome, 2013).

The center for Arab Genomic studies has collected research data from 9 different Arab countries for Down syndrome cases which revealed that there are 6 countries have a higher incidence of DS cases than the international figures. DS incidence in UAE was 1:319, Oman was 1:500, Qatar was 1:546, KSA was 1:554 and Kuwait was 1:581.

The center also approved that the high incidence of DS in KSA is related to the consanguineous marriages, in which these marriages have reached 66.7% of all marriages in KSA. (AlSalloum, 2015), who found that genetic and congenital disorders are mostly responsible for the infant mortality, morbidity and disability. He also suggested that the high maternal and paternal age is responsible for high percent of infants with congenital anomalies especially down syndrome. Others thought that diabetic mother is at high risk to have DS child than the non-diabetic mother. (AlSalloum et al., 2008)

In Saudi Arabia, a study has been developed in Riyadh to determine the ratio of Down syndrome incidence in Saudi population, it was found that 42 persons (23 females & 19 males) of 23,261 babies born alive to Saudi women, that`s gives an incidence of 1 out of every 554 live births with a ratio of 1.8 per 1,000. The study determined the advanced maternal age and the elevated maternal parity are the cause of the increased ratio of Down syndrome. Cytogenetic studies proved that 37 cases were Trisomy 21 and the remaining were translocation type (Niazi et al.,1995).

In fact, KSA is the country with the highest detected number of Down syndrome cases, and the study has revealed there is no significant relationship between Down syndrome incidence and the ethnic or racial background of children`s parents in KSA. In addition, religious and cultural factors play an important role in increasing the number of Down syndrome children born in KSA due to the prohibition of abortion when identifying a baby with Down syndrome in the early stages of pregnancy (AlMalaq,1999).

CLASSIFICATION OF DOWN SYNDROME

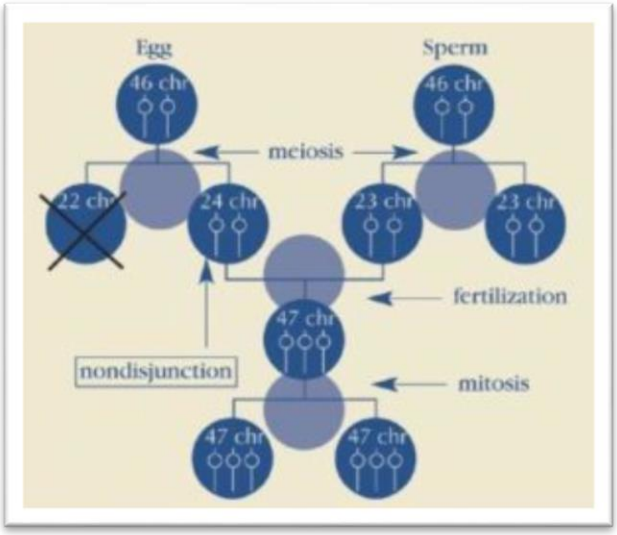
Normal body cells contain 23 pairs of chromosomes, half of them from the mother and the other half is from father to equal 46 chromosomes. In Down syndrome will occur division abnormalities that will result in an extra full or partial chromosome 21(Ch21).

According to the type of disturbance in the genetic division we have classified Down syndrome into 3 categories (there is no differences in the external appearance and no one can differentiate

between the 3 types externally but you must confirm genetic analysis to determine which type is it). (ndss)

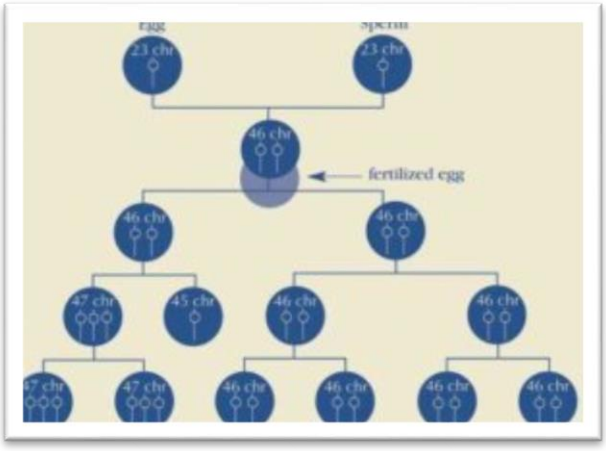
(1) Trisomy 21 (non-disjunction) :

The most common type of Down syndrome, occur in about 95% out of all cases. Caused by cell division error called "non-disjunction" which will result in an embryo with 3 copies of Ch21 instead of two copies, that is repeated in every body cell. This duplication failure occurs before or during conception phase in either sperm or ova.



(2) Mosaic Down syndrome (Mosaicism) :

This is a rare condition of Down syndrome represent about 1% of all cases, in which only some cells has an extra copy of Ch21. The result is some cells containing 46 chromosomes and another containing 47 chromosomes. The mosaic components of normal and abnormal cells had resulted from abnormal cell division after conception phase. It`s thought that this type has fewer characteristics of Down syndrome than the other types.



(3) Translocation Down syndrome :

This type represents 4% of all Down syndrome cases, in which body cells have the normal 46 chromosomes but there`s an additional full or partial copy of Ch21 attached to another chromosome (usually chromosome 14), so it will result in development of the same characters of Down syndrome.

Is it inherited?

Most of Down syndrome types are not inherited because it`s a genetic disorder in fetus, except Translocation type of Down syndrome which can be passed from parent to child. Only some children of translocation type had inherited Down syndrome from one of their parents.

RISK FACTORS

1- Genetic risk factors :

A- Advanced maternal age and related hypotheses :-

The mother age at time of conception is highly related to meiotic errors of Ch21 NDJ. Many studies are put to explain the hypotheses of this relation but nothing is proved to be the correct one.

The most popular hypotheses includes the theory of the oogenesis protracted tenure had interfered with meiotic divisions that may lead to more vulnerable egg for aging effects than the sperms.

Also, the long maturation period of ova in aging women will lead to deteriorative changes that are accumulated over time. Another factors as the decreased amount of meiotic proteins, meiotic checkpoints components, a centromere weakening due to aging that resulted from decreased centromere-associated-proteins, or mitochondrial deletions. All those are thought to be the cause of disrupted spindles and misaligned chromosomes and is known as "chiasma slippage" and it`s supposed to be the first hypotheses. Finally, the high rate of Ch21 NDJ is showed in mothers of Down syndrome having age more than 35 years old (Oliver et al.,2008) due to down regulation of human proteins controlling the chromosomes exchange.

"biological aging" or "ovarian aging" is the second hypotheses which depends on that prediction of biological aging is different between women of the same chronological age, and the frequency of trisomic conceptions are related to her biological age not the chronological age. Biological age is estimated by counting the falling number of follicles during life with decreased total oocyte pool size. The condition will lead to hormonal imbalance in ovary (decreased levels of serum inhibin A & B, estrogen level and increased FSH level). The hypotheses evidence is elevated levels of FSH is reported in women with Down syndrome pregnancies.

"Genetic age" of women is the third hypothesis depends on that all kinds of degenerative changes in ovary and oocyte are caused by genetic aging.

B- Altered recombination pattern and its interaction with maternal age :-

The studies suggested that part of maternal NDJ errors are associated with decreased Ch21 recombination, also the absence of the exchange along the non-disjoined Ch21. There are 3 susceptible pattern suggested to cause the maternal Ch21 NDJ which are : 1) no exchange result in highly MI errors, 2) or the single telomeric exchange also increased MI errors, 3) or the pericentromeric exchange result in highly MII errors.

A study on US population proved that the relation between maternal age and the reduced frequency among the MI cases, that older women (more than 35 years old) are having less recombination along the Ch21 than younger ones (Lamb et al.,2005).

C- Genetic polymorphism and increasing susceptibility of Down syndrome birth :-

Polymorphism is related to increased level of plasma homocysteine and/or low folate level (Sherman et al., 2005). Folate is essential element for S-adenosylmethionine production which act as a methyl donor for DNA methylation, which is essential for gene expression regulation and to maintain chromosomes integrity at centromere. Folate deficiency decreases S-adenosylmethionine production which will directly lead to DNA hypomethylation resulting in chromosomal NDJ.

D- Paternal risk factor for Ch21 NDJ :-

The paternal errors represents about 5 – 10% of Down syndrome causes, studies showed that the altered chiasma positioning might not associate with spermatogenesis NDJ, and doesn`t prove a significant reduction in MI or MII recombination errors, and there`s no relation between advanced age with meiotic outcome groups or spermatogenesis process. This study proved that the frequency of Ch21 NDJ errors has higher susceptibility in female than male.

2- Habitual risk factor for Ch21 NDJ :

There are many environmental and habitual risk factors that mothers may consume before or during pregnancy that will effect on births of Down syndrome. These factors include:

- Maternal cigarette- smoking: highly related to MII errors and thought to reduce the blood & oxygen around follicles.

- Using of oral contraceptives: effect on follicular microcirculation through abnormal hormonal signaling.
- Pre-conception alcohol consumption by mother.
- Exposure to radiation and radioactive materials.
- Low socio-economic status: in which mothers are unaware with the right habits used to develop a healthy fetus.

Some environmental pollutants, as: water fluoridation or contamination with pesticides.

PATHOPHYSIOLOGY

"Aneuploidy"

Defined as the presence of incorrect number of chromosomes in the body cells. Trisomy 21 is a case of aneuploidy, which shows the highest frequency of occurrence (as 1 out of every 700 children) (Kanamori et al., 2000). It originates from the condition of non-disjunction or non-separation (NDJ) of Ch21 during the process of gametogenesis, so formation of disomic gametes with 2 copies of a particular chromosome (Ch21). Then fertilization occur by haploid gamete which lead to implantation of trisomic fetus, which is later called as "Down syndrome (DS)" according to name of John Langdon Down who described this syndrome (Down,1866).

Human chromosome 21 is the smallest chromosome, its length is about 38 MB and is about 3% of its encodes sequence are proteins, Ch 21 contains 225 genes and 59 pseudo genes. In staining with Giemsa stain Ch 21 is appeared as a dark band. The gene catalogue of Ch 21 is containing ten kinases, 5 genes responsible for ubiquitinations pathways and the other 5are responsible for cell adhesions molecules (which are a number of transcription factors and seven ion channels)

The exact gene responsible for the phenotypes is not yet identified, but the several complex phenotypes present in DS condition maybe resulted from the overdose of only one or a few genes within the DS critical region.

The D S critical region is defined as a region of about 5.4 MB on Ch 21 which contains genes sufficient to produce several DS phenotypes (Olson et al 2004)

DS can be caused by three types of chromosomal abnormalities:

1- Free trisomy 21 Non disjunction (NDJ)
2- Translocation
3- Mosaicism

The most errors of NDJ occurs in the maternal oogenesis in meiosis stage I (MI), and a little portion of NDJ errors occurs in paternal spermatogenesis. The high incidence of NDJ errors of maternal meiosis mechanism is mostly related to oocyte maturation mechanism in the ovary (Gondos et al.,1986), in which the oocyte completes meiosis I (MI) then enters meiosis II (MII) then pauses its maturation till it`s fertilized by a sperm then completes its maturation. So, it`s thought that the long development process of oocyte in its microenvironment make it at more risk of chromosomal NDJ and hazards.

While searching the etiology of Ch21 NDJ the researchers have found 2 main risk factors described as: the advancing maternal age & the altered pattern of meiotic recombination, in addition there are other environmental and behavioral factors are explained as a risk factors of Ch21 NDJ.

COMPLICATIONS

Children with Down syndrome may have variety of complications that may appear as they become older in age, these complications are:

1- Heart defects:

Half of children with Down syndrome are born with congenital heart defects which could be life threatening and may require surgery in early infants and others are mild and might go away as the child grow up and may only need to be monitored by a health care provider

2- Gastrointestinal defects:

Which includes abnormalities of the intestine, esophagus, trachea and anus and there is an increase of risk of developing digestive problems such as gastrointestinal block, gastro esophageal reflux or celiac disease

3- Immune disorders:

They have increased risk of developing autoimmune disorders due to abnormalities in immune system and high risk of some forms of cancer and infectious diseases as pneumonia

4- Sleeping apnea:

They have soft tissue and skeletal changes which lead to airway obstruction so children and adults with Down syndrome are at high risk of obstructive sleep apnea, between 50 to 75 % of Down syndrome people is affected

5- Obesity:

They have high tendency to be obese compared with normal people

6- Spinal problems:

Some Down syndrome people may have misalignment of the top two vertebrae in the neck called “atlantoaxial instability” this condition make them at high risk of spinal cord injury due to overextension of the neck

7- Leukemia:

Young children with Down syndrome is at high risk of leukemia

8- Dementia:

They have higher risk of developing dementia and Alzheimer disease and the symptoms appear on age of fifty years old

9- Hip dislocation:

When the thigh bone slips out of the hip socket occurred in 6% of Down syndrome

10- Other problems:

Other health conditions may occur such as endocrine problems(like thyroid disease) , dental problems , seizures , ear infections , hearing problems reach to hearing loss (up to 75% is affected) and vision problems and eye diseases like cataracts.

SIGNS AND SYMPTOMS

Physical symptoms:

There are some common physical features that characterize children and adults with Down syndrome (CDC, 2018), include:

- Flattened face with nose-bridge.
- Brachycephaly (flattened head in the back)
- Almond-shaped eyes slanting upward.
- Small folded ears.
- Short neck.
- protruding tongue out of the mouth lacking the central fissure.
- Gaping mouth with abnormal teeth sometimes.
- Presence of tiny white spots in the iris of the eye “Brush field spots”
- Small broad hands and feet.

- Presence of palmar crease in the palm of the hand (a single line across the hand palm).
- Fingers are small and pinky and sometimes are curved toward the thumb.
- Poor muscle tone and loose joints.
- Their height are shorter than normal children.
- Intellectual disabilities: they suffer from affections in the short and long-memory, delayed language skills and mild to moderate cognitive disorders.

If your baby is Down syndrome and you can`t ensure of that after birth immediately, so here is some physical characters you can through them distinguish wether your baby is Down syndrome or not. Newborns` some physical characters:

- Extra skin at the back of head.
- Eyes slanting upwards.
- Flattened face.
- Hypotonia (muscle weakness) and abnormal flexible joints.
- Abnormal looking ears.
- "Sandal gap deformity": which is a wide gap between 1st and 2nd toes.
- The affected neonates rarely cry.
- Epicanthal folds in the eye inner corner usually present.

Mental symptoms:

Down syndrome affects the child`s ability to think, reason, understand, and to be social. The effects may be mild, moderate or severe, they usually take a longer time to reach important goals starts from crawling, walking and talking (due to joints and muscular weakness),

In school they usually need extra help to learn writing and reading, ending with getting dressed and using toilet by their own.

The most common cognitive and behavioral symptoms are:

- Short attention time and focusing.
- Poor judgment.
- Impulsive behavior.
- Slow learning.
- Delayed language and talking development.

DIAGNOSIS

Are used to screen or diagnose Down syndrome, these tests have little or no risk for the mother and the baby and it gives an approximate results (I cannot tell for sure the baby is Down syndrome or not)

The diagnostic tests performed during pregnancy can confirm a diagnosis, but the tests have a small risk of causing miscarriage, although many health care providers recommend Down syndrome diagnostic tests for pregnant women who are 35 years old or older as it is the highest risk factor of Down syndrome and also if there is another child has Down syndrome or there is a family history of Down syndrome.

In addition, if the diagnostic tests are positive it means baby with Down syndrome will be delivered and family will have time to be prepared for caring of this baby and plan for health care and support services for the child and family

If the mother did not be tested during pregnancy or want to confirm the results of other tests the baby must get tested especially if he has the characteristic symptoms of Down syndrome:

There are two types of Down syndrome tests:

1- Screening tests : tests done during pregnancy (prenatal tests)
- Cell – free DNA (cfDNA) screening
- First trimester screening
- Second trimester screening

2- Diagnostic tests
- Three tests done during pregnancy which are :
  a- Amniocentesis
  b- Chorionic villus sampling (CVS)
  c- Percutaneous umbilical blood sampling (PUBS)
- Diagnostic test done after birth (blood test)

First: Down syndrome screening test (done during pregnancy or called prenatal testing):

1- Cell – free DNA (cfDNA) screening:

It is a blood test done early in 10th week of pregnancy it gives result of risk of Down syndrome (trisomy 21, trisomy 18 and trisomy 13) and also tell us about the fetal sex

2- First trimester screening:

This test is is a combined test that done between 10 th and 14 th week of pregnancy ,**First** is a **blood tests** that measures the level of certain proteins in mother's blood that is called pregnancy associated olasma protein – A (PAPP-A) and the pregnancy hormone known as hyman chorionic gonadotropin (HCG) if it's level is above normal it means higher chance of baby with down syndrome (trisomy 21 and trisomy 18) , **second** is the **ultrasound** for the baby to see signs of down syndrome which is called *Nuchal translucency test* in this test we measure a specific area on the back of baby's neck when abnormalities is found more fluid than usual is collected in this neck tissue

3- Second trimester screening (or called quad screen):

It is a blood tests that check levels of certain substances in mother's blood it could be one or both of:

- A triple screen test : it looks for three pregnancy associated substances which is : alpha fetoprotein , HCG and unconjugated estriol , and it is done between the 16th and 18th week of pregnancy
- A quadrable screen test : it looks for four pregnancy associated substances which are : alpha fetoprotein , estriol , HCG and inhibin A , this test is done between the 15th and 22th week of pregnancy

If the down syndrome screening tests shows abnormal levels that gives higher chance of down syndrome (trisomy 21 and trisomy 18) and also we can find open neural tube defects such as spina bifida, physicians combine the results of both first trimester screening and the squad screening (second trimester) that is called integrated screening tests to confirm the Down syndrome and also ultrasound is used to detect birth defects and fetal anomalies including neural tube defects , so diagnostic tests is needed to confirm or exclude the diagnosis

It is important to note that screening tests may give false positive results and also false negative results as the triple screen test has false negative rate by 35 to 40 % and false positive rate by 5 to 8 % detecting about 60 to 65 % of all incidences of Down syndrome

Second: Down syndrome diagnostic tests:

1- Diagnostic tests during pregnancy:

a- Amniocentesis:

It is done in the second trimester between the 15th and 20th week of pregnancy by taking a sample of the amniotic fluid that surrounds the fetus which is withdrawn through a needle inserted in mother's uterus then analyzed to reveal chromosomes of the fetus , this test has low risk of miscarriage

b- Chorionic villus sampling (CVS):

It is done in the first trimester between the 10th to 13th weeks of pregnancy by taking a sample (cells) from the placenta and used to analyze the fetal chromosomes, the risk of pregnancy loss (miscarriage) from CVS is very low

c- Percutaneous umbilical blood sampling (PUBS):

It is the most accurate test for diagnosis of Down syndrome, it is done between 18th and 22nd week of pregnancy by taking a blood sample from the umbilical cord

There are a diagnostic test called pre-implantation genetic diagnosis which is very useful to couples who are in high risk for Down syndrome, in which invitro fertilization is occurred and then the embryo is tested for genetic abnormalities before it is implanted in the womb

2- Diagnostic tests for down syndrome after birth (diagnostic tests for newborns) :

Firstly Down syndrome is suspected due to the baby's appearance then a blood sample is taken from the baby and examined for the chromosomes which is called chromosomal karyotype test and this test confirm the diagnosis of Down syndrome baby if found an extra chromosome in all or some cells.

TREATMENT

Down syndrome has no treatment as it is a genetic abnormality, but this syndrome is accompanied by several complications that we discussed before and the early intervention for infants and children with Down syndrome makes a great difference in their quality of life.

Every case with Down syndrome has its own criteria and problems so it needs special treatment along different stages of life which needs different services and that is accomplished through a team care which consist of several specialists who can provide medical care and help developing skills, the team care may include according to the child's particular needs the following specialists:

- Primary care pediatrician to provide childhood care
- Pediatric cardiologist
- Pediatric gastroenterologist
- Pediatric neurologist
- Pediatric ear, nose and throat (ENT) specialist
- Pediatric ophthalmologist
- Audiologist
- Speech pathologist
- Physical therapist
- Occupational therapist

Parents are responsible for building a team of health care providers, teachers and therapist to help take care of the child health and education.

INCLUSION OF DOWN SYNDROME IN SAUDI ARABIA

In Saudi Arabia, Down syndrome children number is below 17 years old are about 20,000 according to the researcher's studies. They said that the young Down syndrome children are suffering from ignorance and negligence, but they need better health care services from the day of birth how to deal with those babies with special requirements and needs, till childhood and school stages in which they have to be learnt talking, reading, writing and social communication, and ending with adolescence stage in which they need a suitable jobs meet their needs.

They explained that Down syndrome condition need a number of basic requirements to help them integrating, interacting and communicating with society, this efforts must include refining their skills and capabilities from birth, the provision of health care, need special education and training in private or regular schools as according to the needs of each case, rehabilitation of them, exercise and physical therapy and learning them how to deal with the society as normal people.

Also parents of Down syndrome said that there are several challenges they face with their children as lacking of accurate diagnosis of their condition, poor health care services, lack of specialized centers sometimes, the careless state of rehabilitation of them and lack of specialized sports and vocational training programs.

Early intervention for Down syndrome in KSA:

The government of KSA has made several regulations to ensure that special services are presented for DS children in their early stage which is called early intervention stage.

The initial step includes enacting disability legislation to proof that those people are enjoying the same rights of other normal people in society (ministry of health care in Saudi Arabia, 2010)

This legislations have involved describing the early intervention programs needed for DS children and ways preventing and how to overcome the disability, it also includes the diagnosis and assessment for determination the disability level and depending on determining the special educational needs

Prince Salman center for disability research in 2004 has developed some public agencies providing the training and rehabilitation services, these services include the free provision of the accurate medical, social, rehabilitation, educational and psychological services.

Ministry	The initiatives
Health	- Epidemiological surveillance systems for infectious diseases - Complete vaccinations for DS children - Early detection of DS fetus and health care services for the pregnant mother - Early screening programs before marriage
Education	- Providing early intervention and diagnosis in Reyadh in 2005 - Quantitative expansion in the kinder garten development - Orientation to compulse the kinder garten - Teacher training for the early intervention skills

Private institution and charities	***Establishment of specialized centers for DS:*** - Center for children with DS (Riyadh) - Al Nahda women's charitable society (Riyadh) - Day care center(Ain Al Fares) - The voice of DS society (Riyadh)

There are some shortcomings are directly affecting the early intervention services (EIS) provided in KSA, including that EIS are still in their initial stages in a narrow, random and unorganized progress. The lack of efficiency and profession is still a major cause for the non-effectiveness (Merza, 2002).

The studies also suggested that the EIS available programs represent medical, social and caring services but it doesn`t meet the needs of neither parents nor their DS children, doesn`t raise the awareness of their legal or educational rights. (Merza, 2002)

The lack of coordination and cooperation among the EIS stakeholders who are providing care services in KSA lead to limited legislation applying for the DS rights, so the EIS in KSA is still limited even in the major cities as Riyadh, Jeddah and Dammam and doesn`t meet the increased demand which will result in the heavy financial and therapeutic duty on families.(Al-Zaalah,2015). The EIS are situated and centralized in urban areas though ignoring the requirements of special needs` families in more rural areas as villages and some smaller cities as "Abha" which suffer from the ignorance of EIS centers.

CONCLUSION AND RECOMMENDATION

Many DS cases are happening around the world with high percentage. The most common risk factors are pregnancy over 40 years old (advanced maternal age), consanguineous marriages, parental genetic risk factors of Ch 21.

There are some recommendations about how to decrease the incidence of Down syndrome cases. The recommendations include:

1- Voluntary cancellation of consanguineous marriages, specially in cases of first-cousin marriages in which the risk of Down syndrome incidence is relatively high due to genetic mutations or incorrect chromosomal division, enhancing the occurance of DS offspring.
2- Be sure to make the premarital screening program and genetic mapping for both couples.
3- Avoid to be pregnant after age of 40 years old, it`s proved that after this age the incidence of DS baby is enhanced with a higher probability.

In case you have already a DS child or pregnant with DS baby, the recommendations are all about to be calm, learn how to deal with DS child and try hard to make the child inclusion with family and society. It`s known that DS child is a gift from God.

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