



EGYPTIAN ACADEMIC JOURNAL OF
BIOLOGICAL SCIENCES
ZOOLOGY

B

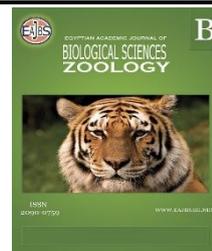


ISSN
2090-0759

WWW.EAJBS.EG.NET

Vol. 15 No. 1 (2023)

www.eajbs.eg.net



Analysis of Attitude of Public Towards Prenatal Screening for Diagnosis of Genetic Disorders

Prakash Shoba¹ S.*, Arokya Glory¹ P. T., Princy Anusha² V., Varshaa². T. B., Venci Candida¹ X., Punitha A.¹ and Anitha¹. C

¹Department of Zoology, Holy Cross College, Nagercoil (Tamil Nadu), India.

² Holy Cross College, Nagercoil (Tamil Nadu), India.

E-mail*: prakash.shoba06@gmail.com,

ARTICLE INFO

Article History

Received:26/5/2023

Accepted:27/6/2023

Available:29/6/2023

Keywords:

Prenatal diagnosis, Genetic disorders, Pregnancy, non-communicable diseases.

With a very large population and high birth rate, and consanguineous marriage favored in many communities, there is a high prevalence of genetic disorders in India. The cross-sectional study was carried out in people of the Kanyakumari District, Tamil Nadu community males and, females both married and single with a wide range of ages and educational backgrounds as well as covering a diverse number of generic diseases. The cross-sectional survey was conducted among people of the Kanyakumari District, Tamil Nadu (n = 201) to determine their practices toward reproductive decision-making. The main objective of the study is to analyze the participant's knowledge of the practices towards prenatal diagnosis (PND) and termination of pregnancy. Genetic testing has the maximum possible potential to reduce the prevalence of genetic disorders by early detection. Studies found that general knowledge of genetic diseases in Tamil Nadu lacks an understanding of the fundamental characteristics of genetic diseases. Primarily due to the occurrence of consanguineous marriages 20%. The practice towards PND (61%) was more favorable than TOP (39%). PND was found to be a good opportunity for early diagnosis and gives parents choice. In Kanyakumari District, most people will have an awareness of genetic disorders, Prenatal diagnosis, and Termination of pregnancy. Mercy (22.60%), religious belief (12.8%), and sin (12.2%) is the main influence on the participant's practices concerning Prenatal diagnosis and Termination of pregnancy. The fetus was diagnosed with a genetic disorder before 120 days of pregnancy, they have undergone abortion favored by 61.2%, and unfavored by 48% of the people. 62% of members responded to the diagnosis of a fetus with genetic diseases before delivery, and 38% were not accepted in prenatal diagnosis. 50.8% of members not knowing the causes of a family history of genetic diseases. But 49.2% know the causes of a family history of genetic diseases. The reason for rejecting the above question was religious belief (12.8%), Ethics (10.4%), culture (9.8%) Mercy (22.6%), sin (12.2%), Others reason (32.3%). For accepting abortion before 120 days of pregnancy (50.2%) members for getting a healthy child (68.9%), to avoid the affected child (31.1%). The current challenge of the research is a comprehensive effort to revisit consanguineous marriages and their effects with more recent using statistical methods to assess the prevalence and effect of consanguineous marriages on pregnancy.

INTRODUCTION

As in other developing countries, India is facing an accelerating demographic switch to non-communicable diseases, and in the cities, congenital malformations and genetic disorders have become important causes of mortality in the perinatal period. Scientific advancements in genetic testing have moved us to an era of individualized preventive medicine. Genetic testing has the maximum possible potential to reduce the prevalence of genetic disorders through early detection and making strategized decisions for prevention (Hamberg and Collins, 2010). Studies found that general knowledge of genetics in India lacks an understanding of the fundamental characteristics of genetic disease (Olwi *et al.*, 2016). This is consequently a major concern in southern countries, which have a high prevalence of inherited genetic diseases, primarily due to the high occurrence of consanguineous marriages (Tadmouri *et al.*, 2009, Al-Al-gazali *et al.*, 2006). Consanguinity or blood-relative marriage is a union between close biological relatives of another person. India is one of the developing countries with the highest prevalence of consanguineous marriages as the majority of the marriages are still tribal (Tadmouri *et al.*, 2009). It leads to a substantial burden of genetic diseases in the country (Al-gazali *et al.*, 2006).

Unfortunately, genetic diseases still receive relatively little overall attention due to the mistaken perception among health planners, clinicians and the general public that inherited diseases are very rare, affect only a small proportion of people, and even if diagnosed, are largely untreatable. However, for the families concerned they represent a substantial, continuing burden, unlike infectious diseases, which generally manifest only for a limited period. Health care within India is provided by an integrated system of village health centers, sub-centers, primary health centers, community health centers, district health officers, and medical colleges. The profound influence of caste endogamy has been confirmed by genomic analysis of modern Indian populations which has confirmed the continuing high level of gene differentiation (Majumder *et al.*, 1999), with marked divisions according to caste rank (Bamshad *et al.*, 2001). While caste endogamy is universal, India is subdivided into two major regions concerning a preference for, or avoidance of, consanguineous marriage. The mainly Indo-European-speaking Hindu peoples in the northern states avoid marital unions between biological kin, because of a prohibition on consanguineous marriage believed to date back to approximately 200 BC (Sanghvi, 1966, Kapadia, 1958).

By comparison, there is a long tradition of uncle-niece marriage and unions between a man and his maternal uncle's daughter (mother's brother's daughter) in South India (Sastri, 1976). Consanguineous marriage is common in all Indian Muslim communities (Bittles and Hussain, 2000). Variations are, however, seen in the levels of consanguineous unions contracted in different branches of Islam and between specific communities, and these differences emphasize the important influence of local and regional customs in the arrangement of marriage contracts.

To eliminate the burden of genetic diseases, patients are required to make some decisions concerning genetic testing. The understanding of the genetic disease and the patients. Toward PND; TOP was less accepted among participants. Religious belief is the main influence on the participants' practices concerning PND and TOP (Alkuraya and Kilani, 2001, Alsuaïman *et al.*, 2013, Alsulaiman and Hewison, 2007).

In this study, we are targeting the cross-section of the Indian community; males and females, both married and single with a wide range of ages and educational backgrounds as well as covering a diverse number of genetic diseases. In India, the prevalence of consanguineous marriage is still high, we found it is mandatory to conduct such a study, considering that the current premarital screening methods are not fulfilling the objectives of

screening (Al-amodi *et al.*, 2018, Ngim *et al.*, 2013). In particular, the main objective of the study is to determine the practices toward PND and TOP.

Linguistically, Consanguinity is a term that is derived from two Latin words "con" meaning common, or of the same, and "sanguine" meaning blood, hence, referring to a relationship between two people who share a common ancestor or blood. In other words, consanguineous marriage refers to unions contracted between biologically-related individuals. In clinical genetics, a consanguineous marriage means a union between couples who are related as second cousins or closer (Alwan and Modell 1997, Modell and Darr, 2002). Among them, this would include double first cousins, first cousins, first cousins once removed, and second cousins. Uncle-niece marriage is prohibited in Islam and so is absent in India. In population genetics, Consanguinity may also refer to unions of individuals with at least one common ancestor such as those occurring within population isolates, small towns, and tribes; intra-community or endogamous marriages. The custom of endogamy among individuals belonging to the same family has been strongly favored in India, with the consequence of the unequal distribution of founder mutations among the population. A large number of studies into the effects of consanguinity on health and disease have not considered such discrepancies.

Analysis of a genome sequence has the potential to reveal information useful for disease diagnosis and prevention, as well as reams of data that is clinically irrelevant or even impossible to interpret with current knowledge (Kohane *et al.*, 2012). Genome-wide sequencing technologies will soon make genome analysis available to many thousands of people in clinical and research settings, for example, the Genomics England initiative plans to sequence 100 000 genomes for the National Health Service (www.Genomicsengland.co.uk). Social science research that offers insight into what potential participants would want to know from their genome sequence is thus both crucial and timely.

When the survey was undertaken in response to a specific question, such as understanding the cause of a child's developmental disorder (Wright *et al.*, 2014). A genome/exome sequence can be an extremely valuable tool for the discoverer of pertinent or pertinent or primary findings, that is, mutations in genes relevant to the disorder. In the absence of a specific clinical question and a relevant phenotype or family history, it is difficult to identify clinically relevant genetic variants among the thousands of variants in an individual. Even if the pathogenicity of a genetic variant could be assured, and factors affecting the penetrance of the variant were clearly understood, the volume of data presents considerable logistical challenges (Wright *et al.*, 2014, Berg *et al.*, 2011). suggest that the interpretation of sequence data could be categorized into 'bins' (Berg *et al.*, 2011) and only particular 'bins' of data interrogated and returned, for example, those relating to serious, treatable conditions.

Genomic researchers are apprehensive about the potential impact this could have; analyzing and reporting findings unrelated to the study objectives risks compromising the research endeavor. In the future, logistical difficulties relating to this may ease, in which case active searching for particular ifs could become feasible (Berkman *et al.*, 2016). Irrespective of the practicalities, others argue that genomic researchers have no duty (legal or otherwise) to an active search for ifs in research.

The development of policy for sequencing in both research and clinical settings should take into account stakeholder views and experiences (Wright *et al.*, 2013, Middleton *et al.*, 2014). A systematic review (Jackson *et al.*, 2012) because of an existing paucity of data that can inform policy. Recently, some valuable, but small-scale studies have emerged from individual countries on the issue of data return in both clinical and research settings. However, as yet there have been no large international studies that gather data across stakeholders from multiple countries and continents.

Relevant stakeholders include, but are not limited to (Kohane *et al.*, 2012) members of the public, who are potential participants in sequencing studies and researchers (molecular scientists and bioinformaticians) who create sequencing assays and made computer-based analysis; (Wright *et al.*, 2015) genetic health professionals (clinical geneticists, genetic counselors, and diagnostic lab staff) - who have expertise in genetics/genomics including data interpretation and explaining results to patients, and who may be called upon to validate sequencing findings obtained in a research context (Berg *et al.*, 2011); non-genetic health professional (surgeons, general physicians, nurses, and midwives) - who work in a healthcare setting and may care for patients receiving results from genomic studies. As genomics moves into mainstream medical practices, there will be an increasing need for this latter group to engage with these issues.

Unfortunately, genetic diseases still receive relatively little overall attention due to the mistaken perception among health planners, clinicians and the general public that inherited diseases are very rare, affect only a small proportion of people, and even if diagnosed, are largely untreatable. However, for the families concerned they represent a substantial, continuing burden, unlike infectious diseases, which generally manifest only for a limited period. Clinical studies indicate that there is a high prevalence of polygenic disorders, such as coronary artery disease, hypertension, diabetes mellitus, psychiatric illnesses (including schizophrenia and manic-depressive psychosis), and asthma in adulthood. The genetic component in these disorders is high. However, because of their high prevalence and a general lack of knowledge of genetics, most physicians ignore their genetic origin.

MATERIALS AND METHODS

This cross-sectional survey was conducted among people of Kanyakumari District from August to October 2021. The questionnaires were sent online (via email or WhatsApp) or handed out to males and females, both married and single. The questionnaire was designed by previously published literature and included additional questions following the local circumstances. All methods were performed under the relevant guidelines and regulations of the Indian Government. Informed consent (signed consent handed out; consent paragraph was included at the beginning of the Google Forms in place of a separate consent form and participants were requested to register their willingness to participate) was obtained from all participants.

The survey was conducted in both English and Tamil languages depending on the respondent's preference. The survey instrument took approximately 5 minutes to be completed. The questionnaire comprised two sections; the first section focused on socioeconomic and background information such as gender, age, education level, marital status, previous experience with unhealthy baby pregnancy, and abortion. While the second section asked about the knowledge of prenatal diagnosis, PND advantages and disadvantages, family history of inherited diseases, and the outcomes on whether participants would consider prenatal diagnosis and their practice toward termination of pregnancy. The outcome variables of the study are TOP and PND, their response was 'yes' and 'no'.

The study also conducts a qualitative analysis, which explains the views of the participants on the advantages and disadvantages of prenatal genetic screening (Fig. 1). The advantages pointed out by the participants were categorized into 1. Early diagnosis and correction of genetic abnormalities; 2. Awareness and medical planning; 3. The choice of abortion; and 4. Psychological readiness. While the disadvantages expressed by the respondents were categorized into six categories (Psychological pressure, Invasive procedure, Inaccurate diagnosis, Against faith, Expensive, and the choice of abortion). The

choice of abortion was common between advantages and disadvantages depending on the participants' view. Some answers have been translated from Tamil to English. Respondents who did not consent to participate in the study were below the age of 18, and/or did not answer the questions of the study outcome i.e., practice towards prenatal diagnosis and termination of affected embryos were excluded from the study.

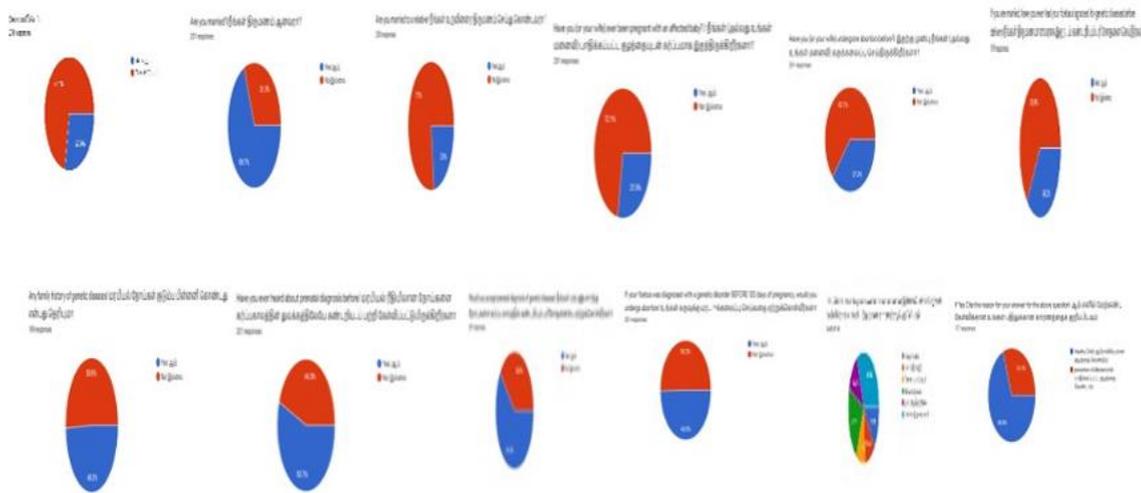


Fig.1: Questionnaire and response recieved

RESULTS

India is a heterogeneous state with diverse cultures and traditional practices in different regions. A majority of the literature on consanguinity in India focuses primarily on the southern states. In response to the questionnaires sent by displays the characteristics of the study sample. Sample characteristics in total, 201. The majority of the respondents were female (72.1%), male respondents in (27.9%), 25 below age (52.2%), and married (68.7%). Of the respondents, 29.5% were undergraduates, and Postgraduates 23.5%. Of the people with pregnant conditions with an affected baby 72%. Of the respondents undergone an abortion before the delivery 37% and 62% had not undergone an abortion (Table 1). Of the people's knowledge of the causes of genetic diseases, only 49% and 51% don't have an idea about this. However, in Indian cultural ethos, consanguinity is practiced in different forms based on the relationship of spouses. Some endogamous communities have a tradition of practicing marriage among cousins while other communities practice marriage between niece and maternal uncle.

Table 1 presents the different types of consanguineous marriages stratified by women's background characteristics. 23% of people are married to relatives or blood relations on the survey, and 77% of the married people are non-relative. The majority (61.2%) would consider the prenatal diagnosis in a future pregnancy. The total responses for PND advantages and disadvantages were n=123 and n=77 respectively.

All the advantages and disadvantages of the PND were categorized based on the opinion of the respondents. Most of the respondents related to the advantages regarding early diagnosis and correction of genetic abnormalities as for disadvantages psychological pressure (n=172, 86%) was the highest. The 37.3% of people undergone termination of pregnancy, and 62.7% of the people not undergone an abortion, members are accepted TOP. The association between socio-demographic characteristics and practice toward PND at the vicariate level is displayed in Table.1. 61% of people accepting prenatal diagnoses of genetic diseases and 38% not accepted the prenatal diagnosis of genetic diseases.

Table 1. Characteristics and background information of the respondents and Practices toward prenatal diagnosis.

Question in the survey	Response	No. of responses	Percentage
Gender			
	Male	56	27.90%
	Female	145	72.10%
Age			
	18-25	15	52.20%
	26-30	37	18.40%
	31-35	18	9%
	36 -40	17	8.50%
	41-45	14	7%
	46-50	10	4.90%
Highest level of education attained			
	10th	9	4.50%
	12th	16	8%
	Diploma	31	15.50%
	ITI	5	2.50%
	UG	59	29.50%
	PG	47	23.50%
	B.E.d	16	7.5%
	MPhil	5	2.50%
	Ph.D	13	6.5%
Are you married to a relative			
	Yes	154	77%
	No	46	23%
Have you (or your wife) ever been pregnant with an affected baby?			
	Yes	145	72.10%
	No	56	27.90%
Have you (or your wife) undergone abortion before?			
	Yes	75	37%
	No	126	62.70%
If you are married, have you ever had your foetus diagnosed for genetic diseases before delivery			
	Yes	72	36.20%
	No	127	63.80%
Any family history of genetic diseases			
	Yes	98	49.20%
	No	101	50.80%
Have you ever heard about prenatal diagnosis before			
	Yes	112	55.70%
	No	89	44.30%
Would you accept diagnosis of genetic diseases			
	Yes	123	61.20%
	No	78	38.80%

Practices Toward Termination of Pregnancy:

The fetus was diagnosed with a genetic disorder before 120 days of pregnancy, they have undergone abortion favored by 61.2%, and unfavored by 48% of the people. 72.1% of people with pregnant conditions with affected babies and 27.9% with members had an unaffected newborn (Table 2). 62% of members responded and accepted the diagnosis of a fetus with genetic diseases before delivery, and 38% were not accepted in prenatal diagnosis. 50.8% of members not knowing the causes of a family history of genetic diseases. But 49.2% know the causes of a family history of genetic diseases. The highest level of the person (55.7%) is ever heard about prenatal diagnosis, (and 44.3%) not accepted it. 61.2%

of members accept the prenatal diagnosis of genetic diseases, (and 38.8%) person not accepted it. If a fetus was diagnosed with a genetic disorder before 120 days of pregnancy (50.2%) of members would not undergo abortion but (49.8%), the reason for rejecting the above question was religious belief (12.8%), Ethics (10.4%), culture (9.8%) Mercy (22.6%), sin (12.2%), Others reason (32.3%).

Table 2. Practices toward termination of pregnancy.

Question in the survey	Response	No. of responses	Percentage
If your foetus was diagnosed with a genetic disorder BEFORE 120 days of pregnancy, would you undergo termination			
	Yes	100	61.20%
	No	101	38.80%
If No, Cite the reason for your opinion the above question			
	Religion	21	12.80%
	Ethics	17	10.40%
	Culture	16	9.80%
	Mercy	37	22.60%
	Sin	20	12.20%
	Others	53	32.30%
If Yes Cite the reason for your choice to the above question			
	Healthy Child	122	68.90%
	Prevention of Affected child	55	31.10%

Table 3. The respondents' opinion towards Genetic disorders

Question: Do you have aware of the following Genetic disorders: Yes/No (%)				
Diseases	Yes	Percentage (%)	No	Percentage (%)
Autism	150	75%	50	25%
Brain Disorders	150	75%	50	25%
cystic fibrosis	135	65	65	35%
Mental Retardation	158	79%	42	21%
Multiple sclerosis	178	89%	22	11%
Hydrocephalus	140	70%	60	30%
Retinal Dystrophy	120	60%	80	40%
Obesity	185	92%	15	8%
Fragile X syndrome	104	52%	96	48%
Hypothyroidism	176	88%	24	12%
Spinal muscular atrophy	135	68%	65	32%
Hearing Loss	170	85%	30	15%
Thalassemia	158	78.5%	42	21.5%
sickle cell anaemia	131	65.5%	69	34.5%
Depression	173	86.5%	27	13.5%
Paralysis	172	86%	28	14%
Microcephaly	141	70.5%	59	29.5%
Cancer	182	91%	18	9%
Arthritis	173	86.5%	27	13.5%
Albinism	155	77.5%	45	22.5%
High blood pressure	184	92%	16	8%
Heart disease	185	92%	15	8%
Cerebral Palsy	144	72%	56	28%
Brain Atrophy	154	77%	46	23%

The reason for accepting the genetic disorder before 120 days of pregnancy (50.2%) members would undergo abortion question was for getting a healthy child (68.9%), and to avoid the affected child (31.1%). 92% of people are aware of genetic diseases of Obesity, Cancer, Heart disease, and High blood pressure. Above 89% of their knowledge on diseases of Multiple Sclerosis, Arthritis, Paralysis, Depression, and Hypothyroidism. Less than 30% of people are unknown for diseases of microcephaly, Cerebral Palsy, Albinism, sickle cell anemia, Spinal muscular atrophy, Thalassemia, Hydrocephalus, and cystic fibrosis. Many people are unaware of genetic diseases below 10% are Retinal Dystrophy and fragile X syndrome (Table 3).

Rejecting abortion due to religious belief shows to be the main influence. They are thinking that abortion is not needed because it is a human or child gifted by God. They have the mentality of thinking that a fetus at 9 months of fetus growth may be recovered from the disease in the development of growth. The effect of the medicine may affect the fetus in development or may cause death .so there skip the abortion. They may be sentimentally attached to the fetus. It might be the first baby, so they skip abortion.

DISCUSSION

Many factors significantly influence the prevalence of genetic disorders. Firstly, consanguineous marriages are common, accounting for almost 40% of marriages among south Indians and Muslims in north India, and a smaller percentage among other groups. Secondly, a large number of infants are born with genetic disorders because of the very large population and high birth rate. Thirdly, improvements in medical care and diagnostic facilities have led to improved identification of genetic diseases which hitherto were submerged by infections and malnutrition.

The current study examined the practice of the Indian community regarding PND and TOP for genetic disorders, in addition to investigating the factors that contribute to their practices. Conducting such a study is highly needed, especially in India where genetic disorders are relatively common due to the high prevalence of consanguineous marriages. In addition to the consanguineous marriages, the high maternal and paternal ages and the tendency to have large families as well as the lack of health measures contributes to the increase in the prevalence of such genetic diseases (Al-Gazali, 2006). Eliminating the burden of genetic disorders depends, at least partially, on public knowledge and practice toward genetic testing (Etchegary *et al.*, 2010).

Across all the socioeconomic categories, cousin marriages are more observed than other types of consanguineous marriages in India. The low percentage of cross-cousin marriages is evident among respondents; whereas the highest percentage of women not married to their uncles. The women married to their uncles and cousins are found more in rural areas than in urban areas. Similarly, the proportion of women married to uncles and cousins is greater among socioeconomically disadvantaged groups such as those having no or less education and poor economic status.

Favorable practices toward PND practice were significantly influenced by higher education levels, older age, prior pregnancy with an affected baby, and prior knowledge of the prenatal diagnosis. Our findings are in line with other studies reporting fairly favorable practices toward PND (Alkuraya and Kilani, 2001). However, despite the positive practices toward PND, participants held a more critical practice when it comes to TOP. Many factors contribute to the acceptance of TOP in addition to being educated (undergraduate and higher education levels), young in age, and having prior pregnancy with an affected baby. People who are married and married to non-relative are more willing to TOP.

Furthermore, people who had an abortion before and had a fetus diagnosed with genetic diseases were more in favor of TOP. Although the majority of participants felt that

TOP is 'acceptable', it is worth noting that their acceptance was conditioned by performing Islamic regulations of abortion. Whereas, the main reason for not accepting abortion was religion. Religion seems to be a major factor in participants' practice toward TOP as previously reported in other studies (Alkuraya and Kilani, 2001).

The rural regions believe that ensoulment occurs after 120 days of pregnancy and as a result, TOP would be forbidden as the fetus is considered a living human. Before 120 days of pregnancy, TOP can be done if the fetal genetic or non-genetic condition is incompatible with life after birth or there will be a great disability and suffering. It is permitted after 120 days when continuing the pregnancy would risk the mother's life (Alamri, 2011). The Council of senior scientists in the Government provided the Ministry of Health (MOH) with an advisory opinion regarding abortion as the following: "Abortion should not be done without a medical decision from a specialized committee that can be trusted, and that committee has to have at least 3 doctors, then it is ok. Also, abortion cannot be done without the approval of both parents or the mother alone if there is direct harm to her only". Here we observed a high acceptance toward TOP in individuals with autistic cases in their family, unlike previous studies that showed a favorable practice toward TOP in hypothetical Down syndrome cases compared to autism (Ngim *et al.*, 2013, Alsulaiman *et al.*, 2012). Both genetic diseases reported to cause stress in the family in coping with the conditions (Sanders and Morgan, 1997), however, they do perceive the severity of the genetic diseases differently (Ngim *et al.*, 2013). The severity of the genetic diseases has a major impact on the acceptance of TOP among families with a history of intellectual disability. In comparison to the previous study, there is a marginal decrease in PND and TOP. The previous study focused on a well-educated region and only college students. In addition, the study did not refine abortion as a single option (Olwi *et al.*, 2016). Contradictorily, the married respondents or their wives ever been pregnant with an affected baby were more likely to prefer TOP, while they were less likely to consider PND. This might be due to the previous experience of having psychological pressure followed by the diagnosis of an affected baby. There was a marginal increase in the rate of acceptance toward PND by the respondents, those who addressed the advantages of PND. One individual's response towards the benefits or advantages of prenatal diagnosis of genetic diseases was "prenatal diagnosis helps in protecting the lives of the child as well as the whole family from the disease burden and the negative aspects of the society". Furthermore, the majority of the responses addressed the advantages of PND. This reflects the positive thinking of the studied population. However, we cannot neglect the view held by a minority of people with the impact of the inaccurate PND and against faith. Moreover, only little percentage of participants felt that the PND is disadvantageous due to psychological pressure or the invasive nature of the procedure.

Transformation Programs in the vision and one of its main objectives is to improve the quality of healthcare services using prevention and therapeutic approaches to control diseases (National Transformation Program 2020). Within the upcoming years, the Kingdom is going to undergo tremendous changes to achieve a modernized healthcare system by implementing several programs that seek to educate the public by raising awareness on important health issues. The present report on the survey would collectively change the public knowledge and practice toward PND and TOP (Alsulaiman *et al.*, 2012). The study has various strengths, this is the first of its kind of cross-sectional survey with a large number of respondents, and the addition of parameters about the positive and negative effects of PND have been included for the first time along with reproductive-decision making. The comparative analysis of reproductive-decision making with additional influencing factors like various disease histories is worth mentioning. The study has several limitations; It is not mandatory that the observation of the study population would translate into a real decision on PND and TOP (Middleton *et al.*, 2016). The study missed the

opportunity to look at practices for different types of prenatal diagnosis (invasive/non-invasive). We believe that our results reflect the practices of the Indians, but final decisions are always subject to change based on the family situation. The study did not include any couples. The major limitation of the study is most of the data were collected through online sources.

The prevalence of late-onset multi-factorial disorders (including coronary artery disease, hypertension, and psychiatric disorders) is also large. Due to inadequate diagnostic, management, and rehabilitation facilities, the burden of these disorders is greater than in Western countries. Although genetic diseases receive little attention from health services, research funding by the government has been liberal. Community control of common disorders like thalassemia, Down syndrome, neural tube defects, and muscular dystrophies deserves high priority, and genetic services should be integrated into the existing primary health care and medical services. Most genetic counseling would have to be provided through training physicians who staff the district and medical school hospitals. To ensure future progress, there is a need to establish additional departments of medical genetics in medical schools.

In terms of implementation, it should be possible to link genetic counseling with family planning services, which would also provide a boost to the expertise and acceptability of family planning professionals. A pulse strategy has been successfully adopted in India for several health initiatives with, for example, two days per year set aside for the immunization of children against polio. The Government of India Department of Health also arranges a 'Protect-the-Mother' campaign on two days in the year, with some 125,000 pregnant mothers examined and advised about their care and management. Similar schemes to create awareness and help organize a screening for common genetic disorders or schemes aimed at disabilities and genetic disorders among the poor could prove useful. However, they would require the widespread mobilization of community workers and health professionals. While the Government of India has identified non-communicable diseases as a target for intervention, currently only cancer, diabetes mellitus, coronary heart disease, and stroke receive attention. Therefore, if real progress is to be made, genetics must be brought into this fold.

Health care, whether for inherited or non-genetic disorders, is a multi-sectorial activity, and empowerment of the population through education, especially of women, is the most important facet of disease prevention. As many people in the country rely on traditional forms of health care, it is important to work with, and not against, practitioners of indigenous systems of medicine. These systems emphasize a holistic approach to health which includes a balanced and nutritious diet, exercise, and a non-stressful life – concepts that can prevent or at least ameliorate many polygenic disorders.

The assessment of the occurrence of consanguinity by background characteristics reveals that they are more prevalent among disadvantageous socioeconomic groups. There is a need to network primary care facilities with genetic units in medical schools and/or in the cities. In the villages and sub-centers, and primary health centers, health workers can be trained to provisionally identify individuals with genetic disorders. Genetic counseling, complemented by simple screening or diagnostic tests, should be provided at the district health centers, while more sophisticated facilities can be provided in medical schools, large hospitals, and regional and national centers.

Many of the disorders, like congenital malformations and complex diseases, affect a large number of people. Genetic counseling and prenatal diagnosis are of great help to the affected families, drug or enzyme replacement therapy is becoming possible for an increasing number of disorders, and gene therapy is on the horizon. A constant effort has to be made to interact with other medical professionals and planners to educate everyone concerned as to the true situation about genetics, emphasizing, the continuing burden of

these disorders in contrast to infectious and parasitic disorders. In part, this can only be achieved by improving training in genetics at all levels, in schools, colleges, and particularly in medical colleges, where the current level of instruction in genetics is poor.

SUMMARY

The fetus was diagnosed with a genetic disorder before 120 days of pregnancy, they have undergone abortion favored by 61.2%, and unfavored by 48% of the people. 72.1% of people with pregnant conditions with affected babies and 27.9% with members had an unaffected baby. 62% of members responded and accepted the diagnosis of a fetus with genetic diseases before delivery, and 38% were not accepted in prenatal diagnosis. 50.8% of members not knowing the causes of a family history of genetic diseases. But 49.2% know the causes of a family history of genetic diseases. The person 55.7% is never heard about prenatal diagnosis, and 44.3% have not accepted it. 61.2% of members accept a prenatal diagnosis of genetic diseases, (and 38.8%) a person not accepted. If a fetus was diagnosed with a genetic disorder before 120 days of pregnancy (50.2%) of members would not undergo abortion but (49.8%) accepted abortion, the Reason for rejecting the above question was religious belief (12.8%), Ethics (10.4%), culture (9.8%) Mercy (22.6%), sin (12.2%), Other reason (32.3%). The reason for accepting the genetic disorder before 120 days of pregnancy (50.2%) members would undergo abortion question was for getting a healthy child (68.9%), and to avoid the affected child (31.1%). 92% of people are aware of genetic diseases of Obesity, Cancer, Heart disease, and High blood pressure. Above 89% of their knowledge on diseases of Multiple Sclerosis, Arthritis, Paralysis, Depression, and Hypothyroidism. Less than 30% of people are unknown for diseases of microcephaly, Cerebral Palsy, Albinism, sickle cell anemia, Spinal muscular atrophy, Thalassemia, Hydrocephalus, and cystic fibrosis. Many people are unaware of genetic diseases below 10% are Retinal Dystrophy and fragile X syndrome.

CONCLUSIONS

Early diagnosis is a good opportunity for the respondents and it gives parent's choice. Respondents with no history of an affected baby were more likely to prefer PND. Education, prior knowledge of PND, and history of the affected baby are significant decisive factors for PND; while education, history of affected baby, abortion, and religious beliefs are the most influencing decisive factors for TOP.

FUTURE SCOPE

The current research is a comprehensive effort to revisit consanguineous marriages and their effects with more recently collected data using robust statistical methods to assess the prevalence and effect of consanguineous marriages on pregnancy outcomes in India. This study creates awareness of the extent of the prevalence of consanguineous marriage in Kanyakumari District and its impact on adverse pregnancy outcomes among women and also on consanguineous marriages and their effects.

Acknowledgement. I am greatly thankful to members of Department of Zoology, Holy Cross College, Nagercoil for helping to complete this work.

Conflict of Interest. None.

REFERENCES

- Al-Amodi AM, Ghanem NZ, Aldakeel SA, Ibrahim Al Asoom L, Rafique Ahmed N, Almandil NB, Naserullah ZA, Al-Jarrash S, Shakil Akhtar M, AbdulAzeez S, Al-Ali AK, Borgio JF. (2018). Hemoglobin A2 (HbA2) has a measure of unreliability in diagnosing β -thalassemia trait (β -TT). *Current Medical Research and Opinion*, 34, 945–951.
- Alamri, Y. A. (2011). Islam and abortion. *Journal of the Islamic Medical Association of North America*, 43, 39–40.

- Al-Gazali, L., Hamamy, H. and Al-Arrayad, S. (2006). Genetic disorders in the Arab world. *British Medical Association Journal*, 333, 831–834.
- Alkuraya, F. S. and Kilani, R. A. (2001). Attitude of Saudi families affected with hemoglobinopathies towards prenatal screening and abortion and the influence of religious ruling (Fatwa). *Prenatal diagnosis*, 21, 448–451.
- Alsulaiman A, Hewison J, Abu-Amero KK, Ahmed S, Green JM, Hirst J. (2012). Attitudes to prenatal diagnosis and termination of pregnancy for 30 conditions among women in Saudi Arabia and the UK. *Prenatal diagnosis*, 32, 1109–1113.
- Alsulaiman, A. and Abu-amero, K. K (2013). Parent's Attitude toward prenatal diagnosis and termination of pregnancy could be influenced by other factors rather than by the severity of the condition. *Prenatal diagnosis*, 33, 257–261.
- Alsulaiman, A. and Hewison, J (2007). Attitudes to prenatal testing and termination of pregnancy in Saudi Arabia. *Public health genomics*, 10, 169–173.
- Alsulaiman, A., Mousa, A., Kondkar, A. A. and Abu-Amero, K. K (2014). Attitudes of Saudi parents with a deaf child towards prenatal diagnosis and termination of pregnancy. *Prenatal diagnosis*, 34, 153–158.
- Alwan A, Modell B (1997): Community control of genetic and congenital disorders., EMRO Technical Publication Series 24: WHO Regional Office for the Eastern Mediterranean Region, Egypt. <https://apps.who.int/iris/handle/10665/119571>.
- Bamshad M, Kivisild T, Watkins WS, Dixon ME, Ricker CE, Rao BB, Naidu JM, Prasad BV, Reddy PG, Rasanayagam A, Papiha SS, Villems R, Redd AJ, Hammer MF, Nguyen SV, Carroll ML, Batzer MA, Jorde LB. (2001). Genetic evidence on the origins of Indian caste populations. *Genome Research*;11 :1574-85.
- Berg JS, Houry MJ, Evans JP (2011): Deploying whole genome sequencing in clinical practice and public health: Meeting the challenge one bin at a time. *Genetics in Medicine*; 13: 499–504.
- Berkman B. E., Shapiro Z.E., Eckstein. L., Pike E. R. (2016). The Ethics of Large-Scale Genomic Research. In: Collmann. J., Matei, S. (eds). *Ethical Reasoning in Big Data*. Computational Social Sciences. Springer, Champ.
- Bittles AH, Hussain R, (2000). An analysis of consanguineous marriage in the Muslim population of India at regional and state levels. *Annals of human biology*, 27:163-71.
- Etchegary, H. Cappellib. M, Potterc. B., Vloetb. M., Grahamd. I., Walkere. M., Wilson. B. (2010). Attitude and knowledge about genetics and genetic testing. *Public Health Genomics*, 13, 80–88.
- Hamberg, M. A. & Collins, F. S (2010). the path to personalized medicine. *New England Journal of Medicine*, 363, 301–304.
- Jackson L, Goldsmith L, O'Connor A, Skirton H. (2012): Incidental findings in genetic research and clinical diagnostic tests: a systematic review. *American Journal of Medical Genetics*; Part A: 3159–3167.
- Kapadia KM, (1958). *Marriage and Family in India*, 2nd edition. Calcutta: Oxford University Press; pp-117-37.
- Kohane IS, Hsing M, Kong SW. (2012). Taxonomizing, sizing, and overcoming the incidentalome. *Genetics in Medicine*, 14: 399–404.
- Majumder PP, Roy B, Banerjee S, Chakraborty M, Dey B, Mukherjee N, Roy M, Thakurta PG, Sil SK. (1999). Human-specific insertion/deletion polymorphisms in India populations and their possible evolutionary implications. *European journal of human genetics*, 7:435-446.
- Middleton A, Morley KI, Bragin E, Firth HV, Hurles ME, Wright CF, Parker M; (2016). Attitudes of nearly 7000 health professionals, genomic researchers and publics

- toward the return of incidental results from sequencing research. *European journal of human genetics*, 24, 21–29.
- Middleton A, Patch C, Wiggins J, Barnes K, Crawford G, Benjamin C, Bruce A. (2014): Position statement on opportunistic genomic screening from the Association of Genetic Nurses and Counsellors (UK and Ireland). *European journal of human genetics*, 8: 955–956.
- Modell. B and Darr A (2002). Science and society: genetic counselling and customary consanguineous marriage. *Nature reviews. Genetics*, 3: 225-229. 10.1038/nrg754.
- Ngim, C. F., Lai, n. m., Ibrahim, H. and Ratnasingam, V. (2013). Attitudes towards prenatal diagnosis and abortion in a multi-ethnic country: a survey among parents of children with thalassaemia major in Malaysia. *Journal of community genetics*, 4, 215–221.
- Olwi, D., Merdad, L. and Ramadan, E. (2016). Knowledge of genetics and Attitudes toward genetic testing among college students in Saudi Arabia. *Public health genomics*, 19, 260–268.
- Sanghvi LD, (1966). Inbreeding in India. *Eugenics quarterly*, 13:291-301.
- Sastri KAN, (1976). A History of South India:from Prehistoric Times to the Fall of Vijayanagar. 4th edn Madras: Oxford University Press; p-66.
- Tadmouri GO, Nair P, Obeid T, Al Ali MT, Al Khaja N, Hamamy HA. (2009). Consanguinity and reproductive health among Arabs. *Reproductive health*, 6, 17.
- Wright CF, Fitzgerald TW, Jones WD, Clayton S, McRae JF, van Kogelenberg M, King DA, Ambridge K, Barrett DM, Bayzatinova T, Bevan AP, Bragin E, Chatzimichali EA, Gribble S, Jones P, Krishnappa N, Mason LE, Miller R, Morley KI, Parthiban V, Prigmore E, Rajan D, Sifrim A, Swaminathan GJ, Tivey AR, Middleton A, Parker M, Carter NP, Barrett JC, Hurles ME, FitzPatrick DR, Firth HV. (2015): Genetic diagnosis of developmental disorders: scalable analysis of genome-wide data. *Lancet*; 385: 1305–1314.
- Wright CF, Middleton A, Burton H, Cunningham F, Humphries SE, Hurst J, Birney E, Firth HV. (2013): Policy challenges of clinical genome sequencing. *British Medical Association Journal*, 347: f 6845.