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SNDT Women's University, Mumbai



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Issues Faced by Mothers of Thalassaemia
Affected Children and the Role of Medical
Social Workers in Mumbai

Dr. Neha Minde & Prof. Dr. Vandana Chakrabarti

2026

Issues Faced by Mothers of Thalassemia Affected Children and the Role of Medical Social Workers in Mumbai

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About SNTD Women's University

SNTD Women's University is the first women's university in India and South-East Asia, founded in 1916 by Maharshi Dr. Dhondo Keshav Karve with the vision of empowering women through education. The University is headquartered at Churchgate, Mumbai, with additional campuses at Juhu (Mumbai) and Karve Road (Pune). It has a vast academic structure comprising 37 university departments, 13 constituent institutions, and 174 affiliated colleges across Maharashtra, Gujarat, Goa, Madhya Pradesh, and Uttar Pradesh, collectively serving over 70,000 students.

The University has consistently maintained strong academic standards and was awarded NAAC A+ Accreditation in 2025. In alignment with the National Education Policy (NEP) 2020, it established the Centre for Holistic Education, Training and Novel Advancements (CHETNA) in 2022 to promote multidisciplinary and innovative learning. It has also strengthened its academic and research ecosystem through approximately ₹100 crore funding under the PM-USHA Scheme (2024) and is developing the Maharshi Karve Women Empowerment Knowledge Campus at Ballarpur, Chandrapur, with a major government investment to expand skill-based and employment-oriented education for women.

Beyond academics, SNTDWU actively promotes innovation, culture, and student development through initiatives such as Abhivyakti Manch, Yuva Mahotsav, and Innovative Mahakumbh, which supports entrepreneurship and has nurtured incubated, funded, and pre-incubation startups involving students and faculty. The University also preserves Indian Knowledge Systems through BHAGYASY (Bhartiya Gyan, Sanskrit evam Yog Kendra) and the Jagarani Project, which highlights the contributions of Indian women scholars under the theme "Nari Se Narayani." It further strengthens global academic engagement through collaborations such as the International Conference on Climate Change (ICCC-2025) with CUNY, USA. Student welfare remains central through initiatives like Earn and Learn, anti-ragging measures, grievance redressal systems, health camps, and leadership programmes. The 75th Annual Convocation (2025) reflected the University's legacy and its forward-looking vision of innovation, sustainability, and ethical leadership for national development.

Message by Hon'ble Vice-Chancellor

It gives me immense pleasure to present this monograph authored by **Dr. Neha Minde**, developed from her doctoral research in the field of Social Work at SNDT Women's University.

The monograph, titled “**Issues Faced by Mothers of Thalassemia Affected Children and the Role of Medical Social Workers in Mumbai**” is based on the scholar's Ph.D. thesis completed under the able guidance of **Prof. Vandana Chakrabarti**. This work represents a rigorous academic inquiry into an important public health and social issue, offering valuable insights into the challenges experienced by married β -thalassaemia carrier women and highlighting the significant role of medical social workers in addressing their needs.

The publication of this monograph reflects the University's commitment to making high-quality doctoral research accessible to a wider academic and professional community. Research of this nature contributes not only to the advancement of knowledge in Social Work but also provides evidence-based perspectives that can inform policy, practice, and future research in healthcare and social welfare.

I congratulate Dr. Neha Minde on this noteworthy achievement. Her dedication, perseverance, and scholarly commitment have culminated in a publication that will serve as a valuable resource for researchers, academicians, students, healthcare professionals, policymakers, and practitioners. I also extend my appreciation to Prof. Vandana Chakrabarti for her guidance and mentorship throughout the research journey.

I am confident that this monograph will stimulate further scholarly discussion and contribute meaningfully to understanding and addressing the social dimensions of β -thalassaemia. May it inspire future researchers to undertake impactful studies that respond to contemporary societal challenges.

On this auspicious occasion of the University Foundation Day (5 July 2026), I extend my best wishes to Dr. Neha Minde and look forward to many more such scholarly contributions that showcase the richness and diversity of research emerging from SNDT Women's University.

Warm regards,

Prof. Dr. Ujwala Chakradeo
Vice-Chancellor, SNDT Women's University

PREFACE

I am glad to present my research work in the form of this monograph, which is an output of an exploratory study conducted during 2017-2024. The original concept to plan this study emerged from my experience in the field of social work for Thalassemia-affected patients and their families, and the reproductive health of women.

Some papers from this research study are published in social science journals; of course, after a thorough peer review and input from experts. Information provided in this monograph is revised, updated, and presented in a flow to engage the readers.

This work contributes to the existing knowledge by reporting the present scenario of challenges faced by the mothers of Thalassaemia-affected children and the possible interventions that can be planned by social work professionals for these women.

ACKNOWLEDGEMENTS

I am thankful to my supervisor, Prof. Vandana Chakrabarti, for her generous contribution, support, and guidance for this work. Preparing this monograph would not have been possible without the cooperation of hospital authorities, site collaborators, and hospital staff. I also thank all the institutional ethics committees that primarily reviewed the proposals and offered their valuable comments, which were incredibly significant to bring out the best in this research. My sincere gratitude to Dr. Sujata Sharma, Dr. Sangita Mudaliar, Dr. Vrinda Kulkarni & Dr. Pragati Kamath, who were supportive and very cooperative for the IEC review process as well as during the data collection process. I am thankful to the monograph committee of SNDT University for the motivation and support provided to me for writing and publication of this monograph.

I am also grateful for the support from my Head of the Department, Dr. Prabhakar Chavan and Dr. Rohini Sudhakar, Dr. Asha Patil for their guidance. I am thankful to Mr. Bharat Bhandkoli, and all other departmental and library staff of SNDT Women's University for their kind help and cooperation.

I express my gratitude to Dr. Geetanjali Sachdeva, Director, ICMR-NIRWoH & Dr. Shailesh Pande, Head of the Department, Genetic Research Centre, Dr. Shaini Joseph, and Mr. Mali, and the project staff for their encouragement throughout the work process. I owe a lot to my mother, Ms. Sulochana Lavande, my aunt Nani, and my husband, Mr. Nitin, my son, Mr. Adwait & daughter, Ms. Tanvi, for their unconditional love for me and a deep faith in my venture!

My sincere thanks to the hospital OPD staff and Thalassemia caregiver mothers and their family members for their involvement in making this proposal a success!

DEDICATION PAGE

I dedicate this monograph book to the departed souls of
my father (Anna) and my uncle (Baba),
who wanted me to bring out the Best in me
to make them proud!!!!

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LIST OF SHORTFORMS & ABBREVIATIONS

ANC	Antenatal Care
ART	Assisted Reproductive Technology
β	Beta
BMT	Bone Marrow Transplant
cfDNA	Cell-free Deoxyribonucleic Acid
CVS	Chorionic Villus Sampling
DNA	Deoxyribonucleic Acid
F.T.N.D.	Full-Term Normal Delivery
GC	Genetic Counselling
GDM	Gestational diabetes mellitus
HB	Haemoglobin
HLA	Human Leukocyte Antigen
ICMR	Indian Council Medical Research
IEC	Information Education Counselling
Ind. Ab.	Induced Abortion
L.S.C.S.	Lower Segment Caesarean Section
MSW	Masters in Social Work
MTP	Medical Termination of Pregnancy
NESTROF	Naked Eye Single Tube Red Cell Osmotic Fragility Test
NFHS	National Family Health Survey
NGO	Non-Governmental Organizations
NHM	National Health Mission
NIPT	Non-Invasive Prenatal Testing
O.P.D.	Outpatient Department
PCR	Polymerase Chain Reaction
PIS	Participant Information Sheet
PND	Prenatal Diagnostic Tests
PPH	Postpartum haemorrhage
RTIs	Reproductive Tract Infection
SBTC	State Blood Transfusion Council
SPSS	Statistical Package for Social Sciences
STIs	Sexually Transmitted Infections
U.S.	United States

ABSTRACT

Having a child with β -thalassemia disease is a challenging situation for the families of the patient. Both parents are carriers of the β Thalassemia trait, and knowing the carrier status may cause psychological turmoil and drastically change the lives of the parents. This monograph is based on a study carried out in Mumbai to explore the issues faced by Thalassemia carrier women at and after the detection of the child's disease. The role of a medical social worker, at this stage, is very crucial. Among all the various phases in a human life from birth to death, the reproductive phase assumes special importance as it overrides three stages in life: adolescence, youth, and adulthood. The women in this phase experience new hopes and desires. Thalassemia carrier women cannot be an exception to this. β Thalassemia carrier women, who are desperate to have a healthy baby, are likely to ignore their own needs. In India, the financial implications of treatment modalities for β -thalassemia and the availability of social services are key dimensions of this issue. There are social work interventions carried out for the prevention and management of Thalassemia, and there are interventions carried out for the reproductive health of the general population. Do these interventions intersect for the benefit of β Thalassemia carrier women, or are these women left out due to their exceptional status, adding to their 'vulnerability' in reproductive health? Are the other social problems of these women addressed by the medical social workers practicing in the hospitals? This study tried to highlight these issues. By examining the efficacy, accessibility, and relevance of existing social work interventions for married β -thalassemia carrier women in Mumbai, this work contributes valuable insights to help medical social workers develop more comprehensive and targeted interventions for this specific population.

Keywords- β Thalassemia, Thalassemia carrier women, reproductive phase, medical social workers, social work interventions

CHAPTER 1

INTRODUCTION & CONTEXT OF THE STUDY

Introduction

Beta (β) Thalassaemia Major is an inherited anaemia and an autosomal recessive genetic disorder (Ishfaq K. et al., 2015) which means that it is inherited by a child from both carrier parents. Both parents have Thalassaemia Trait. Thalassaemia is considered a rare disease as per the new ICMR guidelines for the registry of rare diseases.

It is also called haemoglobinopathy. Haemoglobinopathy is an inherited disorder that involves red blood cells. Normally, individuals who suffer from Thalassaemia are not able to make adequate haemoglobin and therefore depend on periodical blood transfusions (Ahmed, Green, & Hewison, 2005).

It is reported that 10% of the total world Thalassaemia patients are from India (Panja, Ghosh, & Basu, 2012). India has about 65,000 to 67,000 β Thalassaemia major patients in our country, and around 8,000 to 10,000 cases are added every year (National Health Mission, 2016). As per the recent update, there are 35-45 million thalassaemia carriers in India (Colah, Italia, & Gorakshakar, 2017).

Thalassaemia is mostly observed in communities that encourage consanguineous marriages. Marriages within close blood relationships are called consanguineous marriages, i.e., marriages between first cousins. Due to consanguinity, the occurrence of genetic birth defects increases.

Thalassaemia patients have a pale color, get exhausted very soon, and cannot do hard work. Feelings of helplessness, being left out, and grief due to the loss of a child are the psychological problems felt by the patients and their families (Politis, 1998). The social and financial burden of the disease affects the thalassaemia families badly. They are emotionally burdened and financially constrained (Ishfaq K. et al., 2015).

β Thalassaemia is classified as follows:

- a) **β Thalassaemia major**- both the beta-globin chains are involved, and the disorder is manifested early in life; it is called Thalassaemia major. Individuals in this category require regular blood transfusions. They show symptoms like recurrent fever, enlarged liver and spleen, and skeletal changes due to bone marrow expansion.
- b) **β Thalassaemia intermedia**- In this type, both the beta-globin chains are involved, and the disorder presents later in life. These patients may never need or occasionally need a blood transfusion. Symptomatically, they are between thalassaemia major and minor states.
- c) **β Thalassaemia minor (carrier/trait)**-In this type, one of the beta-globin chains is normal and the other is abnormal. Persons having a Thalassaemia trait do not need a blood transfusion for survival, and they are almost asymptomatic.

Role of genetic counseling and involvement of social workers

Genetic counseling is a process wherein the occurrence and the risk of recurrence of the genetic disease in the family are communicated to the parents of the affected child. Counseling is offered to reduce the pain and suffering of the child and the family. The parents are advised about the management of the disease and prevention of the disease so that their anxiety about the disease is reduced. Social workers are also involved in taking social history, providing orientation, preclinical assessments, referrals, coordinating activities, and case management services (Schild, 1977). Couples may not be fully prepared for the information received during genetic counseling. It can trigger a lot of anxiety and guilt among them. There are a lot of tensions involved with childbearing issues. After receiving genetic counseling, certain couples are willing to accept the risks of a genetic disorder in the future. A social worker needs to identify the motivating factors behind this tendency, and counseling skills can help couples to change and modify their behavior patterns. Thus, social workers are primarily responsible for tasks related to the social dimensions of genetic problems (Dils & Smith, 1980). They can clarify genetic information and lessen the impact of emotional distress on the patients.

A social worker can consider the religious and ethnic background of the couple and is in the best position in the genetics team to help with family planning options such as antenatal diagnostic tests, contraceptive information, safe abortion services, artificial insemination, sterilization, etc. (Weiss, 1981).

Social work interventions

Social workers work as liaisons between healthcare professionals and patients. They can work as advocates so that these patients are saved from potential discrimination in society. Social work interventions help to identify the individuals in need, help individuals and families facing chronic conditions, and create and maintain self-help groups (Mizrahi, 2003).

Skilled and knowledgeable help from social workers can help the patients and their families to alleviate recurrent psychological and social stress. Locating and coordinating appropriate services for disease-affected individuals or carriers to ease their burden of disease at all levels can be handled by social workers.

Prevention of the disease and its impact on women

Pregnancy and motherhood are obvious and normal events happening to any woman. They are perfectly normal and natural conditions and not diseases that may require treatment. But these conditions may not remain normal and natural when they are influenced by sudden changes in an individual's life, and hence may need interventions.

There are prenatal testing options available to detect Thalassaemia in the unborn fetus so that this condition can be prevented. Also, when a child affected with Thalassemia major needs a bone marrow transplant (BMT), a healthy sibling is a probable match.

Therefore, having a healthy child is one of the reasons behind planning pregnancy and prenatal screening, but many times, couples do not want to go for any such tests due to financial implications (Safari Moradabadi et al., 2015).

Prenatal diagnostic (PND) tests & screening tests

Available prenatal testing options are as follows (NHM Guidelines, 2016). These tests are conducted in different ways.

1. Chorionic villus sampling -A small sample is taken, around the 11th week of pregnancy, and a tiny piece of the placenta is removed.

2. Cordocentesis - It is done in the 16th week of pregnancy. In this procedure, a needle is used to take a sample of the fluid surrounding the baby for testing.

3. Amniocentesis- Sometimes the results of these tests are not accurate, and there is always a risk of injury to the fetus.

4. Non-invasive prenatal testing (NIPT)- A newly advanced screening test is NIPT, which is non-invasive and can be conducted by a blood test. During pregnancy, the mother's bloodstream contains a mix of cfDNA that comes from her cells and cells from the placenta. The placenta is a tissue in the uterus that links the fetus and the mother's blood supply. These cells are shed into the mother's bloodstream throughout pregnancy. The DNA in placental cells is usually identical to the DNA of the fetus. Analyzing cfDNA from the placenta provides an opportunity for early detection of certain genetic abnormalities without harming the fetus.

Use of family planning methods

Family planning can empower women and families to achieve growth, equality, and sustainable development (Nadda, 2017). Over the last decade, the fertility rate of India has dropped from 2.7 to 2.1, but 31 million women do not use any contraception. Others use sterilization as the only method without maintaining healthy intervals between births. As a result, they can't limit or space births and face reproductive morbidities.

In India, a large number of the population lack the information and means to achieve the highest standard of sexual and reproductive health. Reproductive health care, therefore, should include family welfare counselling, provision of contraceptive information and stock, safe abortion and safe delivery facilities, treatment of STIs and RTIs, and counseling on responsible parenthood. For the benefit of future generations of thalassaemia-carrier couples, genetic

and marital counseling is essential to prevent the birth of an abnormal child (Balgir, 2014). Insight is needed into the unmet reproductive health needs of women.

Even for people without a history of thalassaemia, the decision-making about family planning is complex for couples (Haghpanah S. et al., 2012). Perceptions and attitudes towards family planning would differ from person to person due to various factors like cultural and religious beliefs, history of the disease, pressure from family members, etc. Therefore, there is also a tendency to have the desired family size observed among couples in some countries. Couples having a child with Thalassaemia major have a higher reproductive rate as there is reproductive compensation in families with Thalassaemia, and also in some countries, preference for a male child can contribute to this (Habibzadeh F. et al., 2012). Therefore, in countries where thalassaemia is prevalent, genetic counseling is the most effective way to control the birth of thalassaemia patients (Samavat & Modell, 2004). It is seen that family planning motivation and guidance are left out of the purview of genetic counseling and prenatal screening.

Scope and limitations of the present study

This study focused on married β Thalassaemia carrier women's reproductive phase and issues related to them, and covered the so far neglected aspects of quality of life experienced by these women and possible social work interventions to improve the same. This study did not concentrate on the child affected by Thalassaemia.

Significant reasons for not undergoing PND were explored at the screening phase. Problems not related to reproductive health were also seen to some extent.

To cover the total reproductive phase incidences in the life of Thalassaemia carrier mothers, only those who have undergone PND tests were included in the study. As only those who have undergone PND tests were included, the results cannot be generalized.

The study covered the β Thalassemia carrier women accessing health facilities in Mumbai only.

Though the study highlights these women's concerns, those who did not undergo PND tests remained outside the purview of the study. Some women did not undergo PND tests due to marital disputes, divorce, or desertion by their husbands.

The study did not deal with other genetic diseases such as hemophilia, sickle cell anemia, or chromosomal disabilities, though prenatal diagnostic tests are available for detecting these, too. Therefore, the study findings cannot be generalized to the remaining group of genetic disorders.

As the study considered the retrospective data, it might have faced the recall bias by the women participants. As the study recruitment was done at health facilities, cases not presented at these facilities could not be covered.

Women who did not accompany their children to the hospital could not be reached due to the hospital-based methodology. Women who have lost their child/ all children with Thalassaemia and currently have no living child could not be reached out.

Women who are not able to bring their child for Thalassaemia management to the hospital for various reasons could not be included in the study.

Resource constraints

The exact number of Thalassaemia carrier caregiver mothers was not known. No other setting was suitable to approach the participants. Some mothers did not come to the hospital for a transfusion with their children who have Thalassaemia; they were either preoccupied with younger children and their in-laws, or their husbands brought the children for a transfusion. So, these women were not available for contact. Women who came alone with the child were preoccupied with blood arrangements for their child; sometimes, they travelled to other private blood banks in case of a shortage of blood. A researcher found it difficult to interview such women, as arranging blood was the priority for women. Some women did not want to participate in the study without their husbands' consent. For various reasons, all Thalassaemia caregiving mothers did not undergo Pre-Natal Diagnostic tests, and such women were not eligible for study participation.

CHAPTER 2

CONCEPTUAL AND THEORETICAL FRAMEWORK

Let us understand the basic concepts involved in this study to understand the theoretical framework.

The thalassemia trait is inherited by a woman and her husband from their parents. Neither shows any symptoms of the Thalassaemia major disease. The marriage of two persons having Thalassemia traits may cause Thalassaemia in the offspring. In every pregnancy, there is a 25% possibility of having Thalassemia Major in the fetus. There is a 50% possibility of having a Thalassemia trait in the fetus and 25% possibility that the fetus will neither inherit Thalassaemia major nor the trait.

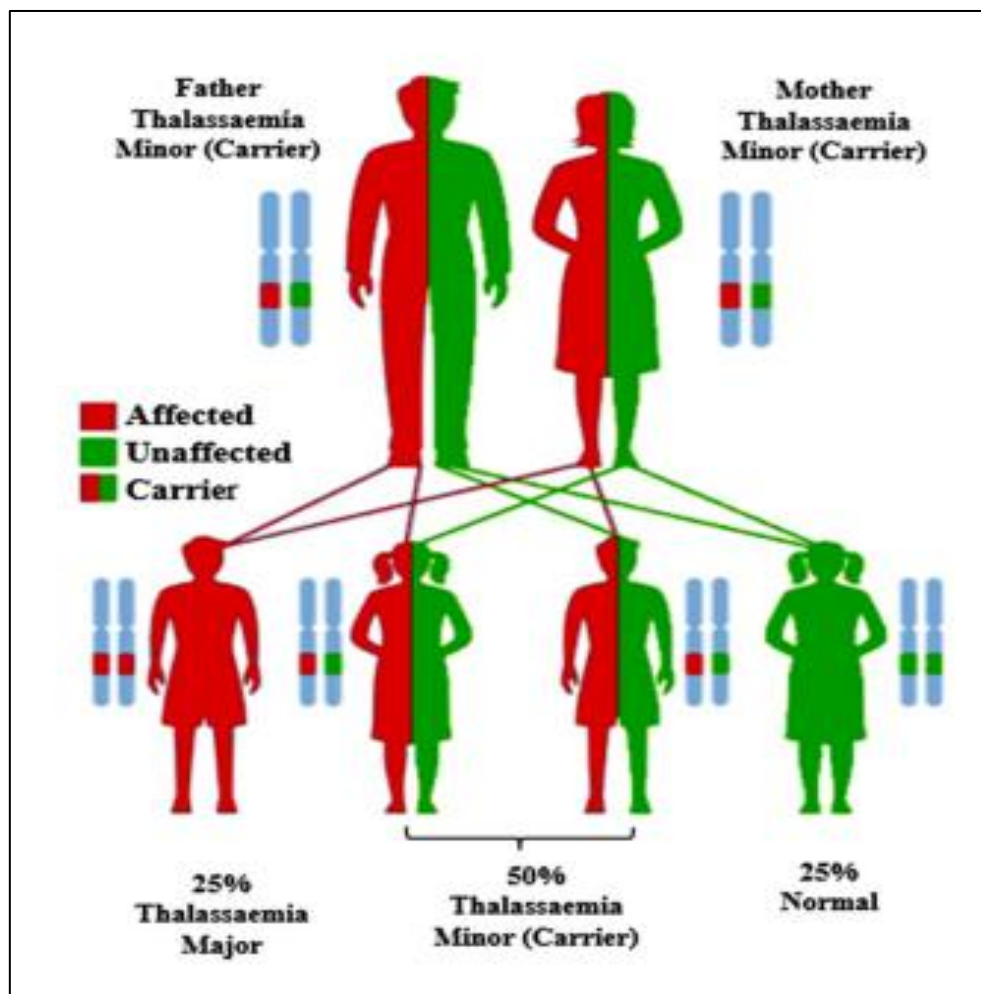


Figure 2.1 Mode of Inheritance in Thalassaemia Major

The above figure 2.1 shows the mode of inheritance of Thalassemia major disease. Thalassemia major shows its manifestation in the affected child early in childhood. The patient needs to be given a blood transfusion and is diagnosed with Thalassemia major.

After the detection of Thalassaemia major in the child, a series of various tests and procedures becomes part of β Thalassemia Carrier woman's life.

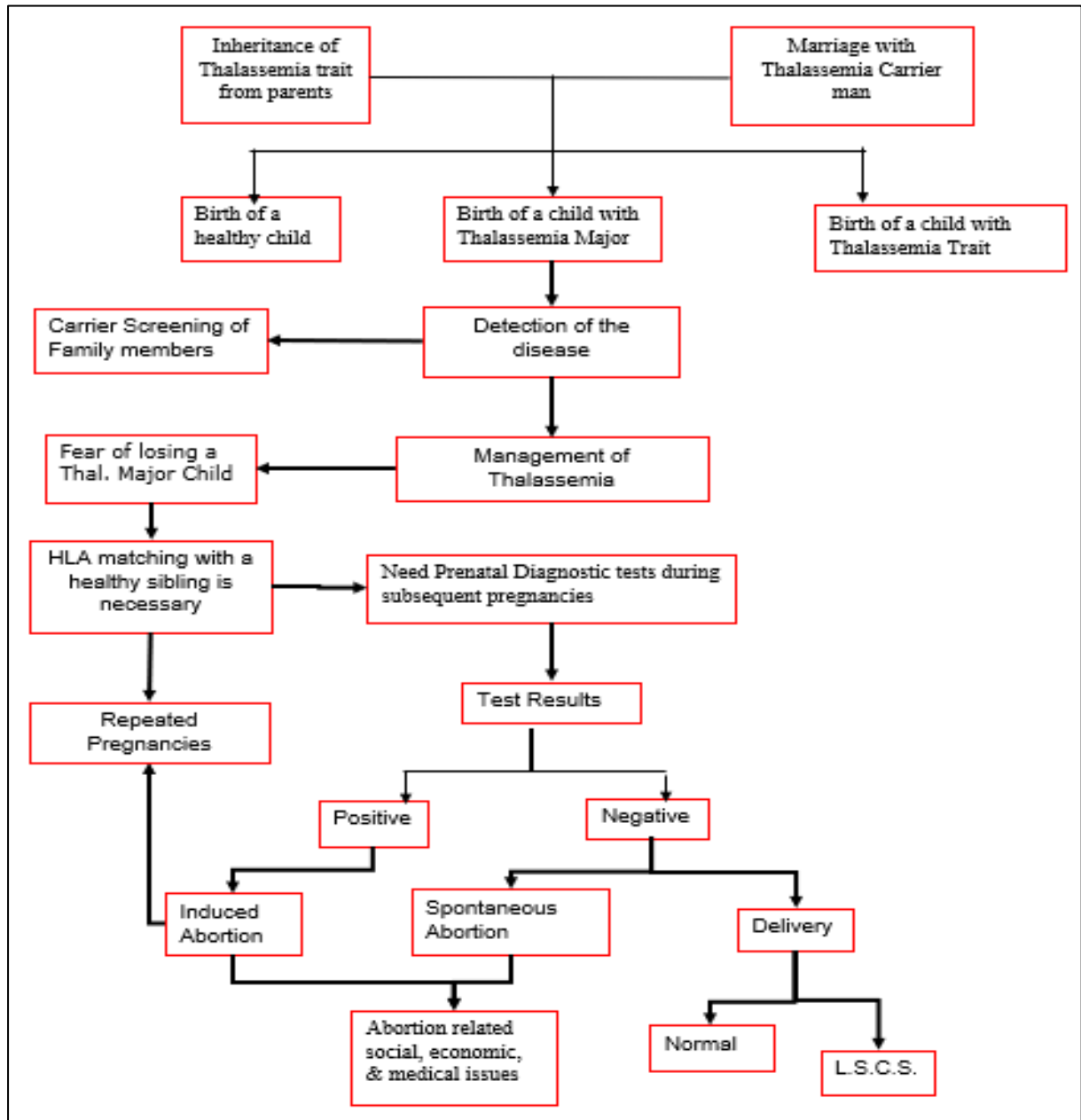


Figure 2.2 Flowchart on lifecycle events in the life of a β Thalassemia carrier woman

The above figure 2.2 provokes the thought process to know the glimpse of issues surrounding the reproductive phase of Thalassaemia carrier women mothering a child suffering from Thalassemia disease.

Assumptions of the study

- Women are the primary caregivers of the family.
- Being a mother of a child affected by a genetic disorder is a multiplied responsibility of a woman.
- Management of thalassaemia is lifelong, and when the child is young, a woman is also burdened with the biological responsibility of giving birth to a child who will not suffer from Thalassaemia.
- All the attention, care, and resources are focused on the affected child, whereas issues related to antenatal care, prenatal screening, and reproductive morbidities of the mother can take a back seat.

- e) Maternal health facilities do not provide comprehensive care to these women. Contraception is not always a choice for women (Nadda, 2017).

This study is about Thalassaemia carrier women who are in their reproductive phase; what problems/issues they face during this phase, and what social work interventions are available to them and needed by them. The focus of existing social work interventions is on the routine treatment of Thalassaemia-affected children. Currently, available interventions focus on easing the financial burden of families related to the management of the disease. These are mainly child-centric social work interventions.

However, factors affecting the reproductive health of such mothers have never been studied. The assessment to improve the scope of social work interventions has never been done. Carrier screening, antenatal screening, and genetic counseling are important for preventing Thalassaemia disease. Social workers' role in these preventive measures has not been explored in the Indian context.

The following research questions were formulated to explore the issues surrounding the reproductive phase of β Thalassaemia carrier women

1. What are the socio-demographic characteristics of married β Thalassaemia carrier women?
2. What are the social work interventions available to these women?
3. How far are the social work interventions utilized by these women?
4. What are the issues related to medical investigations and procedures faced by carrier women who intend to have a healthy child?
5. Do women having a child affected with Thalassaemia seek information related to birth spacing?
6. Do support groups help married β Thalassaemia carrier couples to access reproductive health services?
7. What are the factors determining the fertility decisions of couples?
8. Are genetic counselling services available to these women?
9. What kind of social work intervention is available for parents/ patients affected by Thalassaemia?

Statement of the problem

"Beta (β) Thalassemia carrier women face many problems during the reproductive phase of their life, particularly during pregnancy and childbirth, necessitating targeted social work interventions. Emotional distress, social stigmatization, and limited access to support services present significant obstacles to these women. Social work services in this area are non-existent. Understanding the situation of these women and creating social work services for them will enable Beta (β) Thalassemia carrier women to improve their quality of life."

Aim and Objectives

1. Aim

To study the scope for social work interventions for helping the β Thalassaemia carrier mothers to deal with the reproductive phase of their life and issues related to it, which will enable them to improve the quality of their life.

2. Objectives

- a) To study socio-demographic & clinical characteristics of the β Thalassaemia carrier women who intend to have a healthy child
- b) To study the issues related to various medical investigations and procedures faced by carrier women who intend to have a healthy child.
- c) To study the available social work interventions utilized by these women
- d) To explore various factors affecting the fertility decisions taken by these women
- e) To assess the utilization of the healthcare facilities (public/private) to deal with the issues/ problems related to reproductive health
- f) To study the problems faced by these women related to reproductive health
- g) To develop a model of social work interventions for β Thalassaemia carrier women

CHAPTER 3

REVIEW OF SELECT LITERATURE

Impact of Thalassemia on families

Diagnosis of Thalassemia is a very shocking experience for parents. Parents may feel guilty for having the Thalassemia trait. Women may be blamed by husbands and other family members for having the Thalassemia trait. Misconceptions about the disease prevail due to a lack of awareness. Mental health issues may emerge as a negative impact due to fewer social interactions and stigma attached to the disease.

Direct and indirect costs of the disease cause a huge financial burden for the family. (Riewpaiboon et al., 2010 & Sattari et al., 2012). Loss of wages due to frequent hospital visits, which are either scheduled or unscheduled, may be caused. Migrant parents may face socio-cultural and economic barriers to accessing healthcare services. (Leim et al, 2011) Use of alternative medicines is also reported along with faith and religion coping mechanisms by the parents.

There are ethical and social issues involved in the genetic testing of carrier parents as well as cascade screening of blood relatives. It is a traumatic experience for the other siblings losing a child with Thalassemia due to death. (Ballantyne, Goold, & Pearn, 2006).

Reports suggest that families with a child having Thalassaemia major may face psychosocial burden or depression, social stigma, and therefore prefer isolation. Alcohol addiction may be considered a resort by men as a negative coping mechanism in the family. This can negatively affect the child and the woman caring for the child in a family.

Emotional exhaustion, mental stress, and social stigma faced by mothers of Thalassaemia major children are reported as challenges in a study by Nabavian, Cheraghi, Shamsaei, Tapak, & Tamaddoni (2022). The health of children suffering from Thalassaemia is given a priority over their own health issues, and they face short-term as well as long-term consequences.

Multidisciplinary care approach for the management of Thalassemia

“Family-Based Approach” is recommended in the care of a child having Thalassaemia. Meeting parents of the child having Thalassemia, following them up regularly, supporting them in the management of disease and emotional aspects, providing necessary information about treatment, and also providing written or typed information as a ready reckoner are the components of a family-based approach (Prasomsuk S. et al, 2006). Shortage of trained health personnel in genetic counselling, especially in developing countries, is reported by Ballantyne, Goold, and Pearn (2006). A multidisciplinary team offering genetic services should include at least one paediatrician, an endocrinologist, a nutritionist, a psychologist, and a social worker. As clinical geneticists are few in number, they may not necessarily be part of the team (Ministério da Saúde, 2002). A multidisciplinary care approach involving social workers is recommended for the management of Thalassaemia, according to various reports.

Public health strategies for prevention of Thalassemia

Screening of the general population is accepted for prevention of haemoglobinopathies, by various countries (Fucharoen & Winichagoon, 2007). However, the feasibility of such a strategy is questionable due to cultural and social stigma and its availability in remote areas. A study by Chawla (2014) reports that knowing the carrier status before marriage caused rejection by the alliance. It is perceived negatively by society.

Screening of carrier status during pregnancy and if both partners turn out to be positive, referring the couple for prenatal diagnosis is another strategy for prevention. Colah et al. (2008) & Reema, Ghosh, & Mohanty (2001). However, late registration of pregnancy can be a hurdle for this strategy. Reluctance of husbands to get the carrier screening done was reported by Baxi et al. (2013). Study by Kulkarni et al., (2013). recommends personal follow-ups of the patients in this regard.

Carrier screening, prenatal diagnosis, and determination of pregnancy in case of positive test results is an effective strategy for prevention. Use of the NESTROF test is also documented as a screening test in some Indian studies.

Thalassemia screening tests are essential, and more screening programs are needed in India as a preventive strategy. (Colah, 2015)

Thalassemia has a high prevalence rate in tribal areas. Sengupta (2007) presents an extensive review of literature, mentioning that consanguineous marriages and endogamous mating are the social factors behind this. This article recommends genetic counselling of newly married couples before pregnancy, as one of the prevention strategies for Thalassaemia.

The counselling program was introduced as an intervention in a protocol developed for ANC care of Thalassaemia carrier women, which was not practiced routinely. Baxi, Manila, Kadhi, and Baxi (2013)

The use of family planning methods can be a very important preventive strategy for haemoglobinopathies (Han, Han, & Myint, 2011).

In Iran, where the prevalence of Thalassaemia is very high due to consanguineous marriages, the strategy adopted to prevent Thalassaemia is compliance with standard guidelines of family planning and use of contraceptive methods. Thus, the importance of using contraception should be recognized in parallel with prenatal diagnosis. Under the National Family Planning Program, family planning information is essential for Thalassaemia Carrier couples (Asadi Sarvestani, Hasanifar, & Bagheri, 2019).

Reproductive health issues of couples with Thalassemia trait

A study by Singh et al. (2022) reports that parents having children with Thalassemia had sufficient knowledge about the disease, premarital carrier screening, and treatment modalities, but the majority of them were not aware of antenatal screening, prenatal diagnosis, and the results of consanguinity.

An ICMR study conducted in 2009 reported a 2.8% incidence of spontaneous abortions among women with Thalassaemia traits. Cascade screening is also a preventive strategy. It is the process of informing and testing the immediate blood relatives of the index case to detect the carrier status. In a systematic review by Srinivasan, Won, Dotson, Wright, and Roberts (2020), individual and interpersonal barriers as well as environmental and provider-side factors, are mentioned as barriers to cascade screening. Very few studies report reproductive outcomes of the β Thalassaemia carrier couples. (Balgir, 2014). Higher fertility is observed in carrier couples; infant mortality faced by them is higher, below 10 years mortality is also higher, and children born to them may have a low survival rate. They may follow inappropriate practices such as induced abortion without prenatal diagnosis, delivery without prenatal diagnosis, or continuing pregnancy of the fetus with a positive prenatal test result. In a study from southern Iran by Haghpanah et al (2012), the tendency to have more children was observed. As Iran is an Islamic country, acceptance of abortion is low.

Marital disharmony as well as sexual problems are reported in various studies. The reason behind sexual problems is mainly the fear and guilt of having an affected child.

Socio-behavioural aspects of carrier screening, prenatal diagnostic tests, and bone marrow transplant procedures

Early acceptability of screening tests was positively associated with the educational level of pregnant women. (Sur & Chakravorty, 2016). Refusal of screening tests can also be due to the costs and need for further testing. Low-cost screening tests are needed in low and middle-income countries.

Disclosure of carrier status can affect the prospects of marriage adversely; therefore, carrier screening is challenging in India. In case the woman discloses her carrier status, it is a very sensitive issue. Jadhav, Mukherjee, Lalwani (2014).

Prenatal diagnosis is acceptable to the prospective parents. Still, the accuracy of the test results, the minimal risk of abortion due to the invasive procedure, and access to these tests are debatable issues. Karimi & Cohan (2010) report insufficient or no information about prenatal diagnostic tests, as well as costs and religious beliefs as underlying factors for low acceptance of these tests. The same study also reports unsafe abortions and a high rate of medical abortions. This particular study warrants close monitoring of carrier couples, as many did not use prenatal diagnostic tests during

pregnancy, and 77 couples went for MTP without these tests. A study conducted by Ahmed (2000) in Pakistan reports reasons for the non-acceptance of PND tests, such as the cost of the test and the fear of undergoing the test.

A study by Colah et al (2021) reports some remarkable changes over a period of 30 yrs. Acceptance of PND is increased; couples are also coming for prenatal tests in their first pregnancy, which is remarkable, and a few couples refused termination of pregnancy in case of positive results.

Positive prenatal test results may be a disastrous situation for women; they may feel guilty and ashamed of the results. (Ghai & Johri, 2008). False test results can shatter the lives of parents, and they may lose faith in the medical technologies. It becomes difficult to convince such couples to accept prenatal tests or any other test procedures. They may also have lots of misconceptions about all these tests.

Availability of social work interventions for beta (β) Thalassemia carrier women

The overall state of women is imperative to social dysfunctions such as domestic violence and gender bias. (Cook, Dickens, & Fathalla, 2003). Factors such as poverty, social exclusion, unemployment, poor working conditions, and unequal gender relations significantly influence health and illness patterns. (Walters, 2004). Gender inequity is highest in reproductive health, causing social injustice. As the majority of the contraceptive methods are female-oriented, the responsibility of using them is higher on women, along with the obvious responsibility of childbearing. However, women may not have the decision-making power to use contraception.

Article by (Temmerman, Khosla, Laski, Mathews, & Say, 2015) mentions priority areas for women's health interventions as health information, access to contraceptive services, maternal healthcare and protection from violence. Therefore, understanding the unmet needs of women and handling their concerns with expertise and appropriate referrals is needed. (Cook et al., 2003). Balgir (2014) hints at the unpreparedness of the health facilities and the inaccessibility by women while addressing the needs of women with β -thalassaemia carrier status. During pregnancy, the severity of anaemia increases among the Thalassaemia carrier women; this may cause increased risk of hypertension or anaemia (Ruangyutlert et al., 2023). A study by Vafaei et al. (2022) in Iran reported More complications in neonatal outcomes among women having a Thalassaemia trait. When a comparison was done between two groups of women, women with the Thalassaemia trait and women without the Thalassaemia trait. Thus, β -thalassaemia carrier women may need more attention and interventions to prevent such adverse outcomes. Such women having a child with Thalassemia cannot enjoy their pregnancy. (Lemacks et al., 2013). Such a situation warrants communication with and the company of women who have had similar experiences. (Stone et al., 2010 & Mathiesen, Frost, Dent, & Feldkamp, 2012). β Thalassaemia carrier women require close monitoring for anemia and other complications. Caesarean delivery was more common in carrier women. Thus, warranting regular antenatal monitoring and frequent ultrasound assessments to avoid fetal growth restriction (Amooee et al., 2011).

Women cannot make reproductive decisions autonomously due to patriarchal social constructs, financial dependence, and low education levels. (Gupta, 2010) Services such as abortions and family planning are very important for women's rights and women's health, for Thalassaemia carrier women. Shrivastava and Yadav (2015). Women may be unprepared for the tests due to a lack of adequate understanding of the procedure, which can be harmful (Farell, 2013). In Iran, MTPs following PND tests, Prenatal diagnosis, and abortions of fetuses suspected of Thalassaemia are covered by insurance (Haghpanah et al., 2012).

Women caregivers in the family provide personal care to the affected person; often, they are the mothers. They handle time-consuming and tough tasks (U.S. Department of Health and Human Services & U.S. Department of Labor, 2003). Caregivers themselves may suffer as patients and may face serious physical and mental health issues. They pay less attention to their health, and this is a hazard of caregiving they may face. (Reinhard et al., 2008). Empowerment of mothers through self-help groups is needed (Prasomsuk et al, 2006). Mothers of thalassaemia major children may require comprehensive support for child care, as they encounter physical, emotional, and social problems (Dahnil et al., 2017). Very few studies report such needs in the Indian context. Considered a rare disease, socio- behavioral research in Thalassaemia has often remained a neglected area for research and interventions in India.

Social workers role as genetic counselors

Dils & Smith (1980) discuss genetic counseling in social work practice. Social work as a profession is duly recognised as a profession in Western society. Demand for Genetic counseling is increasing, and not all social workers are trained to impart it. In developed countries, qualified counselors include social workers, nurses, and other health care providers. In some setups, team counseling is practiced. Medical social workers take social histories, do assessments, make referrals, coordinate and mobilize resources, and do casework. They can primarily take responsibility for handling social dimensions of the genetic problem, which can improve the quality of life for both patient and family. Social workers can see that their clients get the maximum benefit from medical treatment and management of diseases (Neser & Suddeth, 1965). Social workers are in a unique position to extend their help if they can expand their knowledge of genetic counseling. Social workers can identify gaps in health care delivery and mobilize communities to obtain services with the need assessments by patients (Weiss, 1981).

No reports are available on social workers imparting genetic counseling in Indian settings. If social workers have training for genetic counseling, they can get an opportunity to offer family planning counseling and adoption counseling simultaneously.

There are very few social workers who work in genetic situations, but the techniques and approaches utilized by them during providing social work interventions are not documented. Schild (1973), Social workers have been involved in genetic counselling for haemophilia (Alabek, Mohan, & Raia, 2015). An article by Mealer, Singh, & Murray (1981) elaborately explains the social worker's role in Genetic Counseling.

In settings dealing with genetic diseases, after the tests recommended by clinicians are conducted, social workers can have focused interventions on family planning, assessing and handling psychosocial issues, interpretation, and sharing of reports (Weiss, 1976).

In India, adoption has been mostly studied in the context of infertility. Irrespective of its mention in management guidelines for genetic disorders, adoption has not been widely discussed and accepted in the Indian scenario. There is a scarcity of studies that present the views and perceptions of couples having a child with genetic disorders, such as Thalassaemia, about adoption. Adoption as an option has been included in the counseling to parents' guidelines on haemoglobinopathies issued by the Government of India. No literature or report in India is available about the consideration to adoption option. Recently, the Juvenile Justice Act amendment done in 2015 permits adoption to individuals from all religions (Bhowmik, 2020). This directly implies the growing need for adoption counsellors in India.

Learnings from the literature review: research gap

Indian studies

β -Thalassaemia carrier women mothering a child with Thalassemia have not been the focus of social work interventions in India. Various socio-cultural aspects of the disease faced by β -Thalassaemia carrier women remain unexplored in the Indian scenario. There is limited research on prenatal genetic testing from women's perspectives. There is limited research on psychological aspects among Beta (β) Thalassemia carrier women related to BMT procedures & PND tests. Social work interventions are mostly patient-centric & lack a holistic approach

Therefore, socio-cultural and ethical issues faced by Indian β -Thalassaemia carrier women are not known.

Although the magnitude of genetic disorders is very high, there is a dearth of socio-behavioral studies in the area of genetics. As considered a rare disease, such genetic conditions often remain a neglected area for socio-behavioral research and interventions. Studies concentrate on high- prevalence areas such as central India, areas where the Thalassemia-affected population is more from certain communities, such as Sindhis, or Tribal areas.

Studies assessing the impact of Thalassaemia on the reproductive life of β -Thalassaemia carrier women are scanty in the Indian context. The lived experiences of mothers as caregivers and their experience of psychosocial stress during the reproductive phase need to be explored in the Indian context

Global perspective (western & middle eastern countries)

A review of literature from Western and Middle Eastern countries shows that Thalassaemia major affects the lives of mothers of children with Thalassaemia negatively (Caro et al., 2002).

The multidisciplinary care approach is observed widely in developed countries due to resource-rich settings. Whereas in low- and middle-income countries, lack of resources & social dimensions, including cultural values, contribute largely to the complexity of genetic problems.

Many developed countries have Public Health strategies for the prevention of Thalassemia and have included prenatal diagnostic testing in public health, whereas developing countries face a lack of adequate resources for basic screening of haemoglobinopathies in public health.

Religious and cultural beliefs play an important role in the decision-making of Thalassaemia carrier parents. Many studies related to β -Thalassaemia carrier women and couples' reproductive behavior are from low- and middle-income countries other than India. Social workers are part of the multidisciplinary teams caring for Thalassemia, and they are recognized as Genetic Counsellors. Many studies report the reproductive behaviour of carrier couples.

Insights gained from the literature review

Many socio-cultural aspects of Thalassemia disease, faced by β -Thalassaemia carrier women, have not been studied and published in the Indian scenario. It is not known whether the opportunities for interventions are missed by social workers. Studies on women accepting prenatal testing are scanty. The training needs of professional social workers need to be explored.

In developing countries, psycho-social and ethical problems are not prioritized while developing the services for patients with Thalassaemia and their families. The methods used for easing the burden of families in resourceful settings may not be applicable in low- resource settings; they need to be altered as per the complex social structures (Ballantyne, Goold, & Pearn, 2006).

The impact of improved treatment and management modalities of the disease can affect the reproductive behaviour of the β Thalassaemia carrier women. This study is planned to look at these effects. How far the uncertainty of life of Thalassaemia affects the child, and influences the childbearing by the mother, is not known.

This insight provokes the following questions from a woman's health perspective: are β - Thalassaemia carrier women from all strata using the new prenatal diagnostic techniques? Are these tests accessible to all such women? Are the decisions taken by women based on adequate information? Do women have the resources to make informed choices? Are the women empowered enough to be able to access health information? What are their problems? What kind of social work interventions can be planned to help women come up with the challenges of reproductive life and improve the quality of life? Especially during the reproductive phase of their life? What are their support systems in day-to-day life?

The tendency to follow inappropriate reproductive health practices among these women is not known. Social work interventions can be planned to improve awareness of β -Thalassaemia carrier women about their reproductive rights. Social work interventions about PND tests and MTPs concerning β -Thalassaemia carrier women are not studied. No studies related to social workers' role as a genetic counsellor are found in the Indian context.

CHAPTER 4

RESEARCH METHODOLOGY

As the focus of the study was to cover the entire reproductive phase of incidences in the life of Thalassaemia carrier mothers, it was essential to include women who have undergone PND tests in their lifetime. However, the exact number of such β Thalassaemia carrier women was not known, and hence, the number of women who have undergone prenatal diagnostic tests could not be estimated. Therefore, it was decided to screen all the mothers, β Thalassaemia carrier women attending hospital O.P.D. and enrol those who have opted for prenatal diagnostic tests in the past. This would also help estimate the proportion of women who do not opt for PNDT tests and the reasons behind this.

Research design

An exploratory, cross-sectional, retrospective, Mixed-Method approach combining quantitative and qualitative data collection was planned to get more information about available social work interventions.

Description of universe & population

β Thalassaemia carrier women from Mumbai are the universe, and among them, those who underwent prenatal tests were the population.

In the Indian context, data about the number of women undergoing prenatal diagnostic tests & delivering a healthy child after is not reported. As communicated verbally by the coordinator from SBTC, the Number of Thalassaemia major cases registered with SBTC in Mumbai was approximately 2000 in the year 2018. But the exact number of β Thalassaemia carrier women from Mumbai could not be estimated, and among them, the number of women who have undergone prenatal diagnostic tests was also not known.

Hence, it was difficult to estimate the sample size considering only the Mumbai region.

Sample selection, sampling technique and sample size

The population of β Thalassaemia carrier mothers was roughly estimated as 1000 & ~ 350 (35%) women were estimated as having undergone at least one episode of PNDT.

Due to the non-availability of the exact estimate of the population, it was decided to use a non- probability sampling method with a multi-stage sampling technique to select the study participants.

Based on the Yamane (1973) formula, the sample size was calculated as follows: $n = N / (1 + N(e)^2)$. The sample size was determined as 100. A purposive sample of 100 β Thalassaemia carrier women from five different public hospitals in Mumbai was drawn.

Research design

As sufficient data was not available about the topic, it was decided to go for an exploratory research design and a cross-sectional study plan, to get information about the study population at one point in time. To support this design, a literature review and interviews with key persons were conducted before planning the study in the first phase.

Retrospective data was collected from β Thalassaemia carrier women who were mothers of Thalassaemia major children. Women were screened by asking them about the history of a minimum of one PND test episode.

In the second phase, enrolled women were interviewed to get quantitative data.

In the third phase, the case studies of Thalassaemia carrier women and interviews with one social worker from each hospital were conducted.

Inclusion criteria

- β Thalassaemia carrier women having a child with Thalassemia and those who have undergone at least one episode of prenatal diagnostic test
- From the age group of 18-45 years
- Willing to participate in the study

Exclusion criteria

- β Thalassaemia carrier women who have not undergone any prenatal diagnostic test
- Pregnant women
- Women not willing to participate in the study

Ethical considerations

The study proposal was reviewed and approved by the institutional ethics committees of all hospitals, as required in all hospital settings for data collection.

Informed consent

A participant information sheet (PIS) and informed consent (IC) forms prepared in Hindi, Marathi, and English were provided to all the participants for their consent to participate.

A separate informed consent forms were prepared for the trained social workers and beta Thalassaemia carrier women who were case study participants.

Voluntary participation and non-coercion

Women participants were invited to participate voluntarily, and no means of coercion were used to enroll them in the study.

Privacy & confidentiality

Utmost care was taken to provide privacy to the participants, as sensitive information was going to be collected from them. They were assured that the information would be kept confidential. No identifiers were used or disclosed in the analysis of the data. Names of participating centres are not mentioned in this monograph to protect the privacy of the participants and maintain the confidentiality of the data.

Data collection tools

A screening tool was developed during the survey to select the participants fulfilling inclusion criteria. A semi-structured interview schedule was prepared to collect quantitative and qualitative data from the eligible study participants. Open-ended questions were asked to get qualitative data. An interview guide was prepared for conducting the interviews with social workers. A case study guide was prepared to conduct the case studies. All the data collection tools were tested and validated before their exact administration at the study sites.

Operationalization of variables from data collection tools was done.

Hypotheses

Although the study was exploratory, based on the interviews of the keypersons and the past professional experience & observations of the researcher, the following Null Hypotheses were constructed and tested for inferential analysis of the quantitative data.

The study was conducted in three phases; phase wise arrangement of hypotheses is as follows.

Hypotheses based on phase I (survey data)

1. There is no significant association between having non-thalassaemia child/children in the family (along with the child having Thalassaemia) and the decision taken for prenatal diagnostic tests.

Hypotheses based on phase II (enrolment data)

1. There is no significant association between the monthly family income of β Thalassaemia carrier women and their use of alternative medicines for the management of Thalassaemia in their child/children.
2. There is no significant association between the place of origin of β Thalassaemia carrier women and their utilization of social work interventions.
3. There is no significant association between β Thalassaemia carrier women's type of family and their access to contraceptives.
4. There is no significant association between the occupational status of β Thalassaemia carrier women and their perception towards Adoption.
5. There is no significant association between the level of β Thalassaemia carrier women's education and their experience of facing domestic violence.
6. There is no significant association between the level of the husband's education and the experience of β Thalassaemia carrier women facing domestic violence.
7. There is no significant association between β Thalassaemia carrier women's consanguinity in the marriage and their experience of facing domestic violence.
8. There is no significant association between the housing condition of β Thalassaemia carrier women and their experience of facing domestic violence.
9. There is no significant association between the monthly income of β Thalassaemia carrier women and their need for social work interventions.
10. There is no significant association between the number of amenities in β Thalassaemia carrier women's houses and their need for social work interventions.

Data analysis and interpretation

Quantitative data were analyzed using the Statistical Package on Social Sciences (SPSS) version 20. Correlational and cross-tabular analyses of quantitative data were done. Descriptive and inferential statistics were used for analyzing the data. The χ^2 test & Fisher's exact test were applied for ordinal or nominal data. A p-value of 0.05 was considered to show statistical significance.

Data collected through semi-structured interviews were transcribed. Qualitative data were analyzed using the thematic analysis method.

CHAPTER 5

RESULTS: DESCRIPTIVE AND INFERENTIAL ANALYSIS

In phase I of the study, review of related literature was done and interviews with key persons such as a paediatrician, basic scientist involved in doing prenatal tests in laboratories (Life Sciences), Obstetrician/Gynecologist conducting prenatal tests, Medical Social Worker dealing with couples accepting prenatal diagnostic tests, NGO representative of NGO working in the field of Thalassemia, support group representative & a genetic counsellor were interviewed by the researcher. Based on the available information, a research methodology was planned to screen all β -thalassemia carrier women coming to the hospital OPDs. Women who fulfilled the inclusion and exclusion criteria were selected as study participants.

Analysis of information received from the experiences of key persons - Phase I

- 1) National, state, or regional level data is not available on cases detected with thalassaemia, which are registered. There may also be unreported cases. Available statistics are based on the number of registered cases with blood banks.
- 2) So far, psychological interventions are not offered to these cases and the family members, who are stressed personally, socially, and economically. Social work interventions can focus on the family's emotional well-being.
- 3) Often, the affected child engages the maximum attention of the parents, and other normal or carrier children get neglected. This is mainly seen in nuclear families. In such cases, parental counselling will be useful.
- 4) Issues faced by women who are mothers of Thalassaemia major children, such as desertion, divorce, and stigma, are not addressed.
- 5) Pregnancies with less spacing and unwanted pregnancies are often ignored. The need for prenatal screening and the bone marrow transplant procedure could be the determining factors. Contraceptive advice and provisions are not done primarily for these couples.
- 6) A lot of misconceptions regarding the disease are not well-researched or documented.
- 7) Issues like gender bias and son preference are also noticed among the families affected by thalassaemia. These cause ethical dilemmas for medical professionals.
- 8) Existing service gaps can be found, and accordingly, social work interventions can be planned.
- 9) There is a scarcity of socio-behavioural research in this area.

This analysis was a very important piece of evidence as it was based on primary information given by the keypersons, who were thorough in their respective disciplines.

Phase I data collected from a survey of the women attending OPDs are as follows.

Table 5.1-Survey of β Thalassemia carrier women at five sites				
Site	Registered cases	Total women Surveyed	Women who had undergone minimum one PND episode	Women did not undergo any PND episode
A	290 (37.17%)	114	26 (22.8%)	88 (77.19%)
B	178 (22.82%)	82	26(31.70%)	56(68.29%)
C	60 (7.69%)	33	12(36.36%)	21(63.63%)
D	125 (16.02%)	46	19(41.30%)	27(58.69%)
E	130 (16.66)	35	19(54.28%)	16(45.71%)
Total	780 (100)	310 (100%)	102 (32.9%)	208 (67.1%)

Out of 310 women contacted during the survey, 102 (33%) women had undergone prenatal diagnostic tests & 208 (67.1%) did not undergo prenatal diagnostic tests in the past.

Reasons for undergoing PND tests were classified as 'related to' & 'not related to' PND tests.

Table 5.2 Reasons not related to the PND tests	
Has other minor/normal children	85
Late detection of Thalassemia	17
Not sure about the next pregnancy	15
Marital disharmony	12
No desire for the next pregnancy	10
Late ANC registration	7
Delivery was done at native or at home	6
Secondary infertility	4
Tubectomy was already done	4
Was pregnant before the detection	2
Advanced maternal age	2
Other children having medical problems	2
Had miscarriage previously	1
Unwanted pregnancy	1
Total	168 (80%)

Table 5.3 Reasons related to the PND tests	
Not aware of such test	11
Opposition by In-laws	10
Scared of false reports	3
Cannot afford the cost of tests	8
Scared of the PND test procedure	8
Total	40 (20%)

Above tables 5.2 & 5.3 classify the reasons for not accepting prenatal tests as reasons related to the PND tests and those not directly related to the PND tests. For reasons related to the test interventions can be offered by the social workers. Among those who underwent prenatal tests (102), two were pregnant and therefore were not included as study participants.

A total of one hundred married β Thalassemia carrier women mothering a child with Thalassemia major disease were enrolled as study participants.

The objective-wise **results of the study based on phase II** are as follows.

The socio-demographic profile of study participants (N=100)

For the socio-demographic profile of the study participants (100) following variables were considered. Age of the women, marital status, education, occupational status of the parents, monthly income of the couple, household amenities, housing conditions, religion, consanguinity in marriage, and place of residence. place of origin, family type, head of the household, Variables such as the number of living children, death of child/ children, child's age at detection of Thalassemia, frequency of blood transfusion, and financial burden faced by the couple. The majority of women were from the age group of 31-35 years. Ninety-seven percent (97%) of women were married, two were widows, and one was separated. More women are less educated than men, and the majority of women are educated till secondary level. 71% of women were

housewives, and 70% families earned a monthly income below 20000 rupees. Seven families own no amenities such as a television, computer, fridge, four-wheeler, two-wheeler, or any other amenities. The majority of families (74%) have a maximum of two amenities at home. Sixty-six percent (66%) of families stay in chawl-type houses or slums. 54% of families come from districts other than Mumbai. Thirty-seven percent of families are migrants from other states. Sixty-one percent (61%) of families are nuclear families. Seventy-eight families are headed by husbands or in-laws; only nine women participants have the decision-making power as heads of the families. Among the study participants. 64% of women are Hindus, 21% Muslim, & 10% Buddhists; the rest are Christian, Adivasi, Jain & Sikh. Thirty-four percent (34%) of marriages are consanguineous. Incidence is higher in Hindus, the percentage is higher in Muslims, 2% of Buddhist marriages are consanguineous. More consanguineous marriages (> 50%) are first-degree consanguineous marriages. Women have a minimum of 1 & maximum of 5 living children, 94% women have $\leq$ three living children. Ninety-one percent of women have one living child with Thalassemia, and nine women have two children living with Thalassemia. Due to the Thalassemia disease, seven women lost one child each, three women lost two children each, and one woman lost four children due to Thalassemia. Fifty percent of children (53) need a transfusion every fifteen days. 25% children need it every 20 days. This data reveals the frequency of hospital visits paid by the parents for the management of Thalassemia.

Reproductive health profile of the β Thalassemia carrier women

The reproductive health parameters of β Thalassemia carrier women were studied to assess their reproductive health status, such as their age at first pregnancy, present status of menstruation, reproductive outcomes in Thalassemia minor women, and number of pregnancies.

Fifteen women reported their first pregnancy at < 18 years of age. Ninety women were regularly menstruating, and four were having Lactational Amenorrhea.

Among 100 women total of 342 pregnancy episodes were reported, and the majority of them had $\leq$ 3 pregnancies. A total of 134 prenatal test episodes were reported by these 100 women.

Types of deliveries, history of abortions, types of abortions among the β Thalassemia Carrier women were considered as reproductive outcomes of the participants. Also, all pregnancy episodes were studied according to the criteria of prenatal tests done or not. The following table shows the breakup of deliveries (pregnancy outcomes) after PND tests and without PND tests.

Table 5.4 Pregnancy outcomes of participants after PND tests and without PND tests (N=100)							
	Sp. Ab.	Ind. Ab.	Preterm birth	FTND	LSCS	Total Episodes	%
Post PND	1	27	1	75	31	135	39.47 %
Without PND	18	40	1	125	23	207	60.52 %
Total	19 (5.55%)	67 (19.59%)	2 (0.61%)	200 (58.47%)	54 (15.78%)	342	

Table 5.4 shows that (135) 40% of delivery episodes were with prior PND tests, and (207) 60% were without PND episodes. In 75% of pregnancy episodes, FTND & LSCS deliveries were seen. 25% of pregnancies were aborted, including 6% due to spontaneous abortions, and 20% pregnancies were discontinued by induced abortion.

So, the magnitude of induced abortion shows the foetal wastage among the study participants, which is worrisome.

Issues related to carrier screening, cascade screening & PND tests

Issues related to carrier screening tests, cascade screening, and prenatal diagnostic test procedures were explored by studying the stage at detection of carrier status, cascade screening, the number of PND test episodes undergone, preference for sons, health issues faced after PND tests, treatments taken for health issues, and any other concerns expressed by Thalassemia carrier women.

Carrier screening tests were done only after the detection of Thalassemia in the child, in all cases of women and 98 husbands. Just two men knew their carrier status before marriage, which they did not disclose to their wives.

The interpretation of carrier screening was not clear in the case of other children of these women. Women had confusion to differentiate between carrier children and children who were not carriers of the Thalassemia trait. 73% of maternal families of the women did not go for cascade screening, 76% of paternal side families did not go for cascade screening. 75% of women have done only one PND test, 20 women have done two, three women did them thrice, one woman did it four times, and one woman did the PND tests seven times. Sixty-five percent of women faced no health issues after PND tests. 35% of women faced issues such as abdominal pain (31), slight bleeding (2), weakness (1), and spontaneous abortion (1).

As a treatment for these health issues, 29 women took painkillers, two were advised bed rest, two were hospitalized, and two were prescribed vitamins.

Factors affecting the fertility decisions taken by the β Thalassemia carrier women

To explore the factors affecting the fertility decisions, women's desire for more children, reasons for wanting more children, reasons for no desire for more children, use of contraception, reasons for not using modern contraception, plan for accepting permanent contraception, and access to contraceptive methods were considered.

The study participants were asked about their desire for more children, assuming that these women would like to compensate for their lost child or children with Thalassemia major, with healthy offspring. However, seventy-nine women said that they did not want any more children. Four women were not sure about their decision. Seventeen women said that they want more children.

Among 17 women who desired more children, the majority of them (64.7%) desired one more child, as they have only one non-thalassemia child. Some women (17.6%) wanted a male child and, therefore, desired more children. Twelve percent of women wanted a healthy sibling for their child with Thalassemia major so that they could get an HLA-matched donor. Six percent of women want a girl child. Data shows that women desiring more children have various intentions behind their desire for more children. They may have family pressure for such a desire.

Out of 79 women who did not desire more children, thirty women (40.5%) had one or more minor children and hence did not desire more children. Sixteen women said that they could not afford more children and, therefore, did not desire them. Twelve women were scared of the positive results of prenatal diagnostic tests and Thalassemia, so they did not desire any more children. Eleven women felt that their family was complete, so no more child was wanted by them. Two women were widows, and one was separated. Two women faced secondary infertility and did not have any option to have more children. One woman said that her past delivery was with a caesarean section; she did not desire any more children. Due to diabetes and a hysterectomy, two women did not want any more children.

Findings suggest that the Thalassemia major disease and its implications play a significant role in women's desire for more pregnancies.

While knowing about the fertility decisions of the Thalassemia carrier women, along with their desire for more children, data was also collected about their use of modern contraception. Out of a hundred women, 67% of women are using modern methods of contraception, and thirty-three women are either using traditional methods or not using any method of contraception. Out of 33 women, thirteen (39.4%) women said that they prefer the traditional method of contraception. Five women (15.2%) said that they have very small houses, so they have very little sex. Four women said they are planning their next pregnancy, so they do not want to use any method as a contraceptive. Reasons such as religious limitations, fear of methods, and indifference to using any contraceptive method were stated by 2 women each (6.1%). Reasons such as the risk of Thalassemia, family opposition, reluctance, irregular menses, and no awareness about

contraception were stated by one woman each.

Out of a hundred thalassaemia-carrier women, twenty-three have accepted female sterilization. Fifty-five women said they did not want to go for it, and nineteen women said that they would accept the option. Three women are not sure about accepting the method.

Findings suggest that 55% of women are not willing to accept permanent sterilization, which is a significant proportion. Permanent methods of contraception are one-time, provider-dependent, and not easily reversible. Therefore, with the insecurity of the life of a Thalassaemia major child, there can be a dilemma in considering this option. Therefore, if they are willing, they may need the help for temporary methods provision and access, during the reproductive phase of their life.

Women's opinions about the difficulty level of accessing contraceptives were asked. Twenty-two percent of women felt that it was very easy, and thirty-five percent of women said that it was easy to access contraceptives. Three percent of women were neutral. Thirty-seven women said it was difficult, and three women said that it was very difficult for them to access the contraceptives.

Out of 62 women who have only daughters, forty-eight women said that they do not face any pressure from the family to have a son, and fourteen women said that they are pressured by their family members to have a son.

When asked about their own desire to have a son, fifty-one women out of 62 said that they did not want any more children. Nine women said that they wanted a son, irrespective of the pressure from family members. Two women said that they want a child, but there is no sex preference.

Utilization of health facilities for issues related to reproductive health

In the current study, four aspects of reproductive health care utilization were explored facility-wise to understand the utilization of health facilities for reproductive health issues. These four aspects were contraception, ANC care & deliveries, prenatal diagnostic tests, and medical termination of pregnancies. Exploration of this utilization is helpful to plan interventions accordingly, considering a particular type of health facility.

Table 5.5- Utilization of health facilities for issues related to reproductive health					
Reproductive health issues	facilities				Total
	Type of health facility				
	Public	Private	NGO	Traditional methods	
a. Contraception	37	64	3	26	130
	28.5%	49.2%	2.3%	20.0%	100%
b. Deliveries	115	105	0	33 (At Home)	253
	45.5%	41.5%	0.0%	13.0%	100%
c. Prenatal Diagnostic Tests	109	25	N.A.	N.A.	134
	81.3%	18.7%	—	—	100%
d. Medical Termination of Pregnancy	21	52	2	0	75
	28.0%	69.3%	2.7%	0%	100%
Total	282	246	38	26	592
	47.6%	41.6%	6.4%	4.4%	100%

Row a) in Table 5.5 shows that all 100 women have had 130 episodes of contraceptive usage (Both temporary and permanent methods). Among them, thirty-seven times (28.5%) contraceptive methods were accessed from public hospitals, sixty-four (49.2%) were from private health facilities, three methods (2.3%) were accepted from the NGO sector & twenty-six times (20.0%) traditional methods were used. Reasons for this may be easy access to a user-

friendly environment at private health facilities and the assurance of the efficacy and quality they offer to avoid method failure. Traditional methods are still preferred; the possible reasons behind this may be inhibitions, shyness, or fear of modern contraceptives.

Row b) in Table 5.5 shows that out of a total of 253 delivery episodes among 100 Thalassaemia carrier women, 115 episodes (45%) have taken place in public hospitals, 105 deliveries (42%) have taken place in private hospitals, and 33 deliveries (13%) are home deliveries. Findings suggest that home deliveries are observed in a considerable proportion (13%) of the population. There is not much difference in accessing private or public health facilities for deliveries among the Thalassaemia carrier women. Due to the trend of home deliveries, antenatal services may not be utilized fully by pregnant women, thus missing important health check-ups.

Row c) in Table 5.5 shows the utilization of healthcare facilities for prenatal diagnostic tests. Out of 134 prenatal diagnostic test episodes, 109 (81%) episodes have been conducted in public facilities, and only 25 (19%) have been conducted in private facilities. Private labs charge a very high amount for PND tests. Therefore, the results clearly show that most of the test episodes have been conducted at public health facilities.

Row d) in Table 5.5 shows that, out of seventy-five episodes of medical termination of pregnancies, 21 (28%) were conducted in public health facilities, 52 (69%) were conducted in private health facilities, and 2 (3%) abortions were conducted in NGO run facilities. Results show that the majority of women prefer private health facilities for abortions. The costs of abortions are higher in private health facilities. Still, the availability and access are easier, though this adds to their financial burden.

For women undergoing MTPs due to positive test results, it's a double burden.

Patterns of utilization of health facilities for various reproductive health concerns of β -thalassaemia carrier women are very realistic and give an idea about which facilities are preferred by the β -thalassaemia carrier women for their reproductive concerns. Based on this data, social work professionals can accordingly extend their scope to different facilities.

Among the other social problems felt by β Thalassaemia carrier women related during the reproductive phase of their life, issues such as domestic violence, partners' addiction, work-life transition, support for childcare in the past, support from family members at present, and for household chores were studied.

Availability of interventions for families having a child with Thalassemia major

Under the availability of social work interventions for families having a child with Thalassaemia Major, along with free provisions of transfusions, medicines, and other provisions, sources of counseling for Thalassemia, sources of counseling for PND tests, sources of genetic counseling, sources of family planning counseling, and adoption counseling.

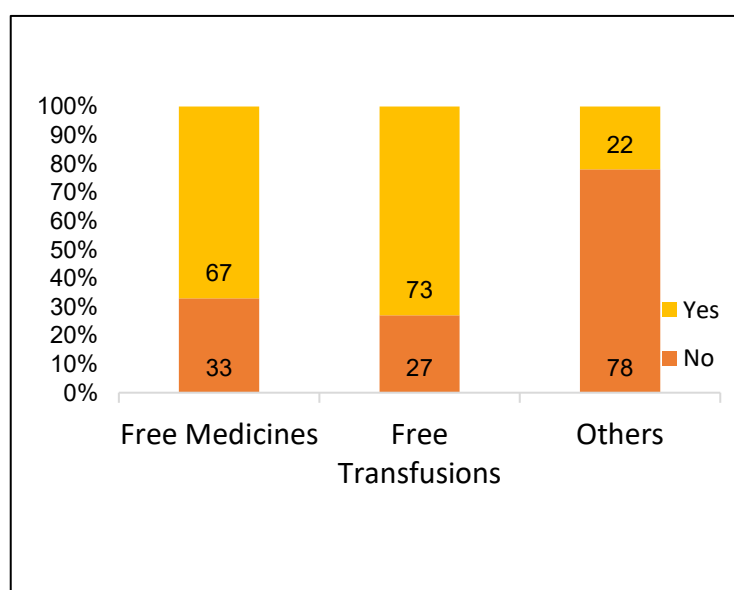


Figure 5.1 Social work interventions for Thalassaemia patients & families (N=100)

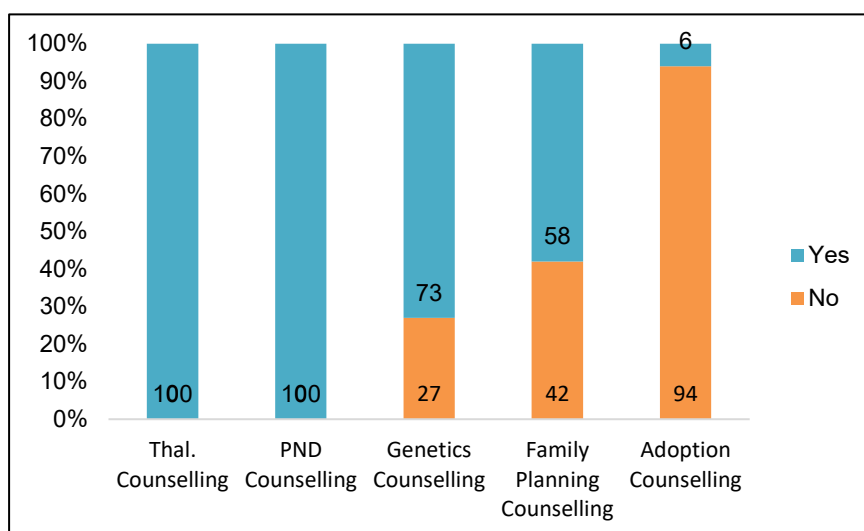


Figure 5.2 Other interventions for families (N=100)

Highlights from descriptive analysis -Phase II

Thus, results from phase II reflect that the majority of the women are from a low socio-economic background. Consanguineous marriages are a challenge to deal with. Adoption is not discussed as an option for reproduction during genetic counselling. Induced abortions due to unwanted pregnancies can be avoided. Preconception care is not effectively advised & monitored. Institutional deliveries should be stressed among these women. Carrier and cascade screening should be reemphasized during follow-ups. Concerns related to fertility desire and dilemmas are not addressed. Partners' support is crucial in the acceptance of the spacing methods & PND tests. Interventions provided by medical social workers are mainly financial assistance and social provisions

Other social problems, such as gender bias, domestic violence, alcoholism, work-life transition, unemployment, and the need for childcare support among these women, were highlighted from the descriptive analysis

Results from Inferential Analysis-Phase II

The following are the results of hypothesis testing, which throw more light on the findings from descriptive analysis. Having a normal or minor child is associated with acceptance of prenatal diagnostic tests. Irrespective of any level of monthly income, alternative medicines are accepted for the child. Women from and outside Maharashtra availed themselves of social work interventions. The type of family does not influence access to contraceptives by β Thalassaemia carrier women. The occupational status of the β Thalassaemia carrier women can influence their perception of adoption. β Thalassaemia carrier women's level of education has an association with their experience of domestic violence. Husband's level of education has an association with β Thalassaemia carrier women's experience of domestic violence. Consanguinity in marriage does not necessarily influence the women's experience of domestic violence. The type of house did not influence β Thalassaemia carrier women's experience of domestic violence. β Thalassaemia carrier women from all levels of income groups assert the need for social work interventions. Irrespective of the level of standard of living, β Thalassaemia carrier women undergoing PND need social work interventions.

Table 5.6 Summary of hypothesis testing results

Sr. No.	Hypothesis	Statistical test	Result	Significance
1	Ho: There is no significant association between having the non-Thalassaemia child/children in the family (along with the child having Thalassaemia) and the decision taken for prenatal diagnostic tests.	Chi-Square Test	$X^2=9.6727$ $df=1$ $p=.00187$	Significant The Null Hypothesis is rejected.
2	Ho: There is no significant association between the monthly family income of β Thalassaemia carrier women and their use of alternate medicines for the management of Thalassaemia in their child/children.	Fisher's exact test in addition to the Chi-Square Test	$X^2= 8.713$ $df=5$ $p=.121>.05$ $p=$ Value of Fisher's exact test is $.102>.05$	Not Significant The Null Hypothesis is accepted.
3	Ho: There is no significant association between the place of origin of β Thalassaemia carrier women and their use of social work interventions.	Chi-Square Test	$X^2=.131$ $df=1$ $p=.717$	Not Significant The Null Hypothesis is accepted.
4	Ho: There is no significant association between the type of family of β Thalassaemia carrier women and their access to contraceptives.	Chi-Square Test	$X^2=0.161$ $df=1$ $p=.688$	Not Significant The Null Hypothesis is accepted.
5	Ho: There is no significant association between the occupational status of β Thalassaemia carrier women and their perception towards adoption.	Chi-Square Test	$X^2=4.328$ $df=1$ $p=.037$	Significant The Null Hypothesis is rejected.
6	Ho: There is no significant association between the level of β Thalassaemia carrier women's education and their experience of facing domestic violence.	Chi-Square Test	$\chi^2=16.259$ $df=2$ $P=0$	Significant The Null Hypothesis is rejected.
7	Ho: There is no significant association between the level of the husband's education and the experience of β Thalassaemia carrier women facing domestic violence.	Fisher's exact test in addition to the Chi-Square Test	$\chi^2=6.704$ $df=2$ $P=0.35$ p Value of Fisher's exact test is $.036 <.05$	Significant The Null Hypothesis is rejected.
8	Ho: There is no significant association between the housing condition of β Thalassaemia carrier women and their experience of facing domestic violence.	Chi-Square Test	$X^2 = .777$ $df= 1$ $p=.378$	Not Significant The Null Hypothesis is accepted.
9	Ho: There is no significant association between the consanguinity of the marriage of β Thalassaemia carrier women and their experience of facing domestic violence.	Chi-Square Test	$X^2=.064$ $df=1$ $p=0.08 >.05$	Not Significant The Null Hypothesis is accepted.
10	Ho: There is no significant association between the monthly income of β Thalassaemia carrier women and their need for social work interventions.	Fisher's exact test in addition to the Chi-Square Test	$X^2= 8.129$ $df=10$ $p=.616 >.05$ p Value of Fisher's exact test is $.666>.05$	Not Significant The Null Hypothesis is accepted.
11	Ho: There is no significant significance association between the number of Amenities of β Thalassaemia carrier women and their need for social work interventions	Fisher's exact test in addition to the Chi- Square Test	$X^2= 8.186$ $df=10$ $p=.611>.05$ p Value of Fisher's exact test is $.641>.05$	Not Significant The Null Hypothesis is accepted.

Salient findings - Phase III

Phase III comprised qualitative data collection and thematic analysis of the data.

Interviews with the medical social workers

From each study site, one medical social worker was interviewed. Their profile was either as a Community Development officer or as a Blood Bank officer. These social workers had very little or no exposure to problems of β -thalassemia carrier women. There were no interventions offered for Thalassemia carrier women's mental & reproductive health issues. These social workers lack specialized social work training in routine practice for families with children having Thalassemia or genetic disorders. These results widened the scope for Social Work interventions for thalassemia-carrier women.

Case studies of β -Thalassemia carrier women

Case studies helped to explore socio-economic and mental health issues faced by these women. They highlighted women's lack of awareness about family planning methods, Bone marrow transplant procedures, and genetic counselling. Case studies revealed family dynamics, son preference, and domestic violence faced by β Thalassemia carrier women. Misconceptions and superstitions about the disease, belief in traditional healing, were also explored in the thematic analysis of case studies.

CHAPTER 6

KEY FINDINGS AND DISCUSSION

This chapter presents a comparison of the results from the descriptive and inferential analysis of this study with findings from other similar studies.

The total number of registered cases with Thalassaemia major from all five out-patient departments is seven hundred and eighty. Percentage distribution is 37%, 23%, 8%, 16%, & 17% from all sites respectively. Among the sites, site A has the maximum number of registrations i.e. 37%. From all five sites, a total of three hundred and ten Thalassaemia Carrier women were contacted for the survey. (Patel et al., 2014).

Findings from phase I of the study:

Acceptance of prenatal diagnosis tests (PND) for the Prevention of Thalassaemia: PND tests are a cost-effective way, as they reduce a significant amount of burden from families having a child with Thalassaemia and indirectly from society. Still, some studies report that not all carrier couples go for PND tests at all times. Despite the strategic approach to the prevention of Thalassaemia, a study conducted in Iran mentions that out of the couples detected as minors, only 25% went for PND (Miri-Moghaddam, Naderi, Izadi, & Mashhadi, 2012).

Reasons for not undergoing PND

Iran is one of the high-frequency regions for Thalassaemia. The study by E Miri-Moghaddam (2012), from Iran, highlights the reasons for not undergoing PND as lack of awareness of the procedure and its importance, high costs of the tests, and disagreement between husband & relatives for the procedure.

In the current study, out of 208 women who did not go for prenatal diagnostic tests (PNDT), forty women (19%) did not undergo them due to reasons related to the procedure. Fear & unwillingness for the prenatal diagnostic test, fear of false reports, non-affordability of the test, lack of awareness about the test, and opposition by family members were the reasons related to prenatal diagnostic tests (40), given for not undergoing PND tests.

The rest of the women who did not undergo any prenatal tests gave reasons that were not directly related to the tests and were very realistic. 168 (81%) women did not undergo these tests due to reasons not related to these tests. These reasons were stated as having other children who are normal or minor, prior acceptance of permanent method of sterilization, marital dispute, prospective plan to undergo the test, delayed ANC registration, late detection of the disease, no desire for next pregnancy, other children are having different health issues, advanced maternal age, home delivery or delivery at native place, unwanted pregnancy or spontaneous abortions.

Social service departments in hospital settings can conduct awareness programs on the importance of premarital or preconception carrier screening and prenatal diagnostic tests as a preventive strategy.

Findings from phase II

In the present study, the mean age of women participants was 35 yrs. The husbands' mean age was 40 years. Which represents the reproductive phase of carrier couples. Ninety-seven percent of women were married, and two women were widows. One woman was separated.

Among women who did not undergo prenatal diagnostic tests (210), the percentage of separated and divorced cases was higher (5%). These findings suggest that an emotional burden caused by Thalassemia on the parents can result in strained relationships, which can directly impact the acceptance of prenatal diagnostic tests. Study findings confirm that being in a stable marital relationship supports women's decision for Prenatal Diagnostic tests. Such couples are seen supporting each other in stressful times. However, a few couples do face strained relationships. Such couples may need counselling and legal help.

Religion

In the present study percentage of Hindu women is 64%, and among the rest, 21% are Muslim, and 10% are Buddhists, one woman is Christian, one is Aadiwasi, one is Jain & two are from Sikh families. A greater percentage of the Buddhist population in the study population is due to consanguineous marriages in the Buddhist community. Creating awareness about the causality of consanguineous marriages for Thalassemia among communities following consanguineous marriages is essential.

Castes

Study participants were mainly Hindus & Muslims. Thalassaemia carrier women from the Hindu religion mentioned their castes. Among the castes mentioned by Hindu women, in castes such as Chambhar, Koli, and Agri, consanguineous marriages are very common. Muslims are the most likely to say they have no caste or tribe (Pew Research Centre, 2022).

Consanguinity

The practice of consanguinity is a big challenge to tackle the problem of Thalassaemia. Premarital genetic counselling is complex in such countries where the tradition of consanguinity is likely to persist (Fathzadeh et al., 2008).

A study by Ahmed (2016) reports 81% of consanguineous marriages in the predominantly Muslim, Multan district of Pakistan. In the study by E. Miri-Moghaddam (2012), in Iran, consanguineous marriages were observed in 83.1% of Thalassaemia major children's parents. In a study by Basu (2015), there were 4.44% consanguineous marriages.

In this study, there were 34% consanguineous marriages. All consanguineous marriages in the current study were observed in Hindus (70%), Muslims (15%), and Buddhists (15%). In other religions, consanguinity was not seen. In countries with a majority Muslim population, the percentage of consanguineous marriages is very high.

Preventive social work interventions, such as awareness creation about the risk of Thalassemia involved in consanguineous marriages, are the need of the time.

Education

A study conducted in Iran on the secondary data gathered from hospital records between 2002 and 2010 found that 52.4% of fathers and 78.4% of mothers of Thalassaemic children had elementary education or less (E Miri-Moghaddam et al., 2012). This study found that fathers were more educated than mothers. Women participants outnumber their husbands in primary education, and men outnumber women in higher education. This shows the gender disparity in achieving higher education.

Disparity in education can be a factor causing an imbalance in decision-making power in the couple. Therefore, building awareness about the disease and its prevention among the less educated women is warranted. Developing information, education, and counselling (IEC) material or audio-visual messages can be helpful in such a population.

Occupational status of Thalassaemia carrier women

A study conducted by Biswas and Mukhopadhyay (2018), "Marital status and women empowerment in India" based on NFHS 3 data (2005-2006) a survey; there were 40 percent women who were employed. These were women from urban as well as rural areas in various states.

A report by Basu and Sidh (2008) on "Work Status and Health of Women" presents a comparative study of Northern and Southern states of rural India, finding that nutritional status and reproductive health status are not just related to work status but to socio-economic status as well.

In the present study, seventy-one women are housewives, and twenty-nine are working women. This shows that a significant proportion of women are financially dependent on their husbands.

Occupational status of husband

The study by Mallik et al. (2010) mentions that husbands of Thalassaemia carriers were mostly unskilled workers (52.6%) or had small-scale businesses (26.7%), and states that about 18% of the annual income of Thalassaemia families is spent on Thalassaemia. In the present study, the percentage of unskilled men was 22.44%, and skilled or semiskilled men were 40%. Those having their own business are 12.24%. Only 19% men are working in the organized sectors, having blue-collar or white-collar jobs. Compliance with Thalassaemia treatment by parents of children having Thalassaemia and acceptance of other treatment modalities, as well as decisions regarding future fertility desires, can be dependent on job security and financial earnings.

Monthly income

A cost-of-illness study conducted by Alshamsi, Hamidi, and Narci (2022) found that 64% of participant families were in the first quartile (lower class) of family income. One more such study conducted in Bangladesh to assess the financial burden of the parents mentions that 75% of families are in lower and middle socio-economic strata (Barua et al., 2022). Similarly, seventy percent of families in the present study have their monthly family income below 20,000 rupees. This shows that a significant proportion of families are from economically weaker sections of society.

Management options and genetic services or consultations warranted in case of Thalassaemia are very costly and out of reach of the poor. Such services should be offered free of charge or at subsidized rates by social workers for families having a child with Thalassaemia major disease.

Household amenities

In this study, household amenities are indicators of poverty, well-being, and standard of living. Inability to buy, own, and maintain them can be due to low income, unemployment, or poor health of family members. In this study, thirty-three percent of women possess only one amenity, and seven have no amenity. Findings from this study confirm that most of the women belonged to the lower and middle-income groups.

Housing conditions

Living conditions in small and shared houses are often detrimental to reproductive health, especially that of pregnant women. According to a study by Engelhardt, Gaudion, Kamhiye, Al-Munjid, and Borde (2022), housing conditions are one of the major social determinants of health and reproductive health. In the present study, 66% of women are living in small houses, and 34% have separate accommodations, which are flats and independent houses, confirming the low socio-economic status of the study participants.

Place of residence

The place of the residential area, whether rural or urban, can also have a direct impact on the utilization of health facilities and the economic burden of the disease. A study by Chawla et al. (2017) found that a caregiver's place of residence can also have an impact on the knowledge, attitudes, and practices of Thalassaemia patients and their caregivers. The current study findings suggest that forty percent of women were staying in Mumbai and suburban areas, and 54% of women are coming from destinations outside of Mumbai, due to a lack of treatment facilities locally. Families spend a considerable amount of time, energy, and money accessing health facilities offering management of Thalassaemia.

Place of origin

Knowing the place of one's origin means finding the geographical location that confirms the ethnicity. A study by Klein & von dem Knesbeck (2018) mentions that there is a difference in healthcare utilization by migrants due to differences in priorities, preferences, information, language, and other support systems. In our study, 38 women have migrated from other states to Maharashtra, and 62 % of the women are from Maharashtra. The reasons for migration were stated as due to work purposes or for a child's treatment for Thalassaemia. In terms of utilization of social work interventions, there was no significant difference.

Family type

A study by Sangani et al. (1990) conducted in Bombay mentioned that 50% of couples lived in joint families and 50% lived in nuclear families. Current study findings suggest that 61% of women stayed in nuclear families and 39% of women stayed in joint families. The number of family members in the house ranges from 3 to 15 in the family. Though women staying in nuclear families get more autonomy and decision-making power, they may not get support for childcare during their hospital visits. Therefore, they may need child care support. Women staying in nuclear families mentioned a lack of social support and isolation from social activities. A study by Kapaya (2015) mentions that a lack of psycho-social support results in delayed ANC care and poor foetal outcomes.

Family composition

Speizer et al. (2015) mention that women's place of residence and with whom they live have an impact on women's healthcare utilization, especially for reproductive healthcare. Especially among the women from joint families, institutional delivery and acceptance of contraceptives are higher.

Similarly, in the present study, women having their in-laws at home were likely to get more support for childcare than the women in the nuclear families, thus making access to healthcare facilities easy.

Head of the household

The headship of the household is an indicator of empowerment. A study by Chakrabarti (2021) mentions that, as the head of the family, women do not necessarily have the power and control of resources. In the current study, only 5 women said that they are the head of the household, which suggests that the decision-making power is hardly shared by women who are married Thalassaemia Carriers. Seventy-eight percent of families are male-headed. In four families (4%) head of the household is the mother-in-law & in five (5%) families head of the household is the woman herself. In thirteen families (13%), husband and wife both are the decision-makers. Mostly in nuclear families, this is seen. In a patriarchal society, only males are considered the head of the household.

Living children

Various studies by Singh et al. (2019), Shukr, Ali, and Yasmeen (2011), and Yagnik (1997) mention that the number of male patients suffering from is more than that of female patients among the living children. In the current study, we have similar findings. Among living children not having Thalassaemia, the number of male children is higher. Preference for a boy child and negligence of females suffering from Thalassaemia can be the factors contributing to this. Sixty-three percent of women have two children each, and twenty-four women have three living children.

Ninety-one women have one child each with Thalassaemia, and nine women have two children living with Thalassaemia. A limited number of children with Thalassaemia can be attributed to deaths of children with Thalassaemia and difficulty in managing the children with Thalassaemia.

Some women have no other child who is healthy. A study by Sangani et al. (1990) reports that 50% of couples had no healthy children. Parents not willing for a second child show a dilemma of the couple or a lesser desire for more children due to Thalassaemia.

History of child's death

In a study by Ismael and Shamdeen (2019), among the Thalassaemia carrier mothers in the age group of 18-46 years, 14 of them had a history of baby death. A study by E Miri-Moghaddam et al. (2012), in Iran, mentions that 4.1% had experienced the death of a child with Thalassaemia. The study by Sangani et al. (1990) mentions that 22% of couples had already lost one or more affected children. 90% of children with Thalassaemia died before 5 years of age, either due to no treatment or under-treatment.

In the present study, out of a total of 20 children lost by 16 women, 11 women have lost their 17 children due to Thalassaemia. Which is 85% of the total deaths. But in this study, sex differences have been found. More girls than boys

have died due to Thalassaemia, as well as other diseases. About the death of children not affected by Thalassaemia, Sangani et al. (1990) mention that there was no sex difference 10 % of children died due to reasons other than Thalassaemia, and 90% died due to Thalassaemia.

Usage of alternative medicines

A study by Sangani et al. (1990) mentioned that 80% of families also used alternative therapies such as Ayurveda or Homeopathy for the treatment of Thalassaemia. A study conducted in Iran, by Bordbar et al. (2018), reported that more than 90% of Thalassaemia patients used alternative medicine therapy as treatment of Thalassaemia. Usage of more than one therapy is reported in the current study.

Child's age at detection of Thalassaemia

The impact of a child's age at detection of Thalassaemia from the angle of a woman's reproductive phase is hardly reported by any studies. Among fifty-six percent of children, detection of Thalassaemia was during the first six months of birth. The maximum age of presentation of the disease is four and a half years. The sooner the detection, the easier it is for these women to accept PND tests in subsequent pregnancy or use contraception for spacing. If the detection of Thalassaemia happens at a later age in a child's life, women cannot decide on prenatal tests. If they have already accepted the permanent method of family planning, they cannot easily reverse their decision. Also, in consecutive pregnancies, they may deliver a child with Thalassaemia, again if they cannot space the pregnancies well.

Frequency of transfusion

Every child suffering from Thalassemia may need blood transfusions at different intervals. A person accompanying the child has to face loss of wages, loss of time, energy, and money, but if she is a woman, she may also need childcare support for her other children at home or support for household chores. Women staying in the joint family may have an advantage in this case over women staying in the nuclear family. Many women also received support from their maternal family members who were staying nearby, while they took the child with Thalassaemia to the hospital. Other siblings of the child living with Thalassaemia may get less parental attention due to the child's frequent transfusion needs.

In this study, fifty percent of children (53) with Thalassaemia required a transfusion at fifteen days. The frequency of transfusion in the number of days ranged from 10 days to 60 days. The more frequent the transfusion needed, the more frequent the parents' visits to health facilities existing at the hospitals, if transfusion is given there. Thus, access to health facilities for women or parents may be higher due to the frequent visits.

Reproductive health parameters of the β Thalassaemia carrier women who intend to have a healthy child

Early marriages and age at first pregnancy

The practice of early child marriages in some communities and regions can be a cause for pregnancies at an early age. In a study by Mishra (2022), a lack of antenatal care, home deliveries, and poor postnatal care was found among these women of the age group 15-19 yrs in Nepal. A study by Paul P. et al. (2019) reports that utilization of maternal healthcare facilities was significantly lower among women who got married before the age of 18 years. Such women may experience anaemia, bleeding, and weakness during pregnancy, and may face adverse pregnancy outcomes. Lack of education, low economic status, traditional beliefs, lack of awareness about the implications of early marriage, and health education are the factors behind early marriages.

In this study, the mean age at first pregnancy was 21.23 ± 3.51 and 15% of women had their first pregnancy before 18 years of age.

Menstrual status

It is a status of women's menstrual cycles. It is an indicator of reproductive health status and fertility (Symul, Wac, Hillard,

& Salathé, 2019). In the current study, 90% of women had regular cycles, and 4% had lactational amenorrhea; this shows that these women were in the reproductive phase. Six percent of women who were not menstruating were in menopause or had undergone a hysterectomy.

Reproductive outcomes in Thalassaemia minor women

Various studies report that some women with Thalassemia trait are found to be anaemic during pregnancy compared to the normal control group of women. (Ismael and Shamdeen, 2019 & Ruangvutilert et al., 2023).

However, these studies do not mention whether all these women had undergone PND tests. In a study by Charoenboon et al. (2016), where women who underwent invasive prenatal tests were excluded, maternal anaemia was found among more carrier women. Pre-term birth was slightly higher among carrier women than in the control group women, but not significantly so. The abortion rate was higher in the present study group. In the current study, some women did mention anaemia during pregnancy, but the exact number of such women is not known, as this was asked retrospectively.

Number of total pregnancies

A study conducted in Iraq, by Ismael & Shamdeen (2019) found the mean of the total number of pregnancies to be 3.54 ± 2.07 among the women in the age group of 18- 46 yrs. In the present study mean gravida is 3.42 ± 1.45074 .

Timing of prenatal diagnostic tests

A study conducted in Ahmedabad included 282 women who underwent PND tests for the prevention of Thalassaemia in the foetus. Out of them, 41% went for PND tests in their first pregnancy (Patel et al., 2014). This study was effectively conducted by the Government of Gujarat and Ahmedabad Municipal Corporation and was successful in avoiding 62 births of the thalassaemia-affected foetus, which saved 58 million Indian rupees of treatment costs.

In the present study, no women accepted PND testing in the first pregnancy. It was only after the index child's presentation with Thalassaemia that the couple was advised PND test, as no women study participant was screened during her antenatal check-up. Very few studies in India report the exact number of Thalassemia carrier women undergoing prenatal diagnostic tests.

Type of deliveries

A very recent study by Ruangvutilert et al. (2023) found no significant difference between the Thalassaemia trait group and normal control group in terms of gestational age at delivery, mode of delivery, estimated blood loss, postpartum haemorrhage (PPH), gestational diabetes mellitus (GDM), and stillbirth. Pregnancy-induced hypertension and anemia in the third trimester were more common among the Thalassaemia Trait group of women. 52.32% of women had a spontaneous vaginal delivery, and 45% had c. section delivery, and 2.32% had stillborn babies in the monitored pregnancies.

In the study by Ismael & Shamdeen (2019), the percentage of normal delivery is 80%, and 20% of deliveries are conducted with C. section. In the present study, out of a total of 256 delivery episodes of hundred Thalassaemia carrier women, 200 (78%) episodes were with full-term normal delivery, 54 (21%) were with c. section, and 2 preterm deliveries occurred. These findings are similar to the findings by Ismael & Shamdeen (2019).

The studies by Ruangvutilert et al. (2023) and by Ismael & Shamdeen (2019) do not mention whether women have undergone prenatal tests and have children with Thalassaemia. In the present study, study participants are β Thalassemia carrier women who have child or children with Thalassemia and have undergone prenatal diagnostic tests.

Abortion

A study on pregnancy outcomes among minor Thalassaemia women by Ismael & Shamdeen (2019) found the mean value of abortions as 0.44 ± 0.73 . A study by E Miri-Moghaddam et al. (2012), in Iran, found that the percentage of unwanted pregnancies was 40%. In the present study, the reason for abortions is unwanted pregnancies in more cases than due to positive prenatal diagnostic test results. This warrants the need for interventions such as family planning

counselling and the supply of contraceptives. Also, timely interventions to refer these women for prenatal diagnostic tests are required.

Type of abortions

The researcher did not come across any studies mentioning the number of abortions post prenatal diagnostic tests, and without doing prenatal diagnostic tests in the life span of Thalassaemia carrier women. However, in this study, there were a total of 31 abortion episodes after PND tests, 30 induced MTP episodes, and 1 spontaneous abortion episode among the 100 study participant women.

Fifty- five abortion episodes were without PND tests. Out of them, fifteen were spontaneous, and forty were induced. Findings suggest the need for effective family planning counselling for these women to prevent foetal loss in case of unplanned pregnancies. As we see that the number of spontaneous abortions is high (31%), though the abortion episode is not post PND, this aspect needs attention to improve maternal health.

Number of deliveries

A study by Sarvestani, Hasanifar, and Bagheri (2019) reports 3.96% fertility rate in the Sistan and Baluchistan provinces of Iran. Polygamy may be one of the reasons for the higher fertility rate. In this region, the mean value of the number of deliveries, 1.98 ± 1.81 (Ismael & Shamdeen, 2019), suggests high fetal wastage due to pregnancy losses.

India's total fertility rate has fallen sharply in the past two decades; in 2019- 21, the average Indian woman was expected to have 2.0 children in her lifetime, nearly one child fewer than 2.9 in 1998-99 (Pew Research Center, 2022). Whereas in the present study, it is 2.56 ± 1.01 , which is more in the case of Thalassaemia minor women, than the above findings. These findings are suggestive of high fetal wastage in the case of Thalassaemia-carrier women in the study.

Issues related to carrier screening, cascade screening, and prenatal diagnostic test procedures

Detection of carrier status

In a study conducted in Iran, by E Miri- Moghaddam et al. (2012), 71.2% of couples were detected of their minor status after their child was diagnosed with Thalassaemia. In the present study, all the 100 women & 98 husbands have done the carrier screening after the detection of Thalassaemia in their child. Two husbands knew their status before marriage, but they did not reveal it to their spouses before marriage.

Findings warrant a need for carrier status screening of the couple during preconception or the early prenatal period, if not done before marriage. The stigma attached to carrier status in society is a reason for the non-acceptance of premarital screening in Indian society.

Cascade screening

A study conducted in Pakistan, by Ahmed et al. (2022) reported a low uptake of cascade screening in Pakistan due to the stigma associated with carrier screening.

The study conducted by Patel et al. (2014) about the awareness of beta- thalassaemia among the close relatives of Thalassaemia patients reports that awareness of Thalassaemia was higher in the participants with a family history of Thalassaemia or who were already tested for beta-thalassaemia than among the first-degree relatives of beta-thalassaemia major ($p < 0.0001$).

A study by Baig et al. (2008) reports that out of 27 family members in a large family with an index case of Thalassaemia and three marriages between carriers and one marriage between a carrier and a non-carrier, cascade screening was performed, and 12 members (44%) screened positive. Thus, cascade screening is a cost-effective method and a practical solution in settings with limited resources and the practice of consanguineous marriages.

In the present study, only 27% of maternal side family members accepted the cascade screening, and only 24% of paternal side family members participated in the cascade screening. Some participants mentioned non-disclosure of a child's Thalassaemia major status as also one of the reasons for less uptake of cascade screening by blood relatives.

The number of PND episodes

A study by Tedgard et al. (1989) mentions that the process of PND tests was very distressful for 13 Hemophilia carrier women out of 29, as they were under a lot of psychological pressure. Women who had to accept termination of pregnancies due to positive PND test results reported psychological trauma. Among those who continued pregnancies due to negative results, eight of them mentioned that they felt stress while doing routine activities till the time of delivery. The study recommends psychological interventions by qualified professionals for such women before and after PND tests. In the current study, the number of PND episodes undergone by Thalassaemia carrier women ranged from one to seven. The Mean of the PND test numbers is 1.35 ± 0.809 . With each PND episode, there are financial costs and unpredictable results involved. In case of positive results, MTP costs are also involved. However, no psychological intervention is provided to women on pregnancy loss.

Son-preference

This means preferring a boy child more than a daughter. Many researchers attribute India's widespread son preference and daughter aversion partly to the higher cost of raising daughters through the dowry traditions (Anukriti, Kwon, & Prakash, 2022). Births of daughters in South Asian countries are often considered an economic liability due to the dowry system in which the bride's family has to give the groom durable assets as a condition of the marriage (Chowdhury, 2010).

A study conducted in Nepal by Rai et al. (2014) mentions that parents having more female children have a desire for more children, to have a son. This has a direct effect on reproductive behaviour and a couple's fertility, even though there is an overall decline in the fertility rate in Nepal.

Despite an overall decreasing fertility trend, son preference still lingers and manifests itself in the form of imbalanced sex ratios (Jha et al., 2011; Jayachandran & Kuziemko, 2011; Yoo, Hayford, & Agadjanian, 2017).

Son preference is believed to be the principal cause of excess female mortality during childhood. Research studies suggest that parents with strong son preference consider their daughters to be less valuable and provide inferior care in terms of food allocation, prevention of diseases and accidents, and treatment of sick children (Pebley & Amin, 1991). A strong preference for sons may also lead to the practice of female feticide or infanticide (Kaur, 1993).

In a study by Sangani et al. (1990) 19% of participants mentioned that they would not provide treatment to a female child having Thalassaemia. Current Study results also show that among the children who died due to Thalassaemia percentage of female children who died was higher (26%) than the percentage of male children (18%). Female children with Thalassaemia major are neglected and deprived of the basic management requirements of Thalassaemia.

Health issues/complaints after PND

No major side effects of prenatal tests except the minimal risk of miscarriage after the prenatal diagnostic tests are reported. In the present study, out of 35 women who faced health issues after prenatal diagnostic tests, abdominal pain, abdominal pain while needle puncturing, weakness, and minor bleeding after the procedure were the complaints.

A study based on a public health program in Gujarat reported no fetal loss after the 282 PND test procedures (Patel et al., 2014). However, in the present study, one woman out of 100 Thalassaemia-carrier women experienced spontaneous abortion after a prenatal diagnostic test.

Treatment for such health issues

As a treatment for these health issues, the majority of women were prescribed painkillers and vitamins for their complaints of abdominal pain and weakness, respectively, and some were advised hospitalization or bed rest at home.

Other issues

A few couples skipped the PND tests, despite knowing about them and though they had accepted them in the past. Also, delays in the test reports may be the cause for delay in MTP, in the advanced stage of pregnancy. The falsity of the

results is attributed to human errors in entering, technical issues with PCR, reports issued without doing Maternal Contamination tests on the sample, and in some cases, nonpaternity (Ahmed, 2007). A Study by Abolghasemi et al. (2007) reported 6 false results of PND tests among 2549 fetuses. In this study, the reported rate of misdiagnosis was 0.37%. Women even mentioned the misdiagnosis or non-thalassaemia major test reports. Such issues weaken the faith of participants in the medical procedures and also spread fear about the test.

Refusal to terminate the pregnancy after the positive PND test results was observed among 16 women in Iran (E Miri-Moghaddam et al., 2012). A study by Abolghasemi et al. (2007) reported that 10 couples did not opt for elective abortion of the affected foetus. A study by Saxena (2017) reports that 65% of women agreed to go for an abortion if the prenatal test report was positive. The decision not to have a pregnancy terminated in the case of the affected fetus was due to religious beliefs, cognitive and socio-cultural factors, according to Karimi & Cohan (2010), Moudi & Miri-Moghaddam (2017). 18% of study participants refused to go for MTP after positive test results.

In a study by Basu (2015), 81.31% women agreed to the MTP in case of positive prenatal test results. In the present study, one woman was not allowed by family members to terminate the pregnancy due to religious beliefs.

Various factors affecting the fertility decisions taken by Thalassaemia carrier women

Desire for more children

After the detection of Thalassaemia in an index child, 60% of parents expressed their desire for more children, according to findings from a study in Iran E Miri-Moghaddam et al. (2012). In the present research study, 20 women had not yet decided to limit their family, but most of the rest had decided against a further pregnancy because of the risk of recurrence. Seven young women without a single healthy child and 27 with only one healthy child had accepted permanent contraception.

Reasons for more children

In the present study, seventeen women desired more children, as they wanted a sibling for their other minor or normal child, wanted a male child, or wanted a girl child, and for HLA matching of a healthy donor sibling for Bone Marrow transplant were the reasons for the desire for more children.

Reasons for no desire for more children

In the present study, more women had no desire for more children. Reasons being, medical issues (5%) such as secondary infertility, hysterectomy, previous LSCS, diabetes, or because they have other minor children or feel that their family is complete (54%). 35.5% felt that they could not afford more children, and they were scared of positive prenatal test results. This means that their desire for more children may be hidden under these presumptions, and they might have compromised their desire to have more children.

Inferential analysis showed that the desire for more children is significantly associated with having a normal or minor living child or children among thalassaemia-carrier women. Death or loss of a child does not necessarily affect the woman's desire for more children.

Use of contraceptives

Furedi (1996) has classified the modern methods of contraception as safe methods and the traditional methods as unsafe methods. A study by E Miri-Moghaddam et al. (2012) found that there was no significant change of contraception among the couples after the detection of Thalassaemia in their child. A study by Khorasani et al. (2008) conducted in Mazandaran Province showed that 64% of couples used safe methods of contraception. A study conducted in Sistan & Baluchestan by Asadi Sarvestani, Hasanifar, and Bagheri (2019), mentioned that 49.3% of women did not use any contraceptive method. In the present study, 67% of women are using modern methods of contraception.

Reasons for not using modern contraceptives

In the present study, 33% of women are not using any safe or modern contraception. The reasons stated for the same are that they prefer traditional methods, privacy issues, religious issues, family issues, reluctance, risk of Thalassaemia, and no awareness of contraception. The risk of unintended pregnancies can be higher among such women needing timely intervention.

Plan for accepting a permanent contraception

Twenty-three percent have already accepted the permanent method, and nineteen are planning to accept it. Among the rest of the women need to accept regular and reliable modern methods is envisaged throughout their reproductive phase.

Access to contraceptive methods

In a comparison of users and non-users of contraception, Asadi Sarvestani, Hasanifar, and Bagheri (2019) state that the desired number of children, distance from health facility, respondent and husband's education level, number of children, ethnicity, woman's occupational status, and place of residence were significant factors. Women staying in urban areas had better access to contraceptive information and services.

In the present study, 40% of women mentioned that access to contraceptives was difficult or very difficult for them. Comparison was done between the two groups: those who felt that access to contraceptive services was very easy and easy, and those who felt that it was difficult and very difficult. Door delivery of contraceptives, access to health facilities and private outlets, husband's support, family support, and good transport services were the factors determining access. Thus, interventions to enhance partner & family support or to improve access to contraceptives can be planned for Thalassaemia-carrier women.

Utilization of health facilities for issues related to reproductive health

Basic maternal and child health depends on appropriate health system utilisation during pregnancy (Mayer et al. 2021). Women from lower socio-economic strata may face discrimination in health and healthcare practices, which can result in a high risk for them. There is inequity in the use and access to reproductive health care (Baru et al., 2010). Financial condition can be one of the determining factors for maternal healthcare utilization (Mishra, Veerapandian, & Choudhary, 2021).

For contraception

A study by Bhate-Deosthali (2011) mentions that contraceptive supply and immunization were predominantly handled by the public sector in Maharashtra in 2005; the role of private facilities hardly existed then. A study by Rout Sahu and Mahapatra (2019) suggested that utilization of public health facilities is low in all other states except Assam and Odisha due to low quality of care and long waiting hours. The same study further confirms that due to the constraints of the public facilities, patients are compelled to go to private health facilities.

In the present study, Thalassaemia carrier women who accessed private healthcare facilities were more likely to utilize them than public facilities for the supply of contraceptives. Very few accessed them from NGOs, and the rest relied on traditional methods, which shows the underutilization of public health facilities by Thalassaemia Carrier women for the supply of contraceptives.

For deliveries

Paper by Mishra, Veerapandian, & Choudhary (2021), which is based on a comparative analysis of NFHS 2005 & NFHS 2015 data on institutional deliveries, mentions that there is a significant drop in home deliveries in India from 61.1% to 20.8%. Utilization of public hospitals for deliveries increased from 18% to 52.1% in the year 2015. Utilization of private hospitals for deliveries went up from 20.8% to 27.1% in the survey data.

A study by Bhat (1999) raises concerns about high costs, inaccessibility, and quality issues in services provided by private healthcare facilities, while pointing to growing undesirable practices in the private healthcare system in India.

Several studies report a higher number of cesarean section deliveries in the private sector. In the present study, Thalassaemia carrier women preferred public hospitals for 45% of deliveries and 41% deliveries at private hospitals. Surprisingly, 14% of delivery episodes were home deliveries. Interventions to institutionalize more deliveries will help monitor the obstetric morbidities among Thalassaemia carrier women, especially to improve reproductive outcomes.

For prenatal diagnostic tests

A study conducted in the Multan region, Pakistan, by Baig et al. (2012) mentions that 90% of the study population was non-affording and accepted PND tests only when they were made available free of charge.

A study by Saxena et al. (2017) found that only 27.5% pregnant women underwent prenatal diagnostic tests. However, this study has not investigated the reasons for not undergoing prenatal diagnostic tests.

The present study has interestingly found out the reasons for women not undergoing prenatal tests, which no other studies reported previously, in the Indian context.

Also, delays in receiving reports, false negative reports, and miscarriages after the tests, such issues were experienced by some women, which indirectly affected other women's decisions to take up these tests.

The present study found that for prenatal diagnostic tests, public health facilities were used in 81% of episodes, and 19% of episodes took place at private facilities. This is mainly due to the very high costs involved in prenatal diagnostic tests.

For medical termination of pregnancies

Data from NFHS 5 (2019-2021) of the total abortions (spontaneous as well as induced) reported, 52.9%, 26.2%, 20.3% & 0.6% abortions at private health facilities, at home, at public health facilities, and other facilities respectively.

Similarly, in the present study, Thalassaemia carrier women have used private facilities for 69% of medical termination of pregnancies, and 28% of episodes have been conducted at public health facilities. They bear a lot of financial burden in case they want to terminate their pregnancies; interventions to improve access to abortion facilities at public hospitals should be planned.

It is also surprising to know that women who are dependent on public health facilities for Thalassaemia management do not opt for the same health facility for termination of pregnancies or for accessing contraceptive methods. Capacity building of health care providers and strengthening the public health system to meet these needs are warranted.

Other social problems felt by β Thalassaemia carrier women related to the reproductive phase of their life

Domestic violence

In the present study, 31% of women who reported domestic violence mentioned that they were harassed by in-laws and by husbands. Violence was mainly in the form of verbal abuse, beating, fights, mental torture, dominance, and threats for a second marriage. Also, blaming the females for the disease in the child was very common.

Interviews with social workers and other study findings mention that such incidents were not reported, and therefore, no interventions to save these women from domestic violence were planned.

Partner's addiction

Alcohol addiction is a very important social issue and is also considered a negative coping mechanism in stressful situations. A study by Nikbakht and Bastami (2016) reported that women with addicted husbands go through psychological vulnerability and undergo distressful feelings along with various problems. They lead a miserable life full of anxiety, worries, and confusion.

In the present study, twenty-two women mentioned that their husbands were alcoholics. Even though not all of them mentioned that they attribute it to Thalassaemia. Husband's addiction can additionally harm such women's mental health

and strain their marital relationship. Also, this may increase the financial burden on the family to some extent. This shows that probing about social issues is needed for women to come out with their hardships and family problems. No other professional, other than a qualified social worker with a good grasp of socio-cultural surroundings, can perform this better.

Work-life transition

In the present study, 25 women mentioned that they were previously working and had left their jobs. Out of them, 10 women had to quit their jobs due to their child's Thalassaemia status. Thalassaemia is a financially burdensome disease for many families, and the heavy dependence of the disease on a single person's earnings in the family is certainly worrisome. Such situations call for interventions with other family members or employers, which might help some women to save their jobs. A suggestion was given by some of the participants to train these women in small groups for vocational courses.

Support for childcare in the past

In the present study, women were asked about who provided childcare to their other children during their frequent visits to hospitals in the past. 26 women mentioned that they did not get any childcare support; they carried their other children to the hospital with them. Seven women said that their husbands took care of other children at home, which implies a loss of wages for their husbands, and one woman kept her other children at their native place and later in the hostel. Findings suggest that other siblings of the child with Thalassaemia need daycare or childcare support during her frequent hospital visits.

Support by family members

In the present study, when asked about the childcare support they receive at present, 13 women mentioned that they don't have any childcare support.

When asked about a person accompanying them to the hospital, ten women said that they came alone, and sixty-six women mentioned that they were accompanied by their husbands. This means that only ten women can independently handle the travel to and from the hospital and all the procedures at the hospital. Whereas the rest are accompanied by their husbands and extended family members to the hospital.

Some women also mentioned that the support groups established at the hospitals by some parents are very helpful during their full-day routine on the transfusion day.

Support for household duties

In the present study, eleven women staying in the nuclear family and four women from joint families mentioned that they do not get any help for household duties when they move out of their house for a child's transfusion at the hospital. Some women start very early in the morning and reach home very late. Women and some family members requested food arrangements for them along with their children, as they had to arrange their meals from outside.

Availability of interventions for families having a child with Thalassaemia major

Availability of social work interventions

A study by Sangani et al. (1990) mentioned that only 17(8.5%) families out of 200 families received financial help from friends, relatives, and social workers.

In the present study, 67 children received free medicines, 73 children received free transfusions, and twenty-two children and families received other interventions such as free ration, tuition fees assistance, and financial assistance for PND tests from hospital social workers.

Specific interventions for mothers having children with Thalassaemia, based on the individual assessment (casework), are lacking in these findings. Opportunities to handle these mothers' specific issues are missed by professional social

workers. Their role becomes limited or rather restricted due to the heavy workload and routine tasks. Also, there is a need to orient them with social work in genetics and preventive genetic counselling. Dehkordi and Heydarnejad (2008) suggest a combined use of audiovisual methods along with printed booklets for parents having a child with Thalassaemia. E Miri-Moghaddam et al. (2012) recommend repetition and perseverance of the information provided to couples having Thalassaemia carrier status for effective prevention of Thalassaemia.

Sources of counseling for Thalassaemia

A study by Saxena et al. (2017) found that parents having a child with Thalassaemia lacked awareness about the disease, prenatal tests, vaccines, and chelators. In the present study, all women mentioned that they received information about Thalassaemia from doctors and blood bank officers. Still, the researcher found that many women had queries regarding the BMT procedure; they were not sure about their other children's carrier status.

Sources of counseling for prenatal diagnostic tests

A study by Karimi, Johari, & Cohan (2010) reported that 25.9% of study participants were not aware of prenatal procedures. This shows that not all couples visiting hospitals for their child's Thalassaemia management are necessarily counselled about the PND tests.

In the present study, since the sample selected was of women who had undergone a minimum of one prenatal diagnostic test, all women were aware of the PND tests, and 95% received the information from doctors, and the rest of them received it from the nurse, social worker, PND test center staff, and other mothers. These findings suggest that the social worker's role in the dissemination of information is secondary in such aspects.

Sources of genetic counseling

In a study by Collins et al. (2001) conducted in Australia, out of ten mothers with Down syndrome, six women received genetic counselling. Whereas all women with cystic fibrosis received genetic counselling as part of a structured education program. Those who received genetic counselling commented about the positive impact of genetic counselling to help them relive from their guilt and felt that it was a timely intervention. Some women who got the information as part of the program felt that there was information overload and therefore such counselling should not be offered in one visit.

An article by Abacan et al. (2019) reports that medical social workers are the allied health professionals in India who also perform genetic counselling along with trained medical geneticists.

In the present study, 73% of women who received genetic counselling mainly received it from doctors and technical staff working at the PND centre. A negligible percentage of women received it from social workers or nurses. Twenty-seven percent of women said that they did not receive any Genetic counselling (GC). As there is a shortage of geneticists in these settings, offering GC in more than one session may not be feasible; reinforcement of information shared in this counselling session with the involvement of social workers is the solution. Involvement of social workers in a multidisciplinary team focused on Thalassaemia prevention and management is rarely seen in India; it is seen in the comprehensive Thalassaemia care models used in developed countries.

Sources for family planning counseling

Asadi Sarvestani, Hasanifar, and Bagheri (2019) mention that among Thalassaemia carrier women living in Sistan and Baluchestan province, 16.4% of study participants did not know about any contraceptives, 49.3% never used any contraceptives. In the present study, sources for family planning (FP) counselling were primarily doctors, family and friends, health workers, NGOs. Very few tried to get more information on their own. 42 couples were not informed about different FP methods. These findings show that opportunities to contact such women were missed. Such opportunities are important for the prevention of Thalassaemia and unwanted pregnancies too.

Adoption Counseling

A study by Sangani B et al. (1990) presents the data from four OPDs in Mumbai, which offered services to Thalassaemia patients and families. Out of 200 families, 10 (5%) families said that they would consider adoption. A paper by Balgir (2014) mentions adoption as an option in preventive genetic counselling. In our study, findings suggest that adoption counseling was done rarely, and only six families were told about adoption by doctors, family, and friends.

In Indian society, adoption has always been considered an option in case of infertility. Guidelines issued under the National Health Mission, Ministry of Health and Family Welfare in 2016, mention adoption counselling and post- test counselling to Thalassaemia carrier couples. These guidelines mention the appointment of MSW-qualified personnel, as Field officers cum counsellors, but in reality, these guidelines are not being implemented due to various factors.

Findings from phase III based on social workers' interviews

Participant social workers working in the social service departments are trained as social workers and either work as community development officers or blood bank coordinators. They mostly offer patient and family- centric and also donor-initiated interventions. Social work practice is mainly philanthropic and common to all OPDs. Mothers having a child with Thalassaemia receive financial assistance offered for prenatal diagnosis, and they are referred from the Thalassaemia OPD by doctors treating Thalassaemia major children.

A social worker's active role as a genetic counsellor is mentioned in a document on genetic counselling for Hemophilia (Alabek, Mohan, & Raia, 2015). Such reports about the role of social workers in Thalassemia in the Indian context are lacking. Various literature from developed countries and countries with a high prevalence of Thalassaemia mentions the extended role of social workers during the reproductive phase of high-risk couples (Fertel & Reiss, 1997). In Indian settings, such social work interventions are lacking. Also, there is a lacuna in the social work training concerning genetic disorders such as Thalassaemia and its impact on family members. These findings reiterate on a widened scope for social work interventions in Indian settings, especially for Thalassaemia Carrier Women.

Findings from phase III based on case studies of Thalassaemia carrier women

Case studies highlight issues such as consanguinity, the out-of-pocket expenditures incurred on prenatal diagnostic tests, preference for a son by themselves or by family members, and the need for contraceptive advice. Also, gender bias results in blaming the woman for the disease, family opposition to prenatal diagnosis and medical termination of pregnancy, harassment by in-laws and/or husband, and fear of divorce or desertion by husband.

Psychological issues such as stress, depression, emotional insecurity, and inability to make decisions about further pregnancy were reported by β Thalassemia carrier women. The use of alternative medicines and belief in traditional healing can add to the out-of-pocket expenses. Social isolation, superstitions, and stigma about the disease are other social issues highlighted.

Findings from case studies warrant social work interventions to improve the quality of β Thalassaemia carrier women's lives.

CHAPTER 7

POLICY RECOMMENDATIONS, ACADEMIC AND SOCIETAL IMPLICATIONS

Policy recommendations

Trained social workers currently working in the hospital setup should acquire skills related to genetic counselling, adoption counselling, and contraceptive counselling. Training of Health providers working in private hospitals for the specific information needs of Thalassaemia carrier women. A dedicated social worker for genetic OPDs, to offer all the following recommended interventions, should be appointed.

Assessment of women's socio-economic conditions

The casework method to assess the conditions of women should be adapted during regular follow-ups and OPD visits, while planning interventions for the thalassaemia carrier women.

For issues such as domestic violence, childcare support, marital disputes, partner's addiction, gender discrimination, etc. Appropriate referrals and legal aid can be provided as required.

Women needing medical advice for low HB and general health should be provided with referrals. A need-based, personalized intervention plan can be prepared. Referrals to the agencies, NGOs, or specialty-based on this assessment can be done.

Providing information and counseling

Awareness about carrier screening tests, cascade screening among other extended family members, and prenatal diagnostic tests should be created. Interpretation of reports should be done & possibility of false reports should be discussed. Reasons for non-acceptance of PND tests should be explored.

Non-directive counseling should be offered. Counselling about the role of consanguineous marriages in genetic diseases should be included in group work. Awareness sessions among communities with the custom of consanguineous marriages can be arranged.

Reinforcement of the information provided at the detection of Thalassaemia by doctors can be done, group work method can be utilized for the same. In the information about Thalassaemia, transfusion- transmitted infections should be included. Information about HLA matching and BMT Transplant at the child's appropriate age should be provided.

Preparing information, education, and counselling (IEC) material and audio- visual content to create awareness should be considered.

Maternal health interventions

The importance of preconception care, early registration during pregnancy, spacing between births, and the use of family planning methods should be emphasized for Thalassaemia carrier women. Follow-ups-Post Screening tests, Post PND tests, Post Delivery, and Post referrals should be maintained.

Dilemmas about fertility decisions can be handled by social workers with expertise, and grief counselling can be offered to Thalassaemia carrier women after the loss of a child.

Interventions with family members

For sharing information related to the inheritance of Thalassaemia, the importance of family planning, and also to clear doubts about treatment modalities of Thalassaemia sessions, can be arranged with other family members, including husbands. Options such as assisted reproductive technology (ART) and adoption should be discussed openly. In case of domestic violence or marital disputes, resistance from family members to providing treatment to the girl child, acceptance of family planning methods, prenatal diagnostic tests, carrier screening tests, and involvement of family

members may be needed. Interventions such as home visits and follow-ups can be planned as needed in case of other social issues- divorce, desertion by husband, or non-cooperation by family members. Legal help for troubled Thalassaemia carrier women.

Also, practices such as black magic and superstitions about the disease should be detected and addressed appropriately. Transport facility to carry patients and their relatives to the hospital can be arranged, and provision of a creche in case of younger children can be helpful.

Interventions with policymakers

Advocacy for social security for children with Thalassaemia and their families is needed. In case of positive prenatal test results, women demand reimbursement of medical expenses, as they may want to go for one more prenatal diagnosis test. Advocacy for carrier screening in all hospitals during antenatal care to prevent the birth of a child with Thalassaemia is needed.

Maintaining an audit of Thalassaemia cases annually by keeping records of lost to follow-up cases with Thalassaemia, deaths related to the disease, and regular follow-ups of families with Thalassaemia major child/children can help to avoid gender discrimination in seeking Thalassaemia treatment for female children.

Social Work Interventions Needed by a β Thalassaemia Carrier Woman

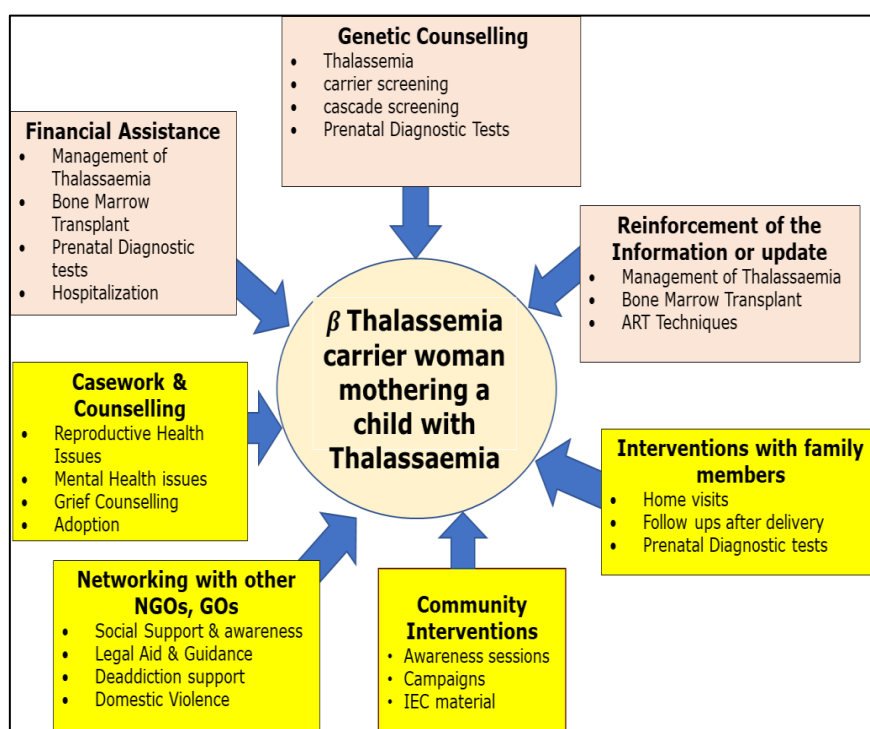


Figure 7.1: Proposed Thalassaemia Carrier Woman-Centric Model for Social Work Interventions Offered In the Hospital Settings

In the above figure, a proposed model of social work interventions is presented for β Thalassaemia carrier women.

This model focuses on existing interventions as well as recommends more social work interventions to help women during their life cycles and to develop a model for professional social workers in Mumbai, thus extending the scope of existing social work interventions.

The upper part (highlighted in cream colour) of this model mentions three broad areas of interventions that currently exist to some extent. The lower part (highlighted in yellow colour) shows the extended scope for social work interventions.

Social workers should be additionally and adequately trained and oriented to offer existing interventions as well as the proposed interventions.

Financial assistance

Financial assistance is given by social service departments for routine management of Thalassaemia, Bone marrow transplant for the child affected with Thalassaemia, prenatal diagnostic tests, and hospitalization of the child or the mother, as families incur very high out-of-pocket expenditure for these.

Genetic counselling

Counselling related to Thalassaemia and carrier screening tests, cascade screening, and prenatal diagnostic tests should be offered by social workers, which is currently provided only by medical professionals.

Reinforcement of the information or update

Providing the update on the information about the disease and periodic reinforcement of the same can be done by social workers.

Casework & counselling

To deal with reproductive health issues and mental health issues, casework and counselling can be done. Grief counselling in case of the death of the child can be offered, and adoption as an option should be discussed.

Networking with other Non-Governmental Organizations (NGOs) and Government Organizations (GOs)

Working with Non-Governmental Organizations and Government Organizations, to provide social support to these women for childcare, fighting the stigma related to disease by providing information, providing legal aid and guidance, preventing domestic violence and addiction among the partners. Creating awareness about preventive measures for Thalassaemia, such as avoiding consanguineous marriages and advocacy efforts with governments are warranted.

Community interventions

Mobilizing community support, conducting awareness sessions, campaigns, and developing IEC material, audiovisuals, can be helpful.

Interventions with family members

Interventions such as home visits and follow-up visits to hospital wards after prenatal tests, deliveries, death of the child, or non-compliance with Thalassaemia treatment should be planned.

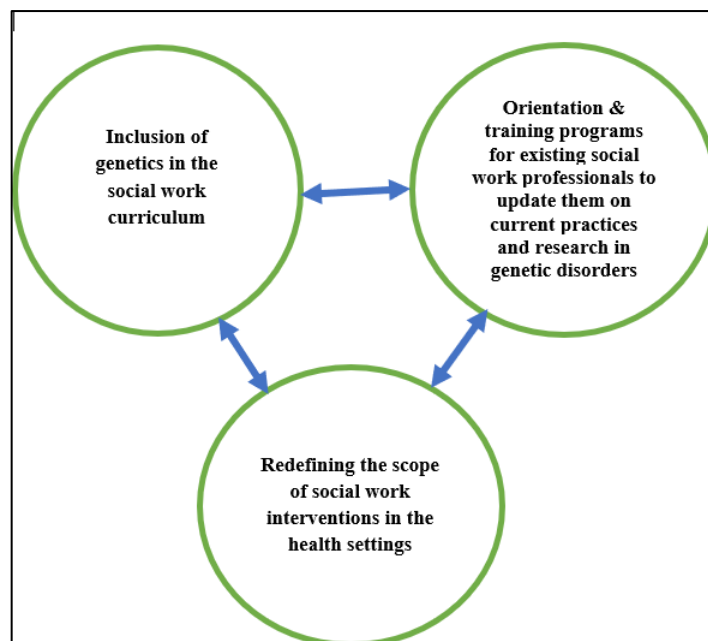


Figure 7.2: Recommended three-pronged approach in social work to deal with Thalassaemia

The three-pronged approach in social work to deal with Thalassaemia is presented in the above diagram.

The existing social work curriculum does not include the syllabi on social work in genetic setups, whereas globally, social workers' role in genetic setups has been accepted. Inclusion of this, along with women's health issues during the reproductive phase, is recommended.

Trained social workers practicing currently in hospital settings are not acquainted with issues other than financial issues faced by families having Thalassaemia. Orientation and training to handle such issues can be planned and provided to them in various ways. Enhancement of their skills to provide genetic counseling is needed. A shift of existing social work interventions in health settings from philanthropic to rights-based interventions would help in redefining the scope of social work interventions for Thalassaemia carrier women. Social work interventions for families having children with Thalassaemia should also aim at improving Thalassaemia carrier women's quality of life.

Academic implications

Genetic conditions may strongly influence the physical and social environment of the individual adversely; social workers can be instrumental in helping their clients change their physical and social environments towards betterment.

Social worker as a genetic counselor

Social workers working in the field of genetics need to be able to differentiate between genetic counselling and other types of counselling. For that, they need specialized training in Genetics to play a role as genetic counsellors. They should be able to understand the types of genetic tests, screening tests, indications for using them, and the interaction of genetics with the environment. Social workers should be aware of the ethical, legal, psychological, and social implications of genetic diagnosis, genetic testing, and research.

Adoption counseling

Social workers should be part of the adoption team and should confirm that, along with all the reproductive options, adoption should be discussed as an option with the β thalassaemia carrier women desiring further pregnancies.

Continuing education and in-service training for social workers

In order to remain updated about government policies and legal provisions for persons affected with genetic disorders and their families, social workers may need continuing education and in-service training, as part of their job profile. With such trainings They will be better equipped to locate community resources and potential service providers for patients with genetic conditions and their families. They can provide effective referral services to specialists, NGOs, and GOs, to improve the quality of life of their clients.

Social workers need to update their interpersonal, psychosocial, and soft skills, etc. through practice. Social workers should be trained to safeguard and respect the individual's right to data privacy and confidentiality, and understand it as a human rights concern. Thus, training in ethical issues involved in genetics should be a part of social work curricula.

Social advocacy

This study found that the group of β thalassaemia carrier couples is marginalised, and it is just the tip of the iceberg that visits the hospitals. They need to be probed to come out with their concerns, as their concerns are often hidden, and they do not get an opportunity to vent out.

A social worker's role is to encourage such clients to bring out their concerns and dilemmas faced due to genetic testing and diagnosis. They should pool their knowledge, skills, and experience to advocate for the programs, facilities, and services needed by the clients and sensitize policymakers to develop guidelines and schemes in the interest of the vulnerable groups, and thus ensure equality and justice.

Advocacy for free prenatal diagnostic tests, medical coverage of such tests, security such as medical insurance, and priority in adoption formalities can be considered in social work practice.

Building partnerships

A comprehensive care approach is helpful for the care of patients and families affected by Thalassaemia. Wherein, a multidisciplinary team involving social workers can work to improve the Thalassaemia affected persons' and family members' quality of life. Hence, social workers need to build partnerships with other medical professionals, paraprofessionals, and patient support groups, etc. They can work in collaboration with NGOs, GOs, and corporates to help achieve desired results.

Creating awareness about genetic conditions

Non-governmental organizations working in the field of Thalassaemia have been instrumental in creating awareness about Thalassaemia in the communities, organizing blood donation camps, carrier screening camps, etc. However, interventions to address the reproductive health issues of parents, the use of contraception, prenatal diagnostic tests, and awareness about social issues like consanguinity, son preference, domestic violence, superstitions, and misconceptions about them are also equally important. Creating IEC content and using print and audio-visual media to create awareness about Thalassemia is also implied.

Inclusion of "social work in genetics" in the social work curriculum

At present, there is no such separate specialized training for social work in genetics. Therefore, to improve the visibility of the social work profession in genetic settings, social workers should be equipped with specialized training. Improved social work curricula should consider including such emerging fields so as to cater to the emerging scope of the social work profession.

Reproductive and sexual health is a human right. Reproductive health indicators of β thalassaemia carrier women attending public hospitals pose challenges for social work practice, research, and policy. Therefore, understanding is very important for social workers. In the context of the nature of Thalassaemia disease and its modalities, β -thalassaemia carrier women face discrimination in accessing reproductive health services. These women face very different kinds of concerns and unpredictable situations. They may face religious, socio-economic, and cultural

constraints. They face issues such as anaemia, unprotected sex, pregnancies, prenatal diagnostic tests, and abortions. This study finds an association between lack of awareness, poverty, and poor reproductive health outcomes and thus warrants interventions by professional social workers. Empowering these women to make reproductive decisions will ensure gender equity and social justice for them. Maternal as well as child health indicators are very important for a low- and middle-income country like India. They contribute to the human development index. Therefore, such marginal groups like β thalassaemia carrier women should not be left out of the social work interventions.

Societal implications

Social workers are change agents. They work for social change, betterment, and the well-being of the disadvantaged sections of society. As a professional, social workers work with various systems. With the basic knowledge of human development and human behaviour, social, economic, and cultural institutions, and their interactions, and a variety of skills, a practising social worker facilitates change in the functioning of individual or social structures.

Social workers are action-oriented professionals and provide comprehensive interventions provide workable solutions for social problems. By mastering various skills such as counselling, group therapy, and other helping techniques, they can contribute to improved psychosocial functioning of disadvantaged individuals, families, and communities.

Social workers consider each individual as unique and treat them as a product of the ecosystem, which functions at three levels, i.e., micro, mezzo, and macro levels.

Thus, social work intervention at one such level or more than one level or all three levels may be applicable. While helping the client, social workers may try & test various action plans for their efficacy, and then propose their application at a larger scale. Thus, social work is an evolving science. Social service departments in public hospitals function within a defined scope, with a defined role, which evolves with changing scenarios. This study found the major role performed by the hospital social workers in Mumbai is that of a social provision.

Development of hospital social services and social action plans, specific to genetics, has not so far been considered a priority. At several hospitals, genetics is covered under the speciality of paediatrics. Therefore, dedicated social workers for genetics as a specialty are an emerging need.

Thalassaemia is more common in low- and middle-income countries. Available literature shows that fifty percent of child deaths in these countries are due to genetic disorders. Findings of this study show the same trend. Social work interventions offered at public hospitals for patients with Thalassaemia and their families are at a superficial level.

Thus, the following section provides the implications for social work practice and research in the above context.

Contribution to the existing literature

This study was an inquiry into the reproductive phase of married β -thalassaemia carrier women, which explored the needs of this vulnerable group and provided scope for extended social work interventions for them. This monograph contributes to the existing literature as a study focusing on thalassaemia carrier women's issues, in the reproductive phase of their lives. It is a social work study in women's health & genetics, which explored various social, psychological, and behavioural issues along with reproductive health issues faced by thalassaemia carrier women mothering a child with Thalassaemia.

By exploring how treatment modalities of Thalassaemia and its prenatal diagnosis can affect women's fertility decisions and their reproductive life, this work suggests widening the scope of social work interventions for Thalassaemia carrier women and their families in hospital settings offering Thalassaemia management.

CHAPTER 8

SUMMARY, CONCLUSION & SCOPE FOR FUTURE RESEARCH

Summary

While throwing light on the issues faced by Thalassemia carrier women during their reproductive phase, this study found that the status of these women participants is exceptional. They are under constant threat of losing a child with Thalassemia and may face psychological issues such as depression. After the detection of Thalassemia in the child, they have a dilemma in planning further pregnancy, as in every pregnancy, there is a known possibility of the disease. Therefore, in all subsequent pregnancies, prenatal testing becomes important. If they do not have any normal or Thalassemia carrier children, they cannot decide to go for accepting a permanent method of contraception and thus remain vulnerable to unwanted pregnancies. They may get disheartened if the results of prenatal tests go wrong or the HLA of a sibling does not match, and the chances of curing the child with Thalassaemia are minimal. They tend to avoid socialization due to the stigma associated with the disease, or get less time for socialization. Some of these women suffer from anaemia due to low blood count.

This research study revealed the socio-demographic profile of the β -thalassaemia carrier women from Mumbai. Reproductive health parameters of the women undergoing prenatal diagnostic tests were explored. The study found out the available social work as well as other interventions utilized by these women. Their need for information regarding birth spacing, methods, and factors determining their fertility decisions were also explored. Social issues faced by them during this phase were reported in this study.

Unmet needs felt by these women related to reproductive health were mandatory screening for Thalassaemia carrier status during pregnancy check-ups, and awareness and information about PND Tests. Financial help for PND tests, Post PND MTPs & hospitalization for the same. Free testing and counselling facilities for women and other family members, i.e., cascade screening. Women needed information regarding sources to get a free supply of contraceptives.

Other social work interventions needed by women participants other than those related to reproductive health were such as regular arrangement of blood/blood camps as they face shortage of blood for the transfusions needed by their children, creating awareness and information about the disease to the general public, training mothers of children with Thalassaemia in hospital wards, OPDs for income generation activities, financial assistance for management of the disease to cover the cost of chelators, blood bags, free transport, lodging facilities, and free food in OPDs for the escort of the thalassemia major patient.

Conclusion

With the detection of the Thalassaemia disease in their children, the status of β Thalassemia-carrier women becomes more vulnerable. The risk of the recurrence of disease in offspring is the major factor affecting their life during the reproductive phase. Also, the requirement of a healthy sibling for a Bone Marrow Transplant is the rationale behind having a healthy child. Therefore, information regarding the issues of their concern about reproduction has to be dealt with, with expertise and empathy. Lacunae exist in the sharing of test reports and information regarding contraceptives, adoption, etc. Interventions in these areas by trained social workers are utterly missing.

Mental health requirements

Women reported psychological distress, domestic violence, resistance from family members as an indirect impact of Thalassaemia disease, and partner's addiction. Unpredictable PND test results, delay in receiving these reports, and ignorance about the carrier status of their children, in such conditions, help & support are needed. Social seclusion and stigma due to the disease conditions suggest the need for psychosocial interventions to help women. To overcome depression and insecurity caused by the loss of a child, positive PND test results, after termination of pregnancy, and also due to having a single child with Thalassaemia, such interventions would be helpful.

Need for information and counseling

Women, irrespective of whether they desire further pregnancies or not, may need information regarding spacing methods, preconception care, or counseling for various tests such as carrier screening tests, prenatal diagnostic tests during the reproductive phase of their life. They may need counseling before & after positive prenatal test results and also post MTP. The relevance of consanguineous marriages in the case of Thalassemia and options such as adoption should be discussed with them.

Other social issues

Gender discrimination in the case of female children having Thalassaemia and preference for a boy child were also reported. Issues such as non-cooperation from the husband and other family members for acceptance of contraceptives need to be handled.

The scope of the hospital social workers in Mumbai is restricted to financial aid for the treatment modalities of Thalassemia major children by donors and family welfare by means of financial assistance for ration, tuition fees, etc, and sponsorship for prenatal diagnostic tests. These are mainly philanthropic interventions.

Globally, the social worker's role in a multidisciplinary team dealing with genetic conditions is dynamic and multifaceted. However, in Indian settings, it is not so. There are missed opportunities that can be utilized to help Thalassaemia-carrier women while they visit hospitals or their child's Thalassaemia care and management. The focus of social work interventions for Thalassaemia-carrier women can be on their health during the reproductive phase. This will not only improve the quality of Thalassaemia carrier women's lives but will also help in reducing the societal burden of the disease by preventing the birth of a Thalassaemia major child.

The study also revealed that enhanced social work interventions for Thalassaemia-carrier mothers will prove as a complementary strategy along with the prenatal diagnostic tests to prevent the disease.

The way for future research

Studies to test the proposed model to improve social work interventions can be planned in the future. This study involved those β Thalassemia carrier women who underwent prenatal diagnostic tests; therefore, its scope is limited. Also, studies in areas such as Tribal areas or private health settings can be planned. More socio-behavioural studies involving more Thalassaemia carrier women who have children affected by Thalassaemia major disease can throw more light on the issues faced by them.

CHAPTER 9

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I, **Neha Minde**, hereby declare that:

1. The monograph titled **“Issues Faced by Mothers of Thalassemia Affected Children and the Role of Medical Social Workers in Mumbai”** is an original scholarly work derived from my PhD thesis entitled **“Study of Problems Faced by Married β Thalassaemia Carrier Women and the Role of Medical Social Workers in Mumbai”**, awarded by SNDT Women’s University in the year **2025**.
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Place: Mumbai

CERTIFICATE / APPROVAL BY RESEARCH GUIDE

This is to certify that the monograph entitled: **“Issues Faced by Mothers of Thalassemia Affected Children and the Role of Medical Social Workers in Mumbai”** is prepared by **Neha Minde** based on the thesis entitled: **“Study of Problems Faced by Married β Thalassaemia Carrier Women and the Role of Medical Social Workers in Mumbai”** submitted to **Department of Social Work**, SNDT Women’s University for the award of PhD degree under my guidance.

I have examined the manuscript and approve it for publication as a monograph.

Name of Research Guide: Prof. Vandana Chakrabarti

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Dr. Neha Minde is a researcher and writer with a deep interest in literature, socio-behavioural research, and creative expression. She has more than two decades of experience in women's health, including reproductive and sexual health, and has also worked with families having a child affected with Thalassaemia major. In this monograph, she has tried to link her first-hand experiences as a social worker working in the field of reproductive health, women's health, and Thalassaemia. Her work reflects a strong commitment to the so far neglected aspects of social work for women having a child with Thalassaemia in India, knowledge sharing, and thoughtful analysis of issues faced by β Thalassaemia carrier women. Through her writing, she aims to present the reproductive dilemmas & vulnerability of mothers who are carriers of Thalassaemia. By presenting her ideas clearly and engagingly, she has made the complex dynamics of the disease accessible to readers. Dr. Neha continues to contribute to the field of academics and socio-behavioural research in genetics with dedication and creativity.

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About the Monograph

Caring for a child affected by thalassaemia presents profound emotional, social, and economic challenges for families, particularly for mothers who often bear the primary responsibility of caregiving. This monograph explores the experiences and concerns of mothers of thalassaemia-affected children in Mumbai, with a focus on the complexities of reproductive health, psychosocial well-being, access to support services, and the unique vulnerabilities associated with carrier status. It also examines the critical role of medical social workers in addressing these challenges and supporting affected families. By highlighting gaps in existing interventions and support systems, the work offers valuable insights for healthcare professionals, social workers, researchers, and policymakers committed to improving care and quality of life for families affected by thalassaemia.

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